



MONASH University

Nurses' Roles in Bereavement Care in Acute Non-metropolitan Hospitals: A Qualitative Study

Anita Raymond

RN, BN, Graduate Diploma (ICU), MN, Graduate Certificate (Academic Practice)

A thesis submitted for the degree of Doctor of Philosophy at Monash University

Faculty of Medicine, Nursing and Health Sciences

Nursing and Midwifery

2021

Copyright notice

© Anita Raymond (2021).

I certify that I have made all reasonable efforts to secure copyright permissions for third-party content included in this thesis and have not knowingly added copyright content to my work without the owner's permission.

Abstract

The bereavement care that nurses provide in hospitals is embedded in the end-of-life care provided to dying patients and their families. Bereavement care is not well defined in Australia or elsewhere in the world, with no research to define the bereavement care roles of nurses in rural hospital settings. Understanding exactly what roles constitute bereavement care is crucial to understanding how bereavement care is provided in acute hospital settings. Therefore, this study aimed to investigate the roles of registered nurses in the provision of bereavement care to dying patients in acute, non-metropolitan hospitals.

A constructivist paradigm was used to understand bereavement care through the nurse participants' eyes within the context of a rural hospital setting. An Interpretive descriptive approach was also followed to provide an in-depth and contextual understanding, given this research sought not only to describe but to also provide an interpretative explanation for the findings related to the roles nurses undertake in bereavement care.

Semi-structured interviews were undertaken with twenty-two acute care nurses within a South East region of Victoria. Acute care nurse participants were recruited with acute care experience in medical, surgical, emergency, critical care, midwifery, renal and oncology units within the region.

Analysis of the data led to the generation of overarching themes with two distinct groups of thematic categories. 'The Doing', which became one group of themes representing the data related to the bereavement roles that nurses undertook for patients and their families during end-of-life care. With the remaining group of themes 'The Coping', represented the impact of care delivery, as the study nurses dealt with the reality of caring for dying patients in the context of a rural hospital.

The metaphor of a 'trekking leader' was used in this study to help describe the provision of bereavement care by nurses during end-of-life care in this study. Interpretation of the findings led to key roles, which included using communication to facilitate bereavement care and creating positive memories for families as part of bereavement care. The importance of self-care to enable coping with the delivery of bereavement care and the identification of bereavement care in the work of end-of-life care were pivotal for rural nurses to sustain the delivery of bereavement care during end-of-life care.

Overall, these findings add to the limited body of knowledge about the roles nurses undertake as bereavement care in non-metropolitan hospitals. While the findings specifically relate to nurses, many themes may relate to other health disciplines, given that a multidisciplinary approach was applied to the provision of both end-of-life care and bereavement care to patients and their families. The findings of this study also offer insights into bereavement care which enhance role clarity for nurses during end-of-life care and, potentially, help facilitate greater ownership of the roles and, enhance the quality of care for dying patients and families in rural hospitals.

The findings also have implications for nursing practice, future research, and nursing education. Recommendations relating to nursing practice include: manageable patient workloads so appropriate person-centred care can be provided by acute care nurses, ad equate skill mix on each shift to support less experienced nursing staff, development of skills to help create positive memories in support of end-of-life care for patient/family and facilitating a better understanding of grief and bereavement models to help align bereavement care with the 'grief work required for individuals as part of the bereavement process. Recommendations related to future research include: involvement of multidisciplinary staff in the delivery of bereavement care and end-of-life care for patient/family, patient/family perceptions of the creation of positive memories during end-

of-life care, strategies to support self-care of acute care nurses in the provision of bereavement care and understanding of the emotional burden associated with caring for patient/family during end-of-life care in non-metropolitan hospitals. Recommendations related to nursing education include enhanced understanding of the bereavement process and the referral to and knowledge of external palliative care and bereavement services.

Declaration

This thesis is an original work of my research and contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Signature:

Print Name: Anita Raymond

Date: 26-11-2021

Publications during enrolment

Raymond, A., Lee, S., & Bloomer, M. (2017). Understanding the bereavement care roles of nurses

within acute care: a systematic review *Journal of Clinical Nursing*, 26(13-14), 1787-1800.

doi:10.1111/jocn.13503

Thesis including published works declaration

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes (1) original paper published in peer reviewed journals. The core theme of the thesis is understanding the roles that acute care nurses undertake in bereavement care roles for patients and families in acute non-metropolitan hospitals. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the School of Medicine Nursing and Health Sciences under the supervision of Associate Professor Susan Lee, Dr Melissa Bloomer (previous supervisor) and Dr Kaori Shimoinaba.

Thesis Chapter	Publication Title	Status (published, in press, accepted or returned for revision, submitted)	Nature and % of student contribution	Co-author name(s) and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
Chapter 2	Understanding the bereavement care roles of nurses within acute care: a systematic review	Accepted	60%. Concept and systematic review and writing first draft	1) Susan Lee, input into systematic review process using the guidelines of Joanna Briggs Insitute, review of papers & development of a synthesised findings table & manuscript review 25% 2) Melissa Bloomer, input into input into systematic review process using the guidelines of Joanna Briggs Insitute & manuscript review 15%	No No

*If no co-authors, leave fields blank

I have not renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.

Student name: Anita Raymond

Student signature:

Date: 26-11-2021

I hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author, I have consulted with the responsible author to agree on the respective contributions of the authors.

Main Supervisor name: Associate Professor Susan Lee

Main Supervisor signature:

Date: 26-11-2021

Acknowledgements

This thesis is wholeheartedly dedicated to my mother, Anne Micallef, who died in 2010 from cancer, in the Gippsland region. Her death was a source of motivation for this study, and it is my hope that this research not only contributes to the existing knowledge gap concerning nursing roles in bereavement care but also to enhancing the quality of bereavement care for patients and their families during end-of-life care in rural hospitals.

Thank you to the amazing nurses who took the time to participate in the study! I would like to also acknowledge my beautiful family – my husband, Rob, and wonderful children, Leila, Richie and Ben, and my father, Fred, for providing me with the courage and unconditional support to complete the requirements of this dissertation. A big thank you to my fantastic work colleagues at Latrobe Regional Hospital for all the encouragement and support over the years with this study.

Finally, a heartfelt thank you to my PhD supervisors, Associate Professor Susan Lee and Dr Kaori Shimoinaba, for their invaluable advice, guidance and patience during this PhD, including Dr Melissa Bloomer, Dr Beverley Taylor, who assisted in the early stages of this study. Your supervision was invaluable and made this research dream become a reality.

I would also like to acknowledge that the services of Kara Gilbert of KMG Communications were utilised to proofread this thesis prior to examiner submission, in accordance with the ethical standards for editing and proofreading contained in the *Guidelines for editing research theses* (2019), as approved by the Institute of Professional Editors Board and Endorsed by the Australian Council of Graduate Research.

Contents

Copyright notice	i
Abstract	ii
Declaration	v
Publications during enrolment	vi
Thesis including published works declaration	vii
Acknowledgements	ix
Contents	xi
Table of Tables	xv
Table of Figures	xvi
Research definitions	xvii
CHAPTER ONE – Introduction and Background	1
Introduction	1
Background and significance of this research.....	1
Theoretical foregrounding	6
A connection to bereavement care	6
Bereavement theories – growing around grief.....	8
Bereavement care in the rural setting	18
Purpose and research questions.....	23
Summary	24
Structure of the thesis	24
CHAPTER TWO – Literature Review	26
Introduction	26
Systematic review	26
Review of literature 2016 – 2020.....	42
Patient-centred care	42
Family-centred care	43
Advocacy roles and professional development needs	44
Timing of Bereavement Care	44
Summary	44
CHAPTER THREE – Methodology	46
Introduction	46

Design.....	46
Constructivism and interpretive description	47
Theoretical framework	49
Trustworthiness and credibility	50
Site selection.....	52
Sampling.....	53
Recruitment and consent.....	55
Hospitals.....	56
Acute care symposium.....	56
Health Alliance Website.....	57
Data collection	57
Semi-structured interviews.....	59
Ethical approval.....	60
Data analysis	61
Limitations to the study design.....	64
Summary	64
CHAPTER FOUR – ‘The Doing’	66
Introduction	66
Overview of participants.....	67
The doing	69
Meeting needs	70
Individualising care	70
Cultural and religious needs of patients and families.....	73
Keeping dying patients comfortable.....	75
Care pathways - an illusion or a useful resource	77
After-death care for families.....	79
Communication guiding care	80
Talking about death – ‘What happens now what happens next’	81
Enlisting multidisciplinary support.....	83
Family expectations - How do we make them see?	86
Being an advocate to support patient and family.....	89
Summary	91

CHAPTER FIVE – ‘The Coping’	93
Making sense of dying	94
Becoming comfortable through experience	94
Learn from role modelling and debriefing	97
Using coping mechanisms.....	100
Coping with our reality	103
Rurality as a reality.....	103
A better space to provide care.....	107
End-of-life care against the grain – we are too busy keeping people alive.....	112
Nurse-to-patient ratios and juggling time to spend with families.....	115
Summary	118
Chapter SIX – Discussion	119
Introduction	119
Leading the Trek on an End-of-Life Journey	121
Communication during end-of-life care.....	127
Communication to facilitate bereavement care	128
Communicating with the wider multidisciplinary team to deliver bereavement care.....	133
Barriers to communication as bereavement care	135
Creating positive memories for families as bereavement care	138
Providing person-centred care as bereavement care.....	139
Providing bereavement care to families after the death of patients	149
Developing skills for creating positive memories as bereavement care	152
Sustaining the provisions of bereavement care during end-of-life care	156
Self-care measures to support the delivery of bereavement care	156
Recognising the bereavement care in end-of-life care.....	162
Summary	166
CHAPTER SEVEN – Conclusions and Recommendations	168
Thesis overview.....	168
Conclusions	171
Nursing roles in bereavement care.....	171
Competence and confidence in the delivery of end-of-life and bereavement care.....	172
Needs and barriers in the provisions of bereavement care	173

Study strengths and limitations	174
Recommendations	175
Nursing practice	176
Education needs for acute care nurses relating to bereavement care.....	179
Further research concerning bereavement care in hospitals.....	181
Summary	182
References.....	184
Appendices.....	205
Appendix 1- ACGB Conference	205
Appendix 2 – Participant Information Consent Form (PICF).....	207
Hospital Nurse PICF.....	207
Acute Care Symposium Nurse PICF.....	214
Health Alliance Website PICF	222
Appendix 3 – Participant Flyer	230
Acute Care Rural Symposium – nurse participants.....	230
Hospital – nurse participants	231
Appendix 4 Interview Schedule Guide	232
Appendix 5 – HREC Approval Certificate	235
Hospital 1	235
Hospital 2	236
Appendix 6 – Monash University Ethics Certificate	237

Table of Tables

Table 4.1 Research Participant Sample.....	68
Table 4.2 'The doing' - bereavement care roles	70
Table 5.1 'The coping' – bereavement care roles.....	93

Table of Figures

Figure 1 Dual Process Model of Coping 11

Research definitions

Bereavement: A process whereby individuals attempt to cope with grief, as they approach death, or as a consequence to anticipated loss, and/or the death of a significant other. The bereavement process includes anticipation of death, death occurrence and subsequent life adjustments following the death of a significant other (Allard, Genest, & Legault, 2020; Overton & Cottone, 2016)

Bereavement care: Nursing care during the end-of-life of dying patients that may impact on the bereavement process for patients and families. Bereavement care includes the process of preparing families for a patient's death, psychosocial support, referral to multidisciplinary services and the clinical interventions performed to maintain the comfort needs of the dying patient (Buckley et al., 2015; Walker & Deacon, 2016). In this study, the term grief care/support is sometimes used to refer to similar bereavement care strategies.

Grief: Grief encompasses the physical, emotional, cognitive, behavioural and spiritual manifestations of human experience that may occur as a reaction to loss and as a consequence of forming emotional bonds to people and possessions (Hall, 2014).

Acute care: Refers to care received within a hospital setting where a patient is provided with active but short-term treatment for acute injury or episodes of illness, with the intent to restore health (World Health Organization, 2015). In the context of this study, acute care units included medical, surgical, emergency, critical care, oncology, and midwifery hospital units.

End-of-life care: In this study end-of-life care refers to nursing provisions to a dying patient and their family in acute care hospitals during the final stages of life, which includes bereavement care for patients and their families as patients approach death (National Palliative Care Standards, 2018).

Acute non-metropolitan hospitals: In the context of this study, the acute non-metropolitan hospitals equate to regions that meet the classification of inner regional – remoteness based on the Australian Standard Geographical Classification System (Australian Institute of Health & Welfare, 2021). The study region was located approximately 104 to 162 km from the closest major capital city and will be referred to as a rural location.

Significant other: In this study, ‘significant other’ refers to the person with a significant connection to a dying patient (Hall, 2014).

CHAPTER ONE – Introduction and Background

Introduction

Approximately half of the total number of deaths each year in Australia occur in hospital settings (Australian Commission on Safety and Quality in Health Care, 2018). Acute care nurses working in hospitals are often at the front-line providing care to patients and their families during the final stages of a patient's life. Providing care to patients and families at end-of-life also involves the provision of bereavement care. The bereavement care that nurses provide is may be significant to the bereavement process that both patients and their families experience in anticipation of death and after death occurrence for families. This study seeks to describe the bereavement care roles of nurses within acute non-metropolitan hospitals to better understand how this care is provided to patients and their families. An interpretive descriptive approach was used to help identify the roles that acute care nurses have in bereavement care. This thesis also identifies the barriers and enablers associated with the provision of bereavement care in non-metropolitan hospitals.

This chapter provides the background information on which the study was founded and details the aim of the project and research questions. Relevant information that impacts on how bereavement care is provided by nurses in non-metropolitan hospitals is discussed as evidence in support of the theoretical fore-structure required for this interpretive descriptive study. Therefore, bereavement models and the context of how bereavement care is provided in a regional setting, including the personal and professional motivations of the author, have been outlined as part of the theoretical fore-structure. An outline of each chapter in this thesis has also been detailed after the summary of this chapter.

Background and significance of this research

The experience of bereavement is very individual, extensive and, often, a difficult journey for the bereaved individual. The bereavement process refers to how individuals cope with grief related to loss through death. For a patient, bereavement commences at the time of terminal diagnosis as they face the reality of death (Overton & Cottone, 2016). For family members, the bereavement process

commences in anticipation to death and continues after the death of their significant other, in which they learn to live with the loss in their everyday life (Hall, 2014). Grief in relation to this study, refers to the impact of loss or perceived losses, as a result of death or the anticipated death of a patient. Grief is a very individual experience and encompasses the physical, emotional, cognitive behavioural and spiritual manifestations of human experience that may occur as a reaction to loss and as a consequence of forming emotional bonds to people and possessions (Hall, 2014). Each individual will anticipate and process loss differently (Allard et al., 2020; Overton & Cottone, 2016).

The death of a significant other and the subsequent bereavement process that follows have been recognised as one of life's greatest stressors and has been associated with a decline in health and mental health, including an increased risk of mortality for bereaved individuals (Buckley et al., 2015; Naef, Peng-Keller, Rettke, Rufer, & Petry, 2020). It is not uncommon for health conditions, such as myocardial infarction, Takotsubo (stress) cardiomyopathy or both, occurring with an increased risk of mood, anxiety, and substance-use disorders, as individuals undertake the process of bereavement and adjust to living with the loss of a significant other as the result of death (Shear, 2015). Family members, therefore, would mostly be at risk of these health conditions, given they are required to adjust to living following the death of the patient.

Death in acute hospital settings, together with the resultant bereavement experience encountered by families, can be a profound experience (Naef et al., 2020), with grief and the subsequent bereavement process described as more pronounced particularly when a death occurs suddenly with no emotional preparation for facing the loss of a significant other (Shariff, Olson, Salas, & Cranley, 2017). Little anticipation of death for families in acute care has been associated with psychological morbidity enhancing the need for effective bereavement care (Walker & Deacon, 2016). It is also evident that an increased occurrence of clinical episodes meeting the pre-loss risk factors for the development of complicated grief occurs in hospital settings (Hall, Hudson, & Boughey, 2012; Neimeyer & Burke, 2012; Shear, 2015). Pre-loss risk factors for complicated grief include death that is traumatic (violent, sudden, prolonged, suicide), pre-existing trauma for the bereaved individual (particularly childhood), prior loss, insecure attachment or relationship with the significant other and pre-existing mood or anxiety

disorders for the bereaved individual (Simon, 2013). Complicated grief is characterised by intense yearning for the deceased, feeling a lack of meaning after loss, and chronic impairment in daily functioning (Rozalski, Holland, & Neimeyer, 2017).

Acute care nurses are the health care providers that spend the most time with patients and their families than any other clinicians in hospital during care at end-of-life (Boyle, 2019), and are expected to have the skills to provide psychological support to patients and families and the physical care for patients to meet their needs (Bloomer, Endacott, O'Connor, & Cross, 2013). Walker and Deacon (2016) indicate that bereavement care provided during end-of-life care is highly significant to the bereavement process for patients and families as they cope with the grief associated with dying. For families, this continues following the death of a significant other, when they leave the supports of the hospital; potentially during acute grief and at various stages of the bereavement process.

Bereavement care has been described as the process of preparing families for a patient's death, providing psychosocial support for patients and families, information sharing, providing referral to multidisciplinary supports and the clinical interventions that maintain the comfort needs of dying patients (Buckley et al., 2015; Naef et al., 2020; Walker & Deacon, 2016). The psychological support for patients who are facing death and experiencing multiple losses and for the suddenly bereaved family members, as earlier identified, requires skilled intervention by acute care nurses who may not have palliative training and rely on their previous education and training along with their personal and professional experiences of death and dying to support the process. In hospitals the risk factors predisposing complicated grief reaction may also be higher, as will be further discussed later in this chapter, which places added pressure and complexity to the role and the need to deliver effective bereavement care for families.

In addition, a number of research studies indicate that acute care nurses often feel inadequately prepared to properly provide end-of-life care especially during the early stages of their nursing careers (Andersson, Salickiene, & Rosengren, 2016; Croxon, Deravin, & Anderson, 2018; Hussin, Wong, Chong, & Subramanian, 2018b) and have limited understanding of loss, grief and bereavement (Griffith, 2018).

Furthermore, acute care nurses have been described as lacking confidence in dealing with the psychosocial needs of families and have insufficient preparation in the care of terminally ill patients (Andersson et al., 2016; Chan, Lee, & Chan, 2013; Hussin, Wong, Chong, & Subramanian, 2018a; Hussin et al., 2018b).

In several research studies, acute care nurses have implied a need for professional development to improve their readiness and competencies in bereavement care (Arbour & Wiegand, 2014; Chan et al., 2013; Hussin et al., 2018b; Mak, Chiang, & Chui, 2013). Some research studies that have focused on the family's experience of bereavement care during end-of-life care received by acute care nurses have been described as limited and not effective. Twenty-six family members shared their experiences of end-of-life care in a qualitative research study by Noome, Dijkstra, Leeuwen and Vloet (2016) in an intensive care unit in Netherlands, reporting that acute care nurses required increased opportunities to assist with patient care, better support to access the use of chaplains, enhanced information and clarification in regard to end-of-life decisions and better support in family meetings. The bereavement care for family care givers was also reported less than optimal in Australian general hospital settings, with only 39.4% of 506 bereaved relatives bereaved relatives of people who had terminal illness reporting being specifically asked about their emotional/psychological distress (Aoun, Rumbold, Howting, Bolleter, & Breen, 2017).

The hospital setting has also been described as clinical and unfamiliar, with the environment for patients facing death not practical for accommodating grieving families (Arbour & Wiegand, 2014; Walker & Deacon, 2016). Environmental barriers, such as a lack of adequate space and privacy for bereaved family members, are issues that also complicate the delivery of end-of-life care in hospitals (Beckstrand, Smith, Luthy, & Macintosh, 2017; Chan et al., 2013). Acute care units in hospitals also specialise in 'active care' which is provided for short term treatment, acute injury or episodes of illness, with therapy being diagnostic with the intent to restore a patient's health (World Health Organization, 2015) and not on palliative and end-of-life care.

Hospitals located in non-metropolitan settings are known to have an increased incidence of death and rate of potentially avoidable deaths, with the mortality risk becoming more statistically significant the greater the distance a person lives from a major city (Australian Institute of Health and Welfare, 2019). The higher mortality rates for populations in non-metropolitan areas have been attributed to potential geographical challenges and a reduction in access to health services (Australian Institute of Health and Welfare, 2019). Data from the National Health Workforce Dataset shows that the total clinical full time-equivalent (FTE) for health professionals per 100,000 population decreased as rural remoteness increased, particularly in the areas of allied health and medical clinicians (Australian Institute of Health and Welfare, 2016). An increased mortality risk and a reduced capacity for referral and specialty service may impact on levels of bereavement care. This reduction in services may also complicate the already challenging role nurses undertake in the care of dying patients and their families. Other literature also identifies the challenges of living and working in smaller regional communities where nurses may care for patients that are known to them within the smaller community making end-of-life care and the associated bereavement care for patients and families extremely difficult to perform (McConnell-Henry, Chapman, & Francis, 2011).

Therefore, to ensure high quality bereavement care is provided to patients and families within an acute non-metropolitan setting, the roles that nurses undertake as bereavement care need to be clarified. A clearer understanding of how this care is provided as part of end-of-life care, including the ability to identify the bereavement care that is patient-centred and the bereavement care that is family-centred, is necessary. Unpacking the bereavement care roles from end-of-life care will also enable better evaluation of clinical practice, against the national standards and guidelines that represent quality and palliative care practices. This research will, therefore, also contribute to the current gap in literature concerning the roles of nurses in bereavement care at end-of-life in the context of non-metropolitan hospital settings. Increased understanding and practice awareness will also identify resources that will help potentially improve the experience of death for patients and families in non-metropolitan locations. This research will also provide information on the barriers and enablers as perceived by the

acute care nurses concerning the delivery of bereavement care in hospitals located in a non-metropolitan setting to help improve practice.

Theoretical foregrounding

This research followed an interpretive descriptive methodology and, therefore, required theoretical fore-structure to substantiate background development. Theoretical fore-structure is a process that determines the key elements to the study and requires the researcher to 'locate' themselves within this 'disciplinary field' and the 'theoretical world' that surrounds it (Thorne, 2016). Theoretical fore-structure encourages the establishment of relevant information which become layers of evidence for which a clinical question can be best developed. This foregrounding process requires the researcher to establish 'disciplinary orientation' for the study and requires the identification of the researchers own 'personal relationship' to the ideas held regarding the topic of enquiry (Thorne, 2016). Therefore, it was necessary to develop a deeper background concerning some of the published grief and bereavement models to be able to locate and understand the context of the process. This also involved identifying how bereavement care is provided within a non-metropolitan setting both within the hospital and external to it. Including the need for the investigator to identify the personal connection and motivation for the research ideas, which contributed to the development of this research study.

A connection to bereavement care

During my personal and professional life, I have experienced grief relating to death, from the perspective of a daughter and that of a Registered Nurse working within a rural hospital setting. Despite many years of nursing experience, working as a clinical nurse specialist and nurse educator within a Critical Care Unit, I felt significantly underprepared for my own bereavement experience following the death of my mother. It was also evident to me that the end-of-life care that my mother received whilst in hospital was highly significant and influential to my own grief and bereavement process during and after the death and the services from the hospital ceased.

After the death of my mother and during my bereavement process, I was not aware of the counselling services available or support groups within the larger community or how to link into these services for

myself or my wider family. I also needed to heavily support my father throughout his bereavement process, assisting him to adapt to living with the loss of his wife and my mother. There was no further contact made from the hospital or the palliative care team to support me or my family after my mother's death following our hospital discharge. I also had a young infant to care for, who was under 12 months old which complicated the overall experience; to make time for myself to grieve and provide care and support to my wider family.

My family relied heavily on general practitioner (GP) care and ongoing referrals to help facilitate ongoing medical care and counselling services. Supporting myself and my family following the death of my mother was an enormous challenge and the resources and services we needed were not obviously available requiring active searching along with guidance through specialist referral services. Given I had a nursing background and still found access to support difficult, other members of the community with no medical or health care knowledge would find this task extremely difficult especially once hospital care ceases. This would especially be the case for individuals like my father who also had a non-English speaking background and poor literacy including digital literacy skills.

My personal experience concerning the death of my mother was a strong motivator and provided ongoing connection to the topic of bereavement care in a non-metropolitan setting. It should also be noted that my nursing background has been predominantly in critical care nursing, and I have limited theoretical expertise in palliative or end-of-life care with no postgraduate qualification except for my professional experience of caring for dying patients and their families in this setting. Therefore, in the background development of this research I attended the Australian Centre of Grief & Bereavement (ACGB) to participate in a short course for health professionals on 'Providing Effective Bereavement Support' in November 2013. The ACGB is an independent non-profit organisation established in 1996 and is the largest provider of grief and bereavement education in Australia.

To acknowledge my own bereavement experience and separate this experience from the study nurse's perceptions and experiences of end-of-life and bereavement care, a reflective journal piece titled 'my story' regarding my own bereavement experience was also completed. This self-reflective work also led

to an abstract submission to the ACGB conference 'Bridging the Gap between Research & Practice'. This abstract was accepted titled 'Personal & Professional Imperatives for Improving Bereavement in Gippsland' and was presented at the ACGB in March 2014 (see Appendix 1). Along with presenting this abstract at the ACGB conference, participation in this two-day bereavement symposium was further enhanced my understanding of bereavement and bereavement care. I have also maintained my membership with the ACGB to keep updated on the topic of bereavement.

It was also apparent, during my earlier years of teaching into a nursing program as a nursing lecturer, that limited information was provided to undergraduate nursing students regarding bereavement care during end-of-life care of dying patients and families. Instead, practical, and theoretical information seemed to focus essentially on patient comfort measures with the related practical laboratory sessions concerning the laying out of the patient after death and preparing the body for viewing. Limited information was provided to the undergraduate students concerning grief or the bereavement process and provisions of care that may support patients and families in anticipation and specifically after death for families receiving care in hospitals.

As a result of these experiences, I had a sense that bereavement care could be managed better for dying patients and their families within an acute non-metropolitan hospital setting. My personal and professional experience of bereavement care within a rural setting has remained a strong motivator to explore the roles that nurses undertake during the care of dying patients, with a particular focus on family-centred bereavement care within rural hospital settings.

Bereavement theories – growing around grief

Grief, in the context of this study, encompasses the physical, emotional, cognitive, behavioural and spiritual expression (Hall, 2014) which can occur when a patient faces the reality of impending death and the family anticipates death occurrence and begins to adapt to loss after a patient's death. Grief for family members, occurs as a result of loss and is defined as the consequence of forming emotional bonds to people and then having to come to terms with or adjust to losing them from their lives (Hall, 2014). For a patient that is dying, this has been described as 'preparatory grief' in which the patient

prepares themselves for final separation from the world, and mourns for the many associated losses along the way (Vergo et al., 2017). Preparatory grief for patients has been identified as grief related to a loss of independence and previous physical condition, anticipated separation from loved ones, grief related to missed opportunities, and missed anticipated events such as children's graduation or the birth of a grandchild, including an inability for continued participation in favourite activities and losing their position or role in a family (Kostopoulou et al., 2018; Vergo et al., 2017). For a family member, grief in the context of this study refers to the associated loss as a consequence of the death of a significant other, but also applies to anticipatory grief that may occur before the death occurs. Anticipatory grief and preparatory grief imply that grief and the bereavement process commence before death occurrence for patients and families, and continue after the death of a significant person for family members.

For family members, manifestations of grief and anticipated loss may lead to emotional disruption which may precipitate the need for gathering with family and friends, making arrangements to reorganise the activities and related responsibilities, commencing financial arrangements to accommodate the situation and including spiritual and psychological preparations that may be necessary to accommodate the loss of a significant other (Shear, 2015). In most cases, the acute experience of grief subsides over a period of time (Hall et al., 2012), as the bereaved individual adapt to living with this loss in their lives (Neimeyer, Herrero, & Botella, 2006; Shear, 2015). In 10 to 15% of cases, however, the symptoms of distress following the death of a significant other becomes more intense and prolonged, and this condition is known as 'complicated grief' (Neimeyer, Harris, Winokeur, & Thorton, 2012; Shear, 2015).

The bereaved individual is believed to experience a prolonged grief reaction or complicated grief reaction in the setting of a sudden or violent death, death of a spouse or child, perception of the loved one suffering, feelings of guilt that they may have somehow contributed to the death additional, lack of understanding of the circumstances leading to death, having limited social support or an underlying psychiatric illness (Cooper, Stock, & Wilson, 2019). These circumstances may be applicable to family members who nurses care for during end-of-life care in hospitals and, therefore, impact on the family's bereavement process. Complicated grief impacts on the intensity and duration of bereavement and can be associated with debilitating physical and mental conditions, such as insomnia, substance misuse,

depression, compromised immune function, hypertension, cardiac issues, cancer, suicide, work and social impairment, which can lead to medical treatment and hospitalisation (Hall et al., 2012). It is also apparent that the symptoms of complicated grief have been reported as lasting anywhere from four to nine years after the death of a significant other (Neimeyer et al., 2012). Individuals experiencing complicated grief are often described as having greater difficulty in adapting or regaining life balance, with acute mourning and intense grief persisting for extended periods (Hall, 2014), including grief that is distorted, repressed or even absent in some situations (Rando et al., 2012).

From the 1980's, there has been considerable development of the understanding of grief and the 'grief experience' that occurs because of the death of a significant other. Researchers have described models that encapsulate 'growing around grief' and models that encapsulate 'learning to live with loss' (Neimeyer et al., 2012). These theories challenge the idea that the process of grief is experienced in linear stages. End stages, such as 'letting go' and 'acceptance', have been challenged with more modern theory which describes no end point to bereavement but a perception that bereavement involves building a new life and learning to live with the loss of a significant other. These theoretical models conceptualise a journey of change, as the bereaved individual learns to live with loss, making strong claims regarding a 'myth of recovery' and conceptualising that individuals instead build their life around loss and address their grief during the complex process of bereavement (Hall, 2014; Stroebe & Schut, 1999; Stroebe, Schut, & Boerner, 2010).

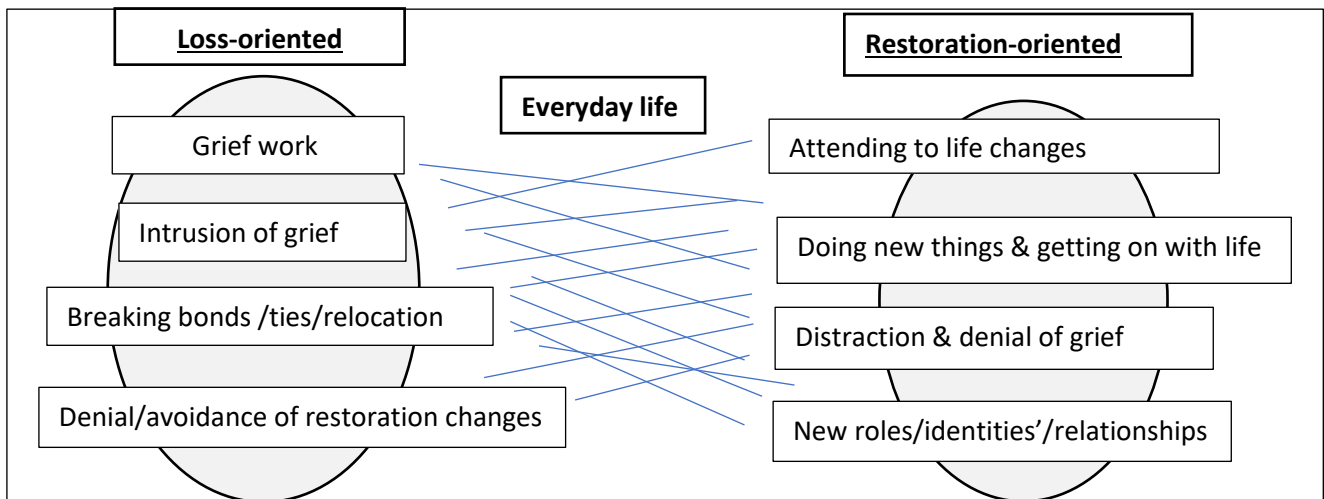
Theorists that conceptualise 'growing around grief' are in stark contrast to previous models stemming originally from the work of Kubler-Ross (1969) who conceptualised grief and bereavement is experienced in a series of five stages: denial, anger, bargaining, depression and acceptance (Kubler-Ross, 2014). Descriptions of grief experience in stages has been highly criticised, knowing that each person's experience of grief is largely individual and unique, making the process hard to accurately fit into anticipated steps or behaviours (Boerner, Stroebe, Schut, & Wortman, 2016). People encountering grief are also described as needing to move backwards and forwards, encountering emotional waves and experiencing good and bad days, as part of the overall bereavement process and are not practically able to progress in stages. The inability of individuals experiencing loss to meet and maintain their grief

experience in stages, like that described by Kubler-Ross, has been associated with the worsening of a person’s emotional distress, with added confusion and questioning of one’s extent of coping as they evaluate themselves against the anticipated stages (Hall, 2014).

Dual Process model of coping with bereavement

One modern theory describes the bereavement process as a dual process model (Stroebe et al., 2010). The model identifies two types of stressors that impact considerably on the bereaved individual as they face the loss of a significant other: the experience of grief (loss orientated) and the living or continued restoration following loss (restoration orientated). The dual process model is a ‘taxonomy’ to describe ways that people come to terms with the loss of a loved one. The model is embedded in one’s everyday life experience and, as earlier discussed, describes the work of learning to live with loss and ‘growing around grief’ (Stroebe & Schut, 1999). Growing around grief is demonstrated in Figure 1, below. The diagram represents how an individual moves from loss-oriented to restoration-oriented dimensions in continued ‘oscillation’, as a means of coping throughout the bereavement journey.

Figure 1 Dual Process Model of Coping



A dual process model of coping with bereavement. Adapted from (Stroebe & Schut, 1999)

Loss-oriented work has been described by Stroebe and Schut (1999) as ‘grief work’ or the concentration on dealing with and processing loss experience. This grief work relates to focusing on the relationship and rumination about the deceased, life together as it has been, circumstances and events surrounding the death, yearning for the deceased and the experiencing of emotions, from pleasurable reminiscing to

painful longing (Stroebe & Schut, 1999). This associated spiritual and emotional turmoil that the bereaved individual encounters has been described as a state of 'chaos', in which behaviour becomes dynamic and unpredictable for the bereaved individual (Hall, 2014).

The second type of bereavement stressor is restoration-oriented that Stroebe and Schut (1999) describes as coping work focusing on what needs to be dealt with, and how, to manage and restore a sense of normality. Restoration work relates to mastering tasks that the deceased may have undertaken, arrangements for the reorganisation of life, the development of a new identity, roles and relationships, and avoidance activities which occupy and distract one from grief (Eisma, deLang, & Stroebe, 2021) . These activities can be as simple as getting up in the morning to attend work, but the focus is on moving forward.

The 'oscillation' fills the central component of the model. This refers to the individuals' alternation between loss- and restoration-oriented coping and has been described as the "process of juxtaposition" of confrontation and avoidance of different stressors associated with bereavement (Eisma et al., 2021) Oscillation represents a dynamic back-and-forth process of coping, focusing on loss-oriented and restoration-oriented work as part of everyday life experience which, in totality, defines the bereavement process by which individuals learn to live with the loss of a significant other (Eisma et al., 2021; Hall, 2014). This process is said to continue to occur for the person who lost a significant other from their lives through death and is the grief work that supports how they adapt to living with this loss in their lives. In time it is anticipated that there may be less 'loss orientated' or 'restoration orientated' grief work occurring in one's life.

Task-based model

Another grief model is the Task-Based Model developed by Worden (2009) which, like the model of Stroebe and Schut (1999), has been described both as a comprehensive framework that guides interventions and enhances a bereaved individual's self-awareness and self-efficacy concerning the bereavement process (Hall, 2014). Worden (2018) proposes that bereavement should be considered as an active process that involves engagement with four tasks as the 'grief work'. The bereaved individual

based on this model is believed to go back and forth covering each individual task in no specific order as they address their grief and adapt to living with the loss of a significant other from their lives.

The four tasks include the bereaved individual's engagement in several areas of grief work which includes: attempting to accept the reality of the loss that has occurred, to work on processing the pain of grief, to adjust to a world without the deceased and to find some sort of connection with the deceased as part of living without the deceased in their lives (Hall, 2014; Worden, 2018). These tasks require the bereaved to actively engage in each and are the focus of the work that counsellors perform with people experiencing grief because of loss through death, if using a task-based model to support.

The first task is 'attempting to accept reality of the loss' and relates to the individual coming to terms with the death and 'realising the impossibility of reunion in their life'. The bereaved person engaging in the work of this task will start to consider spiritual and religious beliefs to ground themselves and interpret what this loss really means to them and how they function and feel connected in their life. The second task, according to Worden (2009), will require the individual to address or analyse the pain associated with their loss, as opposed to suppressing or ignoring it as a method of management. Worden (2018) believes that individuals who chose to avoid addressing the emotional pain associated with loss, through strategies such as alcohol/drugs, avoiding reminders of the deceased, idealizing the deceased or distracting self through work (Worden, 2018), are at risk of suppressing this pain which, if left unaddressed, will return and become more problematic for the individual at some stage during their life. This task essentially involves the individual acknowledging the emotional pain, such as fear, guilt, shame, loneliness, sadness, and talking about them to allow for better understanding and potential to work through them. The third task is adjusting to the world without the deceased and requires the bereaved individual to address three components, which include: internal adjustment and the impact of the loss on oneself, external adjustments which reflect the impact that the loss has had on their everyday connection to the world, and the impact on their spiritual and religious beliefs encompassing their own values, beliefs, and assumptions about the world in which they live. The fourth and final task based on Worden's (2009) task-based model requires the bereaved individual to find a way to connect and remember the deceased through finding an 'appropriate place' for the deceased in their emotional life.

This task is believed to allow the person to resume life in a meaningful way with a different sense of connection to the deceased. It is believed by doing this the bereaved individual can think, reminisce, and connect with the deceased in a positive way while they continue to live their lives.

The task-based model also encompasses several factors that are critical to appreciate and better understand the experience of grief for an individual. These factors include: understanding who the person that died was to the bereaved, and the nature of their attachment, having an adequate understanding of how the person died, and the historical background and experiences that connected the individual with the deceased (Hall, 2014; Worden, 2018). Other factors necessary to appreciate that impact on the grief and bereavement process relate to the personality traits of the bereaved individual which may impact on how the emotional responses are displayed. Social mediators and concurrent stressors which may be impacting on the bereaved individual at the given time that they are managing the loss of a significant other are also significant to the grief and bereavement process (Worden, 2009).

Niemeyer constructivist theory of bereavement

Niemeyer's constructivist theory describes grieving as a process of reconstructing a world that has been challenged by loss (Neimeyer, 2013). It is believed that the individual can be supported in doing this using expressive therapies which will enhance narrative and assist a person to find meaning in their loss, fostering a new perspective or hope to make sense of their situation (Neimeyer, 2013). The constructivist techniques focus on the need for 'meaning making' by the bereaved which is believed to be imperative for the bereavement process. Constructivist theory sees the loss as the challenge for the bereaved individual which requires a reconstructed meaning of his/her story with the integration of the loss into their life (Neimeyer, 2012). It is thought that individuals are motivated to construct meaning through self-narrative because our sense of self is established through the stories that we construct about ourselves and share with others (Neimeyer, 2012).

It is proposed by Neimeyer (2013) that, after the death of a significant other, the bereaved individual is required to engage in one of two general meaning making processes. This can occur via assimilating the loss experience into their pre-loss beliefs and self-narratives which in effect maintains consistency with

who they are/were. This essentially requires some re-construction of their understanding in a way that re-affirms their core beliefs about themselves and the world with loss being part of this (Neimeyer, 2013; Neimeyer et al., 2012; Neimeyer, Prigerson, & Davies, 2002). The idea of 'assimilating' confirms the bereaved losses into meaning so that a reconnection or reconfirmation occurs with for example a social or religious group that assimilate the same values or are in support of the same beliefs which helps to make sense overall of the loss and drive meaning in a situation.

Alternatively, as per constructivist theory, individuals also cope with grief through accommodating the effects of loss. Accommodating the effects of loss occurs through reorganising, deepening, or expanding beliefs and self-narratives to adjust to the new reality which sometimes requires seeking validation or connection with a new field of social group (Neimeyer, 2013). The bereaved is said to have completed meaning making when they come to appreciate the new changes and the personal growth that has occurred during the process. From the constructivist perspective individuals who exhibit a normative grief reaction are successful at engaging in meaning making as discussed either through the concept of assimilating or accommodating to the loss which contributes to their adjustment, and they do this through narrative expression (Worden, 2018).

Adaptive grieving styles

Martin and Doka (2000) conceptualised adaptive grieving styles which are reflections of an individual's use of cognitive, behavioural, and affective strategies based on their own diverse variables which are influenced by their personality and culture. Factors such as culture, gender, socialisation, birth order, temperament may influence grieving styles of individuals according to this grief model (Doka & Martin, 2010; 2011). This model conceptualises grieving styles as being on a continuum with an intuitive pattern on one end and instrumental pattern on the other end and a blended pattern located in the middle of the continuum. These terms or continuum labels are described as the way individuals deal with grief and the processes used to adapt to grief and the loss in their lives.

For example, an intuitive griever focuses most of their work into the affective domain and less to cognitive which means that grief for this individual consists primarily of extreme sadness and painful

feelings and a need to spontaneously express their feelings through crying. In addition, an intuitive griever has a need to express and share these inner feelings with other people. It is therefore important for intuitive grievers to allow time for personal expression of grief and to seek out others who have experienced a similar loss. Talking about loss for an intuitive griever has been described as essential and a very important component of their bereavement process (Doka & Martin, 2011; Martin & Doka, 2000).

In comparison an instrumental griever is less likely to display emotion and or to share their experiences, with their emotional experience theorised as being less intense than an intuitive griever. Martin and Doka (2000) describe an instrumental griever as someone who often reports that “they cannot cry and cannot remember the last time they cried” (p.41). The instrumental griever is believed to adapt to grief with a desire to actively manage their emotions rather than express them with their activity or ‘grief work’ being predominantly cognitive with a focus on problem solving rather than focusing on the pain of loss. The instrumental griever is also less likely to spend time sharing their feelings and if they discuss their loss, they are less likely to focus on feelings but rather the problems associated with the loss such as financial concerns, lifestyle adjustments or the additional responsibilities that they may now need to manage (Doka & Martin, 2021).

The final grieving style and the one that is the most prevalent style for many individuals, according to Martin and Doka (2000), has been labelled within this model as the ‘blended griever’. Blended grievers naturally display active adaptation to loss using a combination of both cognitive and affective ways; however, one style tends to be the most dominant style or approach utilised. The blended griever would, therefore, use both approaches of the intuitive and the instrumental griever, although one approach and the techniques associated with it will be slightly more dominant than the other. This grief model is heavily focused on individuality and how individuality is shaped for people based on their cultural norms, including their gender and social expectations. Doka and Martin (2011) believe this theory is the underlying connection to the fact that “the majority of instrumental grievers are men, and that women are generally more intuitive” (p. 44).

Continuing bonds

The theory of Continuing Bonds challenged the long-standing belief that ties to the deceased person need to be relinquished or that grieving requires 'letting go' in order for adaptation to loss to take place (Klass, 2006). This theory aligns with the idea that an individual learns to grow around loss and this occurs by the identification of ways to continue to connect but through different ways than previously known or experienced. Continuing bonds is therefore a theory that supports a continuing relationship with the deceased and a recognition that death may end a life and not necessarily a relationship (Hall, 2014).

This model conceptualises that an individual learns to still feeling connected with the deceased and this approach becomes a way of adapting and learning to live with the loss of a significant other. The relationship for the bereaved is therefore said to continue with the deceased through several approaches to maintain an ongoing feeling of connection with the individual. For example, the bond with the deceased continues through talking openly to the deceased, visiting the grave, feeling the presence of the deceased and participating in traditions/rituals or linking and connecting with objects and possessions of the deceased (Hall, 2014). Other examples of continuing bonds can be keeping photos of the deceased, incorporating, and acknowledging loved ones in special events, thinking about what advice the deceased would give regarding making important decisions, living life in a way that the bereaved individual knows and that they would be proud or planning to acknowledge the anniversary of the death (Hall, 2014; Stroebe et al., 2010)

The theory of continuing bonds may overlap in some of the grief work for the bereaved as identified in the other theories such as Stroebe and Schut (1999) the dual process model which required the individual to focus on restoration orientated work which includes the development of new relationships and roles. 'Continuing bonds' may also be relevant to Worden (2009) task model that identifies the need for a bereaved individual to find some sort of connection with the deceased without them being physically in their lives as part of the fourth task.

The grief models that have been described have included the: Dual Process Model, Task Based Model, Constructivist Model, Adaptive Grieving Styles and Continued Bonds and these models have conceptualised several different approaches that are significant to grief and the bereavement process. Although each model has described a different theory as to how individuals adapt to loss in their lives, what is common is the complexity of the bereavement process and that each model requires significant 'grief work' from the bereaved individual, to adjust to life without their significant other. It can also be concluded that the individuality of a person including their culture, personality, values, spiritual and religious beliefs impact on grief experience and potentially the approaches that may be adopted by the bereaved individuals to manage their loss. There was also no specific length of time that accounted for the bereavement process with an indication that individuals need to attend to 'grief work' frequently and move back and forward during the process addressing the different aspects or tasks associated with the theoretical models.

It was anticipated at the early stage of the research that dying patients and families receiving end-of-life care by acute care nurses may be actively undertaking their own bereavement process given the circumstances they faced concerning serious illness and impending death. Therefore, this background development concerning bereavement theory was useful knowledge for the researcher to help understand the interactions that acute care nurses reported with both patients and families during end-of-life care.

Bereavement care in the rural setting

The AIHW (2019) indicates that Australians living in rural and remote areas have shorter lives a higher incidence of disease and injury including poorer access and use of health services compared with metropolitan areas. The incidence of death and the rate of potentially avoidable deaths are considerably higher in more remote living areas, with the mortality risk becoming more statistically significant the greater the distance lived from a major city. In 2017, the mortality rate for people living in remote areas was 1.4 times higher for males and 1.5 times higher for females than those who lived in major cities, and

the standardised death rate was lowest in Australia's major cities. The median age of death also decreased with increase in remoteness for both males and females (AIHW, 2019).

The associated higher mortality rates for populations in non-metropolitan regions have been attributed to potential geographical challenges and a reduction in access to health services, lower socio-economical characteristics and a higher population of Indigenous Australians, all risks which are more common in regional and remote areas (AIHW, 2019). The rural location of the study is also associated with a significant disease burden which accounts for the highest incidence of cancer and cardiac disease along with mental health illness in the state (Australian Bureau of Statistics, 2020). The leading causes of death for all regional and remote areas include coronary heart disease, lung cancer, chronic obstructive pulmonary disease (COPD), diabetes and suicide (AIHW 2019).

Within the non-metropolitan hospital settings, nursing staff provide bereavement care as part of the end-of-life care that they deliver to dying patients and their families. No specialty training is required for acute care nurses to deliver end-of-life and bereavement care and nurses in all areas of the hospital with varying levels of experience may be expected to provide this care to patients and families regardless of the unit specialty or location and as part of routine care.

In 1994, Palliative Care Australia devised thirteen Australian National Standards for quality palliative care these national standards have recently been reviewed as a 5th edition and refined to nine standards: care standards (1-6), which describe the systems and enablers necessary to deliver high quality clinical care and governance, and standards (7-9), which focus on quality management, quality improvement and benchmarking (Australian National Standards, 2018). Each standard has been developed to support and ensure quality and consistent practice measures are maintained for patients and their families during end-of-life care. These standards are the benchmark for quality end-of-life care and something that nurses in hospitals should follow in the delivery of care for patients and families.

Within these standards, there are clear recommendations that relate to the care of families during the palliative and end-of-life process. These guidelines have direct implications for nurses in clinical practice, highlighting the need for a support system, a thorough assessment and the appropriate care planning

and facilitation of effective bereavement and grief support measures (Palliative Care Australia, 2019). It is, however, unclear how these standards, particularly those relating to bereavement care, are reflected on and/or delivered to dying patients and their families during end-of-life in acute hospital settings. These guidelines have also been described as being reflected in end-of-life care pathways that are used as resources for nurses in the during the delivery of care to dying patients (Palliative Care Australia, 2019).

Hospital nurses within the non-metropolitan settings are expected to use these end-of-life care pathways as a tool for the delivery of end-of-life care and bereavement care. These end-of-life pathways are attached as appendices to end-of-life care policies and procedures within the hospital services in the study region. At the time of the research the end-of-life care pathways used in the study region were commonly referred to as Pathway for Improving the Care of the Dying (PICD). Although the PICD pathways were all slightly different across the hospital sites, the information provided to prompt the delivery of bereavement care was the same. This information included questions, blank sections or tick boxes allocated to the tool to help prompt the nurse to complete an assessment for a patient and family concerning their psychological, social, spiritual, religious, and cultural needs relating to death and dying. Questions that prompted the offering of chaplaincy and social worker including specific cultural needs or other special needs during and time of death was also provided. Questions for the nursing staff concerning the insight of patients and family members into the condition was also to included and to be assessed by the nurse with the patient and family. Small text box sections to confirm that the plan of care had been explained and discussed with patient and family were also evident on the pathways. Signatures spaces for nursing, medical and allied health professionals were also indicated on the care plan, signalling that the tool was also for multidisciplinary use. Minimal space existed for further documentation except for a final variance page that had single lines allocated for additional information to be added. In all the relevant hospital services, further packs with information/brochures about the bereavement services provided by the Australian Centre of Grief & Bereavement (ACGB) including information about the process of death and dying were available for family members. The practice of

sending condolence cards from hospitals to next-of-kin after the death of patients was occurring at all the non-metropolitan hospital sites in the region.

Within the study region, bereavement assessment was the work of social workers or specialised nurse practitioner /palliative care nurses within each hospital services. Formal bereavement assessment using standardised tools and bereavement risk assessment were not undertaken by acute care nurses in, the region. The absence of a validated bereavement assessment tool to holistically assess bereavement risk is a well-known gap that has been acknowledged within the Palliative Care Social Work Australia meetings. “Due to the lack of empirical evidence to support a particular tool pre-death and prior to 6 months’ post death “structured assessment” through “conversational exploration of risk factors and strength/resilience factors is recommended” Hall et al (2012) as cited in (*National Palliative Care Standards, 2020*).

There is a regional palliative care consortium within the regional setting. This consortium was established in 2011 to support treating teams who have patients in need of specialist input or advice in support of quality palliative care. All hospital services within the region can access nursing support provided by a Palliative Care Nurse Coordinator and/or Palliative Care Nurse Practitioner. The consortium is part of an alliance with fourteen member agencies within the region including all the regional health services that provide inpatient or community palliative care for the residents of Gippsland. The regional consultancy service is one of eight regional consortia established as part of the Victorian Government’s palliative care policy released in 2004. The Consortium’s role is to help deliver and facilitate the Victorian Government’s current policy, ‘end of life care and palliative care framework 2016’, across the region. The regions consortium vision is that people within the region with a life-threatening illness and their families will have access to a high-quality service which provides evidence-based, coordinated care and support that meets their individual needs (Gippsland Palliative Care Consortium, 2017). The regional consortium also supports a clinical practice group to enhance the provision of quality palliative care through the development of common clinical policies and procedures for member services within the consortium. The clinical practice group have representatives from the regional hospitals, local palliative care services, GP’s, palliative care medical, nursing, and allied health

specialists. The consortium also comprises of a consortium management group comprising representatives from each member agency. The consortium management group monitors and reviews the implementation of policy as well as the integration of care for people with a life-threatening illness as well as measuring care for families across the service system (Gippsland Region Palliative Care Consortium, 2017).

In terms of access to grief and bereavement support within the study region, an on-line search in 'October 2014' during the same period as data collection, uncovering approximately 12 local and government agencies supporting grief counselling. Despite the regional consortium having a significant website with information regarding grief and bereavement, enquiries about counselling and support groups were directed from this web page by hyperlink to the Australian Centre for Grief and Bereavement (metropolitan locations). The option for grief counselling and support is also a potential for the community via General Practitioner (GP) referral, however as earlier indicated rural settings, including the one under study, had difficulty attracting and retaining skilled professionals particularly GP's. The region under study had an estimated 144 FTE registered medical professionals per 100,000 people compared to 292 in Victoria as a whole, with other smaller local government areas making up the region having an even lower rate (Gippsland Primary Health Network , 2021).

Within the region under study, the services of a Health Advocate group operate as the local community voice, identifying local issues that are significant to the people of the region with the organisation reporting such issues directly to the Victorian Minister for Health. The Health Advocate group in 2019 presented a report to the Victorian Minister for Health including recommendations to improve end-of-life care and palliative care services in the region. The Health Advocate group report indicated that palliative care outcomes and community experience could be greatly improved through the establishment of a palliative care facility to create a more nurturing and peaceful environment with specialist care for patients and families. The need for a hospice was also described as necessary to provide direct access to spiritual support and provide better respite options for patients and families. Another recommendation was the need for a shift in thinking and a commitment to achieving more of a

home-like environment within the hospital setting, to improve the dying experience for patients and families (Improving Palliative Care Services in Latrobe, 2019). This recommendation was supported by concerns that the hospital environment was clinical and driven by ‘treatment and cure’ with limited space for bereaved families to gather with their loved ones. The report further indicates that because of limited collaboration and coordination of services the palliative care system within the rural area was ‘fractured’ and needed to be more community friendly to assist with improving the end-of-life care and related grief and bereavement care that is provided following the death of patients for families and carers (Latrobe Health Advocate, 2019).

Based on the information presented that supported the theoretical fore-structure of this research, inclusive of the bereavement theory, the rural delivery of bereavement care to patients and families and the researcher’s relationship to the research, a basis for research motivation has been established. In addition, the difference between preparatory grief and anticipatory grief of both patients and families has acknowledged a disparity between individual losses and potential needs in support of grief care. This information has substantiated an overall understanding of bereavement care in the region under study, with further clarity required concerning bereavement care in hospitals and how nurses provide this to patients and families within the region. Therefore, the following research aim and research questions were established.

Purpose and research questions

The overall purpose of this study was to understand how nurses in non-metropolitan hospital settings provide bereavement care to patients and families during end-of-life care. The aim of this study was:

To investigate the roles of registered nurses in the provision of bereavement care during end-of-life care of dying patients, in acute non-metropolitan hospitals.

The specific research questions, developed to accomplish the aim of this study included:

1. What are the roles of nurses in the provision of bereavement care for patients and families during end-of-life care?

2. How do nurses believe they develop competence and confidence in the provision of bereavement care for patients and families?
3. What needs and clinical barriers impact on the nurses' provision of bereavement care for both patients and families, in acute non-metropolitan hospitals?

Summary

This introductory chapter has provided the background into the significance of the research topic and outlined the research aim and study questions. The significant role that nurses undertake in hospitals in the delivery of bereavement care to patients and families has been outlined including issues that may influence the delivery of bereavement care in a non-metropolitan hospital setting. The approaches undertaken in the delivery of bereavement care from a rural community and clinical perspective have also been highlighted. The author's connection to the research topic has also been provided through reflection, to enable an understanding of the influence this experience has had on the study questions. The background information and theoretical and practical information provided have supported the evidence building that is required as theoretical fore-structure for interpretive description.

Structure of the thesis

This thesis presents a study aimed at identifying and describing the roles that nurses in non-metropolitan hospitals perform, as bereavement care during care of patients and their families at end-of-life. The thesis is presented in seven chapters. The introduction chapter has presented the background of the study and highlights the important role acute care nurse have in the delivery of bereavement care along with the complexities that relate to the acute care environment and the skills required to deliver effective bereavement care. The theoretical fore-structure was also outlined for this interpretive descriptive study which orientated the author within the relevant bereavement theory, and the disciplinary context of how bereavement care is provided in a rural setting. The personal and professional connections to the research topic were also described. The aim and the research questions were also detailed as part of the introductory chapter.

In addition to the information provided in the first chapter concerning bereavement theory, the second chapter presents a published systematic literature review that identifies related research papers to define the nurse's roles in bereavement care in an acute hospital setting, following relevant inclusion and exclusion criteria. This review was updated using the same search terms and data bases to identify new information concerning nurse's roles in bereavement care, providing an overview of all relevant literature from 2006 to 2020. Chapter two, using the techniques consistent of systematic review, has synthesised existing qualitative literature relating to the roles of nurses in the provision of bereavement care to complete the theoretical fore-structure required for an interpretive descriptive study. The methods chapter follows, and the approach to data collection and analysis using the methodological basis of interpretive description. Information is detailed concerning the ethics, recruitment data collection and analysis.

Chapter four and five detail the findings of the study, with the results being separated into two distinct thematic groups that relate to the roles that acute care nurses undertake as part of bereavement care. 'The Doing' theme is described in chapter four and details the specific bereavement care roles that the study nurses performed during end-of-life care. 'The coping' theme is described in chapter five and details the impact of delivering bereavement care and how the study nurses dealt with the reality of caring for patients at end-of-life care within non-metropolitan hospitals. An interpretation and discussion of the results is provided in chapter six. The main findings of the study are described through the metaphor of a 'trekking leader', with appropriate application to the literature and relevant bereavement theory models. Barriers and enablers for nurses in the delivery of end-of-life care are also outlined throughout the chapter. The final chapter provides the study's conclusions and enhanced role clarity with respect to how nurses provide bereavement care in acute non-metropolitan hospital. Recommendations for nursing practice, policy, education, and future research have been outlined to finally conclude the thesis.

CHAPTER TWO – Literature Review

Introduction

This chapter includes a published paper of a systematic literature review of nursing roles and responsibilities in providing bereavement care during the care of dying patients in acute care hospitals and review of literature subsequently. The systematic review had a mixed method design and was undertaken using the following databases: Cumulative Index Nursing and Allied Health Literature Plus (CINAHL Plus), Embase, Ovid MEDLINE, PsychINFO, Care Search and Google Scholar. Included studies published between 2006 and 2015 were part of the systematic review, including those that identified nursing participants and were completed in acute care hospitals and concerned the care of adult patients. The results of each of the seven studies that met the inclusion criteria were subject to thematic analysis following critical appraisal, which was undertaken using the guidelines of the Joanna Briggs Institute (JBI, 2014). The review was accepted for publication in the *Journal of Clinical Nursing* in August, 2016, and published in 2017 (Raymond, Lee, & Bloomer, 2017). The review paper also featured as the Editor's Choice Article in the *Journal of Clinical Nursing* during the month of August in 2017.

Systematic review

The published paper, containing the systematic review, is presented on the following pages.

REVIEW

Understanding the bereavement care roles of nurses within acute care: a systematic review

Anita Raymond, Susan F Lee and Melissa J Bloomer

Aims and objectives. To investigate nurses' roles and responsibilities in providing bereavement care during the care of dying patients within acute care hospitals.

Background. Bereavement within acute care hospitals is often sudden, unexpected and managed by nurses who may have limited access to experts. Nurses' roles and experience in the provision of bereavement care can have a significant influence on the subsequent bereavement process for families. Identifying the roles and responsibilities, nurses have in bereavement care will enhance bereavement supports within acute care environments.

Design. Mixed-methods systematic review.

Methods. The review was conducted using the databases Cumulative Index Nursing and Allied Health Literature Plus, Embase, Ovid MEDLINE, PsychINFO, CareSearch and Google Scholar. Included studies published between 2006–2015, identified nurse participants, and the studies were conducted in acute care hospitals. Seven studies met the inclusion criteria, and the research results were extracted and subjected to thematic synthesis.

Results. Nurses' role in bereavement care included patient-centred care, family-centred care, advocacy and professional development. Concerns about bereavement roles included competing clinical workload demands, limitations of physical environments in acute care hospitals and the need for further education in bereavement care.

Conclusions. Further research is needed to enable more detailed clarification of the roles nurse undertake in bereavement care in acute care hospitals. There is also a need to evaluate the effectiveness of these nursing roles and how these provisions impact on the bereavement process of patients and families.

Relevance to clinical practice. The care provided by acute care nurses to patients and families during end-of-life care is crucial to bereavement. The bereavement roles nurses undertake are not well understood with limited evidence of how these roles are measured. Further education in bereavement care is needed for acute care nurses.

Key words: acute care, bereavement, death, grief, hospital, inpatient, nurses

Accepted for publication: 2 August 2016

Authors: Anita Raymond, RN, MN, PhD Candidate, School of Nursing and Midwifery, Monash University, Frankston and Lecturer, Federation University Australia, Churchill; Susan F Lee, PhD, RN, Senior Lecturer, School of Nursing and Midwifery, Monash University, Frankston; Melissa J Bloomer, PhD, RN, Senior Lecturer, School of Nursing and Midwifery, Deakin

University and Centre for Quality and Patient Safety Research, Geelong, Vic., Australia

Correspondence: Anita Raymond, PhD Candidate, School of Nursing and Midwifery, Monash University, PO Box 527, Frankston, Vic. 3199, Australia. Telephone: +61 (05) 51226977.

E-mail: agric10@student.monash.edu

What does this paper contribute to the wider global clinical community?

- Understanding bereavement care roles of nurses' can influence the provision and quality of bereavement care provided within acute care.
- Acute care nurses' need to receive appropriate professional development and training to support their role and ensure quality bereavement care.
- Although national practice recommendations exist for end-of-life care, it is not clear how these recommendations are measured and whether they are fully achieved in acute care hospitals. The development of clearer clinical policy and directive guidelines can support this process.

Introduction

The experience of bereavement is a very individual, extensive and often a difficult journey for the bereaved individual. The bereavement process refers to coping with grief and has been described as the entire period of anticipation, death and subsequent adjustment to living, following the death of a significant other (Christ *et al.* 2003). The experience of bereavement is recognised as one of life's greatest stressors, and this period has been associated with a decline in health status, risk of mortality and psychological morbidity (Buckley *et al.* 2015). Bereaved family members are also known to be at a much higher risk of developing mental and physical health problems (Valks *et al.* 2005).

Bereavement care refers to provisions of nursing care that impact on the grief and the bereavement process for families, this care is commonly provided during end-of-life care for dying patients. Nurses within acute care hospitals are in the unique position to meet the needs of the suddenly bereaved and skilled interventions are necessary in providing psychosocial support to families during end-of-life care (Walker & Deacon 2015).

It has been suggested that a nurse's manner and preparedness for the death of a patient can have a positive impact on the subsequent bereavement experience for families (Buckley *et al.* 2015). Nursing bereavement care for families may include psychosocial care, referral to and supported implementation of interdisciplinary services and the clinical interventions performed to maintain the comfort needs of dying patients (Fauri *et al.* 2000, Jackson *et al.* 2009). Bereavement care includes the process of preparing families for impending death and continues immediately following death and up until patient death (Buckley *et al.* 2015).

Nursing bereavement care is provided for families during end-of-life care. End-of-life pathways and protocol directives also include bereavement care measures (Jackson *et al.* 2009). The origins of the Pathway for Improving the Care of the Dying were to import the principles of palliative care into general hospital wards (Jackson *et al.* 2009). Clarification of the exact bereavement roles that nurses undertake during end-of-life care will help identify exactly what clinical supports are put into place for grieving families within acute care hospitals.

Acute care refers to care received within a hospital setting where a patient receives active but short-term treatment for acute injury or episodes of illness with intent to restore health (World Health Organization 2015). Death within acute care can therefore be an unexpected event, with the resultant grief and bereavement for families of

dying patients more pronounced (Fauri *et al.* 2000, Kent & McDowell 2004, Brown *et al.* 2006, Van der Klink *et al.* 2010). The acute care environment is clinically focused, treatment orientated and often not practical to accommodate grieving families (Valks *et al.* 2005, Caswell *et al.* 2015). There is also a need for hospitals to have more suitable quiet rooms with adequate space and privacy for bereaved families (Al-Quarainy *et al.* 2009).

Some families also feel that they receive minimal information about the end-of-life practices, and others report a discrepancy between the clinical information provided and a need for follow-up bereavement services (Van der Klink *et al.* 2010). Communication between hospital staff and bereaved family members has been reported as ineffective, causing distress and dissatisfaction (Caswell *et al.* 2015). Nurses in acute care settings are also described as lacking confidence in dealing with the psychosocial needs of patients and report they have received insufficient preparation in the care of terminally ill patients (Addington-Hall & O'Callaghan 2009).

In 1994, Palliative Care Australia devised 13 Australian National Standards for quality palliative acute care (2005). Similarly, the Australian Commission on Safety and Quality in Healthcare (ACSQHC) also specify 10 essential elements for safe and high-quality end-of-life care (2015). In the UK, the National Institute for Health and Care Excellence (NICE) described 16 quality statements guiding end-of-life care (2014), and in the USA, eight domains of clinical practice guidelines are described for quality palliative care (National Consensus Project 2013). These extensive and detailed recommendations seek to ensure quality, and consistent practice measures are maintained for patients and their families during end-of-life care. The quality care recommendations are detailed and highlight elements such as the need for a support system, use of a team approach in facilitation of care, thorough assessment and planning, patient-centred communication, bereavement counselling and holistic care encompassing spiritual and religious measures (Palliative Care Australia 2005; National Consensus Project 2013; NICE 2014; ASQHC 2015). Despite these recommendations, the roles that nurses undertake in bereavement care within acute care hospitals are not entirely clear. Nor is it clear, how these recommendations are reflected or measured in the care of patients and their families.

Investigating the roles and responsibilities of nurses' during the care of dying patients can clarify what is involved in the process of bereavement care for families in acute care hospitals. A clearer understanding of bereavement roles will also enable a better measure of how such nursing

provisions align with the recommendations of safe and high-quality end-of-life care. It is also anticipated that a clearer understanding of bereavement care will help to inform the development of bereavement resources and nursing strategies that may facilitate and improve the experience of death in acute care hospitals for patients and families.

Methods

Relevant publications were found in an extensive literature search involving the databases CINAHL Plus, Embase, Ovid MEDLINE, PsychINFO, CareSearch and Google Scholar.

The initial search terms used were as follows: '(bereav* OR (grie* AND death)) AND nurs* AND hospital* AND inpatient*'. These search terms generated limited research studies and the search was broadened to 'bereave* care AND nurs*'. The search was then expanded following review of the related research publications and the reference list of relevant studies. Both quantitative and qualitative design studies were included in the review. The search dates started from 2005, following on from a literature review on bereavement care within acute care hospitals conducted by Brown *et al.* (2006), and all studies up until December 2015 were considered for inclusion in this systematic review. The systematic review was completed using the guidelines of the Joanna Briggs Institute (JBI 2014).

The inclusion criteria used for this systematic review included research publications concerning nursing bereavement care in acute care hospitals and nursing bereavement care concerning adult death. The exclusion criteria included research publications involving multidisciplinary bereavement care other than nursing where nursing bereavement data were not reported separately, palliative care specialty nurses or palliative care settings, paediatric or neonatal patient groups, community services, opinion, commentary, letters to editors, discussion papers and literature reviews.

The database search identified $n = 344$ research publications. Duplicates were removed, and the studies were appraised on relevance of the title and abstract. Inclusion of studies at this stage was reduced significantly by the following exclusion criteria; studies not reporting data provided by nurses separately from other health professionals, studies not reporting data about bereavement roles, studies reporting on bereavement care related to the care of children and not that concerning adult death. Finally, the full text of $n = 27$ studies was examined in detail. A further 19 studies were excluded as nursing data were not reported separately or nursing roles were not adequately described and eight studies remained. The included eight studies were

subject to critical appraisal using the JBI guidelines which outlined a process for the appraisal of qualitative and quantitative evidence (2014). Three researchers undertook the critical appraisal process independently and studies scoring <50% were excluded, resulting in one study being excluded based on low score (Donnelly & Dickson 2012). Having three authors appraise each study independently minimised biases in appraisal scoring and the critical appraisal scores were highly consistent between the three assessors. On completion of the critical appraisal, $n = 7$ studies of which four were qualitative, and three were quantitative. Refer to Appendix 1.

The qualitative findings were extracted and subjected to critical review by the researchers to determine the levels of finding credibility (JBI 2014). Findings were rated as: unequivocal (UE) if the findings were considered to be beyond reasonable doubt; credible (C) where the finding was accompanied by an illustration but lacked clear association; unsupported (US) if the finding was not supported by illustration (JBI 2014). Only one finding, 'family as a patient' (Popejoy *et al.* 2009) was excluded from the synthesised findings as it was rated as US. The qualitative findings were then evaluated via means of thematic content analysis. Thematic content analysis refers to the process of grouping finding illustrations into similar categories (Polit & Beck 2014). Finding illustrations from each of the included studies were also assessed by each of the authors to determine suitability in each category. Themes were generated to suit the finding illustrations within each category. The themes needed to describe the role that the acute care nurse was providing during end-of-life care for patient and families as specified in the overall aim of the systematic review. These categories became the overall synthesised themes. Some synthesised themes required the generation of further subthemes to better represent the findings.

Whilst meta-synthesis is the most common method used for combining and integrating evidence from a number of different studies (Finfgeld-Connett 2010), meta-synthesis was not suitable in this case as the statistical measures used in the studies were not consistent and hence did not enable comparison (Cooper *et al.* 2009). As a result, critical interpretive synthesis was used to incorporate the findings and enable the integration of qualitative and quantitative evidence in a cross-study synthesis of findings (Mays *et al.* 2005, Flemming 2009). Each statistical quantitative data finding was matched to a synthesised qualitative theme adding evidence to the overall synthesised themes. The qualitative findings fitted with the recommendations of the quantitative research and findings were grouped accordingly (Flemming 2009). A synthesised theme table was then

generated to demonstrate the mixed-method finding results with the relevant overall themes and subthemes. Refer to Appendix 3 for the synthesised systematic review findings.

Results

There were four synthesised themes generated from this systematic review, including patient-centred care, family-centred care, advocacy and professional development.

Of the seven studies included in the systematic review all studies used acute care nurses as participants. Three of the four qualitative studies describe the use of phenomenology and interpretive descriptive approach as a methodology. The sample size of the qualitative studies ranged from 15–22 participants. Two of the three quantitative studies detailed a post-test-only survey and Likert scale design. The sample size of the quantitative studies ranged from 91–406 participants. The included articles were conducted in Canada, Hong Kong, Columbia and USA. Refer to Appendix 2 for a more detailed overview of the selected studies.

Nursing roles in bereavement care

This systematic review identified that nurses undertake varied roles in the provision of bereavement care and these roles were complex. The bereavement roles could be separated into four synthesised themes based on the finding data. The overall synthesised themes included patient-centred care, family-centred care, advocacy and professional development (Nelson *et al.* 2006, Hansen *et al.* 2009, Popejoy *et al.* 2009, Arbour & Wiegand 2013, Chan *et al.* 2013, Mak *et al.* 2013, Kurian *et al.* 2014).

The theme patient-centred care was represented in all the included studies and was the most significant theme with four subthemes. Patient-centred care was illustrated by finding data that represented the nurse managing the physical comfort needs of patients, maintaining palliative measures as part of end-of-life care and also the emotional comfort needs of patients. The patient-centred care theme also included the clinical workloads of nurses and the physical environment in which nurses worked. The themes of physical care and emotional care were both equally represented as a nursing role in the findings, as both themes were identified in four of the seven studies (Hansen *et al.* 2009, Arbour & Wiegand 2013, Chan *et al.* 2013, Mak *et al.* 2013, Kurian *et al.* 2014). Seventy percent of intensive care nurses in the study by Kurian *et al.* (2014) indicated their role was to help dying patients come to terms with grief. Facilitating emotional care, another synthesised subtheme

for patient-centred care, involved nurses supporting patients as they come to terms with death. Emotional support within the studies was reflected as supporting and facilitating traditional, cultural or religious practices and spending time with patients to provide psychological support (Hansen *et al.* 2009, Mak *et al.* 2013). Popejoy *et al.* (2009) describe nurses' actively involving patients in end-of-life planning and provide examples of enabling home visits and family to stay/sleep at the bedside as means of emotional support measures for dying patients.

The provision of patient-centred care was also seen to be highly proportional to the clinical workload and physical environment, as both subthemes impacted significantly on the level of patient-centred care that nurses were providing. Four studies indicated that patient workload dictated the amount of time that nurses could spend with dying patients and their families (Nelson *et al.* 2006, Hansen *et al.* 2009, Arbour & Wiegand 2013, Mak *et al.* 2013). The physical environment was also a factor that impacted on the quality of patient-centred care with issues of limited space and privacy for patients (Hansen *et al.* 2009, Chan *et al.* 2013, Mak *et al.* 2013). The studies indicate that nurses spend the majority of bereavement care, attending to the provision of patient-centred care. The provision of patient-centred care is challenging for nurses due to the multiple responsibilities this incorporates and the fact that this care was highly subject to patient workload and working in less than ideal physical environments to care for dying patients (Hansen *et al.* 2009, Arbour & Wiegand 2013, Chan *et al.* 2013, Mak *et al.* 2013, Kurian *et al.* 2014).

A need for increased professional development in the area of bereavement care was identified as another highly significant synthesised theme, evident in six of the seven included studies (Nelson *et al.* 2006, Hansen *et al.* 2009, Arbour & Wiegand 2013, Chan *et al.* 2013, Mak *et al.* 2013, Kurian *et al.* 2014). The lack of professional development in the area of bereavement care was frustrating for nurses, and they often sought guidance from more senior colleagues (Hansen *et al.* 2009, Arbour & Wiegand 2013, Chan *et al.* 2013). Nurses also spent considerable time reflecting on the bereavement care they provided and the measures put in place during end-of-life care for patients and their families, in an attempt to evaluate their own clinical performance and potential for improvement (Nelson *et al.* 2006, Hansen *et al.* 2009, Popejoy *et al.* 2009, Chan *et al.* 2013, Mak *et al.* 2013). Little direction or structure in the process of bereavement support for patients and families was evident; this included the use of interdisciplinary team members and the coordination of their services, spiritual or chaplain care and additional or follow-up care

support measures (Kurian *et al.* 2014). The lack of spiritual support and/or chaplaincy support after hours was another issue, impacting on the quality of bereavement supports (Kurian *et al.* 2014).

Family-centred care was another role of nurses caring for dying patients, and this involved ensuring that family members were given the opportunity to be present at the bedside of patients and making time to support and spend with families (Hansen *et al.* 2009, Popejoy *et al.* 2009, Arbour & Wiegand 2013, Kurian *et al.* 2014). It was evident that a large part of the role that nurses undertook was ensuring that families were provided with opportunities to be with patients, and this involved judging when to contact family members due to change in patient condition and supporting family members at the bedside during their grief (Popejoy *et al.* 2009, Arbour & Wiegand 2013, Chan *et al.* 2013). Sixty-eight percent of nurses indicated that providing bereavement support for families of those patients under their care was considered standard routine work (Kurian *et al.* 2014). Family support measures took the form of providing information about the dying process and providing emotional support and reassurance during end-of-life care (Hansen *et al.* 2009, Arbour & Wiegand 2013). Family support also included the encouragement of a family presence at the bedside which was said to assist families in a better understanding of the dying process and enabled families to say final goodbyes (Popejoy *et al.* 2009, Arbour & Wiegand 2013). Part of the family-centred care also involved a nurse's attempts to create positive memories in ensuring that dying patients looked comfortable, clean and with minimal technological intervention (Arbour & Wiegand 2013).

The final theme was the advocacy role the nurse performed at the bedside. The studies found that nurses ensured that relevant clinical information based on the requests of the patient, family and doctor was communicated and advocated for (Nelson *et al.* 2006, Hansen *et al.* 2009, Popejoy *et al.* 2009, Arbour & Wiegand 2013, Chan *et al.* 2013). The need to be an effective communicator was paramount to the advocacy role, and this role was also connected with the provision of patient-centred care and family-centred care (Popejoy *et al.* 2009, Chan *et al.* 2013). Nurses needed to be patient advocates to ensure that the physical and emotional care needs of patients were being managed (Nelson *et al.* 2006, Hansen *et al.* 2009, Popejoy *et al.* 2009, Arbour & Wiegand 2013, Chan *et al.* 2013). Advocacy roles include communicating with doctors to ensure the patients had appropriate symptom management, listening to the patient and ensuring that their wishes will be honoured and helping the family let go or understand the need to withdraw aggressive or curative care and start

palliative and end-of-life care (Arbour & Wiegand 2013). It was also evident within this synthesised theme that families of patients placed heavy reliance on nurses to contact them whenever any change in a patient's condition occurred (Chan *et al.* 2013). Nurses often described themselves as communication mediators between the family, physician and hospital during bereavement care (Popejoy *et al.* 2009).

Discussion

This systematic review has identified the multiple and complex bereavement roles that nurses have within acute care hospitals. The quality of bereavement care provided to patients and families may be highly dependent on nursing workload demands and the physical environment in which the nurse is working. Bereavement care is also highly influenced by the clinical experience of nurses and the level of professional education in end-of-life care and death competence. There is also some indication that increased guidelines or bereavement programs could better support nurses' providing end-of-life care within acute care hospitals. The systematic review findings are discussed in relation to four themes; patient-centred and family-centred care, workload and physical environment, professional development, collaboration and advocacy.

Patient-centred and family-centred care

Nurses were seen to be integral to the provision of patient-centred care, and this systematic review, like other studies (Thompson *et al.* 2006, Arbour & Wiegand 2013, Chan *et al.* 2013, King & Thomas 2015), has demonstrated that nurses were committed to ensuring patients received a 'comfortable death' or 'good death'. Routine physical care could also be described as a constant backdrop that facilitated nursing interactions with families (Pincombe *et al.* 2003). It was during provisions of patient-centred care that nurses commonly engaged with family members to explain end-of-life care measures and provide support. It was also identified that patient-centred care created opportunities for family involvement in physical care with significant attention provided to a patient's physical appearance (Donnelly & Dickson 2012, Bloomer *et al.* 2015). The systematic review findings were not indicative of when nurses' cease bereavement care for families. There was also a lack of evidence to indicate exactly what roles nurses have with families after the death of patients. Follow-up contact with families, referrals to bereavement counsellors and/or support groups or the provision of written information about grief and bereavement was not evident in the findings and

worthy of further research. It was also unclear how long family members remained with patients after death and how this is accommodated in acute care hospitals by nurses.

The international quality care recommendations produced by Palliative Care Australia, ACSQHC, NICE and the National Consensus Project to ensure quality and consistent practice measures are followed for patients and families during end-of-life care and are essentially very difficult to measure within acute care hospitals, due to a lack of understanding of the procedure and process of bereavement care (Palliative Care Australia 2005; National Consensus Project 2013; NICE 2014; ASQHC 2015). The results of this systematic review provide some indication of the roles and responsibilities of nurses during bereavement care; however, the limited quality evidence validates the need for further research in this area. The quality care recommendation that advised patient-centred communication and shared decision-making was the one quality care recommendation supported as an outcome of the systematic review findings. The synthesised findings which support nurses' acting in an advocacy role confirmed open communication lines between the patient, family and the supporting medical teams, during the care of dying patients' as indicated by these guidelines (Nelson *et al.* 2006, Hansen *et al.* 2009, Popejoy *et al.* 2009, Arbour & Wiegand 2013, Chan *et al.* 2013). Although recommendations exist for safe and high-quality end-of-life care, the inability to measure quality bereavement care or how these recommendations are reflected in practice continue to impact on the quality of end-of-life care, which many studies still describe as extremely poor (Valks *et al.* 2005, Addington-Hall & O'Callaghan 2009, Al-Quarainy *et al.* 2009, Van der Klink *et al.* 2010).

Workload and physical environment

The clinical workload of nurses and the physical environment pose significant challenges to the provision of bereavement care during the death of patients and potentially after death for families. Nurses providing bereavement care also managed other clinical workloads and demands which hindered the amount of time and care nurses could provide for patients and families (Hansen *et al.* 2009, Arbour & Wiegand 2013, Mak *et al.* 2013). The issue of juggling clinical workload demands and providing bereavement care was a regular occurrence (Thompson *et al.* 2006). Issues such as limited space for family meetings and the lack of privacy were identified as physical barriers to quality bereavement care (Thompson *et al.* 2006, Al-Quarainy *et al.* 2009, Nelson *et al.* 2010, Chan *et al.* 2013, Slayter *et al.* 2015).

Peaceful deaths for patients and improved bereavement outcomes for families, have been attributed to provisions of privacy and adequate space to dying patients in acute care hospitals (Thompson *et al.* 2006, Al-Quarainy *et al.* 2009, Slayter *et al.* 2015). In a study by Thompson *et al.*, it was seen that nurses manipulated the care environment to optimise end-of-life care which involved creating privacy by the potential use of private rooms, relaxing the numbers of family permitted to visit and visiting hours times (2006). It is however not known how the issue of workload demands and acute care hospital environments impact on the provisions of bereavement care after the death of patients for families.

Professional development

Professional development needs in bereavement care should be considered in terms of death competence. Shortcomings in death competence for nurses were identified within this systematic review. Death competence has been described as a specialised skill in tolerating and managing patients' problems related to dying, death and bereavement (Gamino & Ritter 2011). Death competence relates to the development of the necessary cognitive and emotional competencies required to manage death or matters related to death (Gamino & Ritter 2011). Cognitive competencies include having the appropriate training and field experience in bereavement care which allow for the identification of individuals who need grief counselling (Gamino & Ritter 2011). Areas such as effective communication, sensitivity in cultural diversity and self-confidence in providing palliative care have also been described as self-competence in death work (Chan *et al.* 2015). This systematic review highlighted that nurses would benefit from additional professional development to improve their readiness and competencies in the provisions of quality bereavement care (Nelson *et al.* 2006, Addington-Hall & O'Callaghan 2009, Hansen *et al.* 2009, Arbour & Wiegand 2013, Chan *et al.* 2013, Mak *et al.* 2013). It was also evident that over 50% of the nurses had not received sufficient education, training or experience for dealing with newly bereaved families and this finding was heightened if the nurse was beginning practice or novice nurse (Popejoy *et al.* 2009) with limited experience (Benner 2013). Deficiencies in levels of professional development were also complicated by the lack of written instruction and/or limited procedures, protocols or algorithms for nurses to guide the bereavement care process and assist with the timeliness of end-of-life decisions (Hansen *et al.* 2009, Chan *et al.* 2013). The positive impact of written instruction and structured bereavement programs to

support dying patients and their families was also recommended in a number of studies (Pincombe *et al.* 2003, Valks *et al.* 2005, Hansen *et al.* 2009, Van der Klink *et al.* 2010, Kurian *et al.* 2014). The mentoring of novice nurses by more senior clinicians in end-of-life care was also described as necessary in the data findings (Arbour & Wiegand 2013). There was evidence to suggest nurses appeared to be learning 'on the job' from other colleagues who provided good examples of bereavement care (Hansen *et al.* 2009, Chan *et al.* 2013). Nurses also spent considerable time reflecting on the bereavement care they had provided and how their interventions had influenced dying patients and families (Nelson *et al.* 2006, Hansen *et al.* 2009, Popejoy *et al.* 2009, Chan *et al.* 2013, Mak *et al.* 2013). Previous experiences of sudden and anticipated deaths of patients and the traumatic responses of families also 'haunted' nurses as they provided care, and this experience was emotionally taxing (Hansen *et al.* 2009, Shorter & Stayt 2010, Kurian *et al.* 2014). These nursing issues relate to limitations in death competence and more specifically emotional competence. Emotional competence relates to having the emotional intelligence and experience to cope and face the suffering of patients and bereaved families (Gamino & Ritter 2011, Chan *et al.* 2015, 2016).

Collaboration and advocacy

Decisions regarding the care of dying patients and families were highly influenced by nurses functioning in an advocacy role during end-of-life care. The activities of nurses and communication of information regarding a patient's condition were integral to decision-making concerning bereavement care. Nurses working in advocacy roles facilitated communication between families and medical teams, to assist in the understanding of end-of-life and bereavement care (Caswell *et al.* 2015, Walker & Deacon 2015). Nurses were also identified as interpreters of information, being able to speak in 'plain language' for families and translating medical information to assist in decision-making (Caswell *et al.* 2015, Slayter *et al.* 2015, Walker & Deacon 2015). The systematic review similarly identified multidisciplinary collaboration, which was integral for the provision of bereavement care in acute hospitals (Pincombe *et al.* 2003, Porock *et al.* 2009, Caswell *et al.* 2015, Chan *et al.* 2016). Multidisciplinary teams commonly included doctors, nurses and social workers who met frequently to plan patient care and family support (Porock *et al.* 2009, Chan *et al.* 2016). Nurses also advocate for dying patients and influence family decisions to attend hospital. Other studies have similarly identified nurses recognising symptoms of

patients being close to death and contacting family with information to facilitate a family presence during death (Caswell *et al.* 2015, Slayter *et al.* 2015). However, following the death of patients within acute care hospitals, it was unclear whether multidisciplinary collaboration continued in attempts to support families with bereavement care. Further research is necessary to determine whether after patient death, nurses work in isolation with families or whether they still use multidisciplinary teams in the provision of bereavement care.

Conclusion

Limited research has been conducted in the role of nurses in the provision of bereavement care in acute care hospitals. Only seven international studies were of high enough quality and met the inclusion criteria for this systematic review. The findings from this systematic review have identified the multiple and complex roles that nurses have in the provision of bereavement care. The synthesised findings of the studies demonstrate that bereavement roles for nurses include patient-centred care, family-centred care, advocacy and professional development. The effectiveness of these nursing roles on bereavement outcomes for families still remains unclear, with further research in this area imperative to help generate conclusive recommendations. The impact of clinical barriers, such as the physical working environment and workload, demands also require further clarification on the provision of quality bereavement care during end-of-life care and after death. The findings of this systematic review imply that nurses may feel underprepared and undereducated in the provision of bereavement care and may have deficient levels of death competence. Further investigation is needed to determine the scope and extent of education and training needed by nurses, to enable them to provide quality bereavement care. The issue of professional development needs to also be considered in terms of competence versus confidence. It should be established whether acute care nurses actually lack competence in knowledge and skill acquisition in bereavement care or instead lack confidence, in applying their knowledge and skills during the care of dying patients and their families. Levels of death competence also need to be investigated. The lack of clear protocols and directive guidelines to support the bereavement process may impact on the quality of bereavement care provided and compound the deficiency in education and professional development within acute care hospitals. It should also be acknowledged that a lack of evidence exists regarding bereavement care roles for nurse after the death of patients and whether nurses work in isolation or

continue to function as part of a multidisciplinary team during this period. The duration of postdeath bereavement care is unclear, including how bereavement care after death is accommodated by nurses within acute care hospitals.

Relevance to clinical practice

The findings of the systematic review indicate the complex and multiple roles nurses have in bereavement within acute care hospitals. It is evident that workload demands and the environment impact on the quality of bereavement care that

can be provided. Acute care nurses find bereavement care challenging and often seek further professional development. It is also evident that whilst national practice recommendations exist for end-of life care, it is not clear how these recommendations are measured and if they are fully achieved in acute care without supportive guidelines or protocols.

Contributions

Study design: AR, SFL, MJB; data collection and analysis: AR, SFL, MJB and manuscript preparation: AR, SFL, MJB.

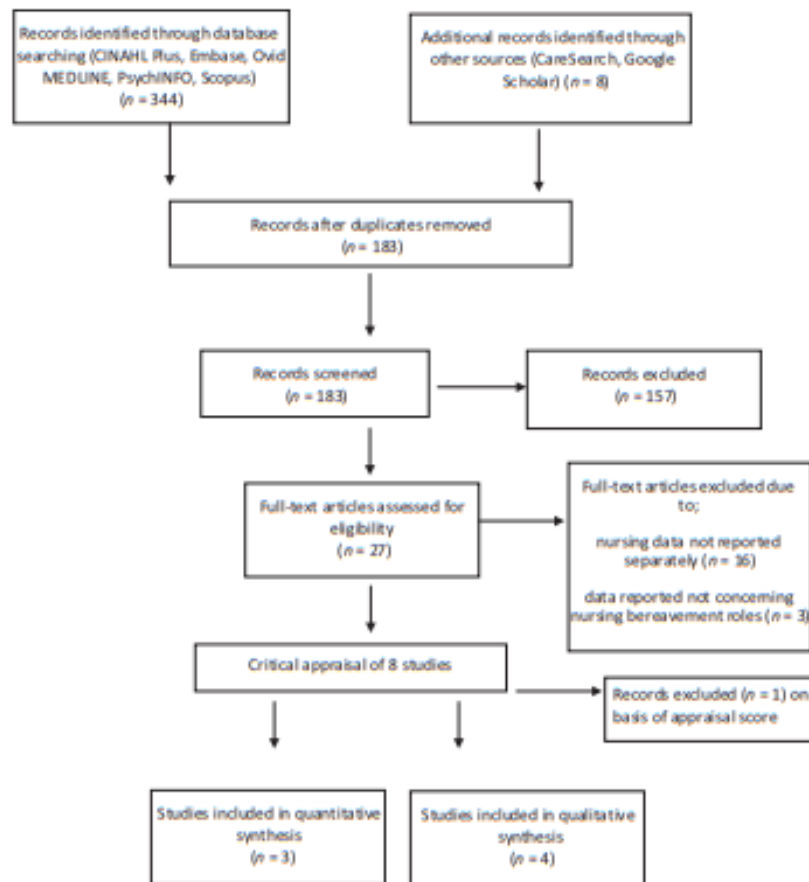
References

- Addington-Hall JM & O'Callaghan AC (2009) A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *Palliative Medicine* 23, 190–197.
- Al-Quarainy R, Collis E & Feuer D (2009) Dying in an acute hospital setting: the challenges and solutions. *The International Journal of Clinical Practice* 63, 508–515.
- Arbour R & Wiegand D (2013) Self described nursing roles experienced during care of dying patients and their families: a phenomenological study. *Intensive & Critical Care Nursing* 30, 211–218.
- Australian Commission on Safety and Quality in Healthcare (2015) *National Consensus Statement: Essential Elements for Safe and High Quality End-of-Life Care*. Australian Commission on Safety and Quality in Healthcare, Sydney, Australia. Available at: <http://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-for-safe-high-quality-end-of-life-care.pdf> (accessed 24 July 2015).
- Benner P (2013) *From Novice to Expert*. Available at: http://currentnursing.com/nursing_theory/Patricia_Benner_From_Novice_to_Expert.html (accessed 20 October 2015).
- Bloomer M, Endacott R, Copnell B & O'Connor M (2015) 'Something normal in a very, very abnormal environment' – nursing work to honour the life of dying infants and children in neonatal and paediatric intensive care in Australia. *Intensive & Critical Care Nursing* 33, 5–11.
- Brown A, Buchan M, Copeland S, Dempster P, Grundy M, Ramadge F, Unwin R, Wicock E, Wimpenny P & Work F (2006) Literature review on bereavement and bereavement care. *Joanna Briggs Collaborating Centre for Evidence-Based Multi-Professional Practice*, The Robert Gordon University, Aberdeen, UK. Available at: <https://www.rgu.ac.uk/files/dmfile/bereavement-and-bereavement-care-literature-review.pdf>
- Buckley T, Spinaze M, Bartrop R, McKinley S, Whitfield V, Havyatt J, Roche D, Fethney J & Toller G (2015) The nature of death, coping response and intensity of bereavement following death in the critical care environment. *Australian Critical Care* 28, 64–70.
- Caswell G, Pollock K, Harwood R & Porock D (2015) Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study. *BioMed Central Palliative Care* 14, 1–14.
- Chan H, Lee L & Chan C (2013) The perceptions and experiences of nurses and bereaved families towards bereavement care in an oncology unit. *Supportive Care in Cancer* 21, 1551–1556.
- Chan W, Tin A & Wong K (2015) Coping with existential and emotional challenges: development and validation of the self-competence in death work scale. *Journal of Pain & Symptom Management* 50, 99–107.
- Chan W, Tin A, Wong K, Tse D, Lau K & Chan L (2016) Impact of death work on self: existential and emotional challenges and coping of palliative care professionals. *National Association of Social Workers* 41, 33–41.
- Christ H, Bonanno G, Malkinson R & Rubin S (2003) *Bereavement Experiences after the Death of a Child*. National Academy Press, Washington, DC.
- Cooper H, Hedges L & Valentine J (eds). (2009) *The Handbook of Research Synthesis & Meta-Analysis*, 2nd edn. Russell Sage Foundation, USA.
- Donnelly S & Dickson M (2012) Relatives' matched with staff's experience of the moment of death in a tertiary referral hospital. *Internal Medicine Journal* 42, 3.
- Fauri DP, Ertner B & Kovacs PJ (2000) Bereavement services in acute care settings. *Death Studies* 24, 51–64.
- Finfgeld-Connert D (2010) Generalizability and transferability of meta-synthesis research findings. *Journal of Advanced Nursing* 50, 204–211.
- Flemming K (2009) Synthesis of qualitative and quantitative research: an example using critical interpretive synthesis. *Journal of Advanced Nursing* 66, 201–217.
- Gamino L & Ritter H (2011) Death competence: an ethical imperative. *Death Studies* 36, 23–40.
- Hansen L, Goodell TT, Dehaven J & Smith M (2009) Nurses' perceptions of end-of-life care after multiple interventions for improvement. *American Journal of Critical Care* 18, 263–271.
- Jackson K, Mooney C & Campbell D (2009) The development and

- implementation of the pathway for improving the care of the dying in general medical wards. *International Medicine Journal* 39, 695–699.
- Joanna Briggs Institute (2014) *Reviewers' Manual*, 2014th edn. Joanna Briggs Institute, Adelaide, SA, Australia.
- Kent H & McDowell J (2004) Sudden bereavement in acute care settings. *Nursing Standard* 19, 38–42.
- King P & Thomas S (2015) Phenomenological study of ICU nurses' experiences caring for dying patients. *Western Journal of Nursing Research* 35, 1292–1308.
- Kurian MJ, Daniel S, James A, James C, Joseph L, Malecha AT, McCorquodale E & Mick JM (2014) Intensive care registered nurses' role in bereavement support. *Journal of Hospice & Palliative Nursing* 16, 31–39.
- Mak YW, Chiang VCL & Chui WT (2013) Experiences and perceptions of nurses caring for dying patients and families in the acute medical admission setting. *International Journal of Palliative Nursing* 19, 423–431.
- Mays N, Pope C & Popay J (2005) Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health Services & Policy* 10, 6–20.
- National Consensus Project (2013) *Clinical Practice Guidelines for Quality Palliative Care*. Available at: http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf (accessed 24 September 2015).
- National Institute for Health and Care Excellence (2014) *End of Life Care for Adults*. Available at: <https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-5-Holistic-support-social-practical-and-emotional> (accessed 24 September 2015).
- Nelson JE, Angus DC, Weissfeld LA, Puntillo KA, Danis M, Deal D, Levy MM & Cook DJ (2006) End-of-life care for the critically ill: a national intensive care unit survey. *Critical Care Medicine* 34, 2547–2554.
- Nelson JE, Puntillo KA, Pronovost PJ, Walker AS, McAdam JL, Ilaos D & Penrod J (2010) In their own words: patients and families define high-quality palliative care in the intensive care unit. *Critical Care Medicine* 38, 808–818.
- Palliative Care Australia (2005) *Standards for Providing Quality Palliative Care* (pp. 1–38). Available at: http://www.health.qld.gov.au/cpre/pdf/standards_palliative_care.pdf (accessed 24 September 2015).
- Pincombe J, Brown M & McCutcheon H (2003) No time for dying: a study of care of dying patients in acute care Australian hospitals. *Journal of Palliative Care* 19, 77–86.
- Polit D & Beck C (2014) *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. Wolters Kluwer - Lippincott Williams & Wilkins, Philadelphia, PA.
- Popejoy L, Cheyney L, Beck M & Antal L (2009) Intensive care unit nurse perceptions of caring for the dying. *Journal of Hospice and Palliative Nursing* 11, 179–186.
- Porock D, Pollock K & Jurgens F (2009) Dying in public: the nature of dying in an acute hospital setting. *Journal of Housing for the Elderly* 23, 1–28.
- Shorter M & Stayt LC (2010) Critical care nurses' experiences of grief in an adult intensive care unit. *Journal of Advanced Nursing* 66, 159–167.
- Slayter S, Pienaar A, Williams A, Proctor K & Hewitt L (2015) Finding privacy from a public death: a qualitative exploration of how a dedicated space for end-of-life care in an acute hospital impacts on dying patients and their families. *Journal of Clinical Nursing* 24, 2164–2174.
- Thompson G, McClement S & Daeninck P (2006) Nurses' perceptions of quality end-of-life care on an acute medical ward. *Journal of Advanced Nursing* 53, 169–177.
- Valks K, Mitchell ML, Inglis-Simons C & Limpus A (2005) Dealing with death: an audit of family bereavement programs in Australian intensive care units. *Australian Critical Care* 18, 146.
- Van der Klink MA, Heijboer L, Hofhuis JGM, Hovingh A, Rommes JH, Westerman MJ & Spronk PE (2010) Survey into bereavement of family members of patients who died in the intensive care unit. *Intensive and Critical Care Nursing* 26, 215–225.
- Walker W & Deacon K (2015) Nurses' experience of caring for the suddenly bereaved in adult acute and critical care settings, and provisions of person-centred care: a qualitative study. *Intensive & Critical Care Nursing* 33, 39–47.
- World Health Organization (2015) *Health Systems and Services: The Role of Acute Care*. Available at: <http://www.who.int/bulletin/volumes/91/5/12-112664/en/> (accessed 2 September 2015).

Appendix 1

PRISMA 2009 Bereavement search flow diagram



Appendix 2

Overview of selected studies

Authors (Year) Country	Aims Study design	Sample/Setting	Method	Results	Appraisal score Appraiser 1 (A1) Appraiser 2 (A2) Appraiser 3 (A3)
Nelson <i>et al.</i> (2006) Canada	Aim: To identify the Barriers to improved end-of-life care in the intensive care Unit. Strategies likely to improve end-of-life care. <i>Quantitative</i>	Sample of nursing and physician directors of 600 Adult ICUs	Self-administered mail survey	Nursing only data barriers: No. (%) rating <ol style="list-style-type: none"> 1 Competing demands for clinician time 80 (14.2) 2 Inadequate communication between ICU team and other clinicians about patient prognosis 89 (15.8) 3 Psychological/Emotional stress of providing care to dying patients 87 (15.4) 4 Insufficient attention to diverse cultural norms and customs with respect to dying, death and grief 5 Insufficient training in communication about end-of-life 83 (14.7) 	A1 = 6/7 A2 = 6/7 A3 = 6/7
Wah Mak <i>et al.</i> (2013) Hong Kong	Aim: Explore the experiences and perceptions of nurses caring for dying patients and their families in the acute medical admission setting <i>Qualitative Interpretive Descriptive</i>	15 nurses	Semi-structured interview	Four themes: <ol style="list-style-type: none"> 1 Lack of preparedness for patients deaths, 2 Reflecting on their own nursing roles for dying patients, 3 Reflecting on the meaning of death and their personal experiences of the death of their own family member 4 Coping with caring for dying patients 	A1 = 8/10 A2 = 8/10 A3 = 8/10
Popejoy <i>et al.</i> (2009) Columbia	To identify intensive care nurse perceptions of caring for the dying <i>Qualitative</i>	365 bed community hospital 22 participants	Focus groups	Five themes: <ol style="list-style-type: none"> 1 Helping the patient through, 2 Telling bad news 3 Grieving as a process 4 Family as the patient 5 The dying patients effect on the nurse 	A1 = 8/10 A2 = 7/10 A3 = 8/10

Appendix 2 (continued)

Authors (Year) Country	Aims Study design	Sample/Setting	Method	Results	Appraisal score Appraiser 1 (A1) Appraiser 2 (A2) Appraiser 3 (A3)
Kurian <i>et al.</i> (2014) USA	To ascertain ICU's nurses' current practice and beliefs about bereavement care, their role in bereavement support and their interest related to bereavement <i>Quantitative</i>	Intensive Care RNs 110 participants	Post-test-only survey design using a convenience sample	No. (%) rating 1 ICU nurses have an important role to play in helping bereaved patients come to terms with their grief 80 (73) 2 Bereavement support to relatives of those patients who were under my care should be routine work 75 (68) 3 Bereavement support to relatives <i>other</i> than those patients who were under my care should be routine work 57 (52) 4 Visiting newly bereaved patients is intrusive to grief 44 (42) 5 ICU nurses should maintain contact with newly bereaved patients (e.g. letter, phone calls)	A1 = 5/7 A2 = 5/7 A3 = 5/7
Hansen <i>et al.</i> (2009) USA	To describe nurses perceptions of (1) knowledge and ability (2) work environment (3) support for staff (4) support for patients and families and (5) stress related to specific work situations in the context of end-of-life care <i>Quantitative</i>	Intensive Care RN's at a University Medical Centre 91 participants phase 1 127 participants phase 2	5 subscale tools consisting of a 30 items scored on a four-point Likert scale Written comments analysed from qualitative description	1 More education and training necessary to support staff with bereavement care 2 Work stress related to end-of-life care 3 Nurses increased confidence with experience in providing end-of-life nursing care and accessing resources necessary for effective end-of-life care 4 Improvements needed for communication between healthcare team and with patients' families	A1 = 6/9 A2 = 6/9 A3 = 6/9

Appendix 2 (continued)

Authors (Year) Country	Aims Study design	Sample/Setting	Method	Results	Appraisal score Appraiser 1 (A1) Appraiser 2 (A2) Appraiser 3 (A3)
Arbour and Wiegand (2013) USA	Understand experiences of critical care nurses and perceptions of activities that they perform whilst caring for patients and families <i>Qualitative</i>	19 Critical Care Nurses Hospital Setting	Descriptive – phenomenological study Interviews	1 Educating the family 2 Advocating for the patient 3 Encouraging and supporting family presence 4 Managing symptoms 5 Protecting families and creating positive memories 6 Family Support 7 Mentoring and teaching	A1 = 8/10 A2 = 8/10 A3 = 8/10
Chan <i>et al.</i> (2013) Hong Kong	Explore the perceptions and experiences of bereavement care among nurses and the bereaved family members <i>Qualitative</i>	15 Nurses 15 Bereaved family members Oncology Unit – Hospital Setting	Semi-structured interviews	Nursing only data: 1 Promoting comfort to dying patient and care to families 2 Physical environment may hinder quality bereavement care 3 Providing bereavement care is emotionally taxing on the RN's 4 Education needs – RN's inadequately prepared to provide bereavement care	A1 = 7/10 A2 = 7/10 A3 = 7/10

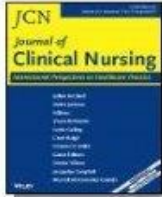
Appendix 3

Synthesised findings table

Synthesised theme	Subthemes	Mak <i>et al.</i> (2013)	Chan <i>et al.</i> (2013)	Popejoy <i>et al.</i> (2009)	Arbour and Wiegand (2013)	Hansen <i>et al.</i> (2009)	Kurian <i>et al.</i> (2014)	Nelson <i>et al.</i> (2006)
Patient-centred care	A: Physical care		X		X	X	X	
	B: Emotional care	X		X		X	X	
	C: Clinical workload	X			X	X		X
	D: Physical Environment	X	X			X		
Family-centred care	A: Facilitating family presence			X	X			
	B: Spending time and supporting families			X	X	X	X	
Advocacy			X	X	X	X		X
Professional development	A: Seeking further education and training in bereavement care	X	X		X	X	X	X
	B: Reflective practice	X	X	X		X		X

Journal of Clinical Nursing

© John Wiley & Sons Ltd



Edited By: Editor-in-Chief: Debra Jackson Editors: Sue Barnason, Carol Haigh, Leslie Gelling and Graeme D Smith

Impact Factor: 1.214

ISI Journal Citation Reports © Ranking: 2016: 52/114 (Nursing (Social Science)); 55/116 (Nursing (Science))

Online ISSN: 1365-2702

SEARCH

In this journal

Advanced > Saved Searches >

Recently Published Issues | [See all](#)

Current issue: August 2017

Volume 26, Issue 15-16

Special Issue: Abuse and Violence in Families

July 2017

Volume 26, Issue 13-14

June 2017

Volume 26, Issue 11-12

May 2017

Volume 26, Issue 9-10

April 2017

Volume 26, Issue 7-8

New Special Issue

New Special issue from the **Journal of Clinical Nursing**
Abuse and Violence in Families

[Download now](#)

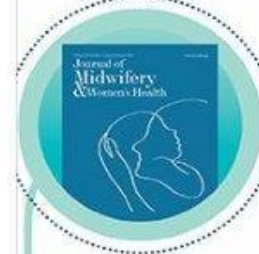
WILEY

Read the latest Special Issue: **Abuse and Violence in Families**, edited by Denise Wilson, Rosa Maria Gonzalez-Guarda and Jacquelyn Campbell

Editor's Choice

Understanding the bereavement care roles of nurses within acute care: a systematic review
Anita Raymond, Susan F Lee, Melissa J Bloomer

Providing bereavement or end-of-life care in acute care settings can be extremely complex and will often challenge the knowledge, skills and expertise of even the most experienced nurses. At the same time, supporting dying patients and their families is a crucial part of bereavement process. In this systematic review, Raymond et al (2017) explore some of the factors that might limit a nursing team's ability to provide high quality bereavement care, including the competing demands of clinical workloads, the physical limitations of acute care settings and further education in bereavement care. Many nurses will have experienced the considerable frustration of not being able to spend as much time as they would like with patients and their families when they need it most. There is only one opportunity to get end-of-life care right and to support all those involved. It might be unreasonable to expect that those needing bereavement care in acute care settings will receive the same standard of care as those being nursed in palliative care settings, but it is undoubtedly the case that much could be done to improve bereavement care in acute care settings. This systematic review highlights some of the issues that need to be considered if this is to be achieved.



2016 Best Review Article from **Journal of Midwifery & Women's Health**

Midwifing the End of Life: Expanding the Scope of Modern Midwifery Practice to Reclaim Palliative Care

WILEY

Review of literature 2016 – 2020

An updated review of the literature was completed, following the methods described in the Raymond et al. (2017) publication in the *Journal of Clinical Nursing*, for the period 2016 to 2020. The search strategy was repeated using the same data bases and search terms, Cumulative Index Nursing and Allied Health Literature Plus (CINAHL Plus), Embase, Ovid MEDLINE, PsychINFO, Care Search and Google Scholar, and the search terms, bereave*care AND nurs*. In total, seven papers were identified (Coombs, Mitchell, James, & Wetzig, 2016; Egerod et al., 2019; Egerod, Kaldan, Coombs, & Mitchell, 2018; Kalocsai et al., 2020; McAdam & Erikson, 2016; Naef et al., 2020; Walker & Deacon, 2016) that met the inclusion criteria of being research studies concerning nursing bereavement care in acute hospitals and nursing roles in bereavement care concerning adult death. A search of the grey literature repository, *Care Search – Palliative Care Knowledge Network*, using previously used search terms uncovered no relevant grey literature related to this review. Overall, most of the relevant new research papers were located within the CINAHL database. All the new papers concerned bereavement care in adult acute, critical care, intensive care or emergency settings, and all the papers had nurses as research participants. The studies were completed in Australia, New Zealand, United Kingdom, Canada, United States of America, Switzerland and Denmark. The evidence within the new papers were extracted and examined for similarity and difference to the synthesised themes generated from the Raymond et al. (2017) systematic review: person-centred care, family-centred care, advocacy and professional development. An additional section on the findings was synthesised from the new literature, related to the timing of bereavement care provided by nurses in acute care.

Patient-centred care

Patient-centred care, which was illustrated in the findings synthesised from the data, was reflected in nurses managing the physical and emotional needs of patients and the impact of the clinical environment on bereavement care. Previous studies (Egerod et al., 2019; Raymond et al., 2017) likewise identified the maintenance of comfort measures in the end-of-life care for patients as a nursing role in bereavement care. No reference was made to the provision of emotional support for dying patients in any of the seven included papers published since 2016. The busy clinical environment was a perceived

barrier for nurses, impacting on their availability of time to spend with patients (Kalocsai et al., 2020; McAdam & Erikson, 2016; Naef et al., 2020), and noise levels within critical care and intensive care units impacted on the respectful delivery of bereavement care (Coombs et al., 2016; Kalocsai et al., 2020).

Family-centred care

Family-centred bereavement care has been defined in earlier published findings (Raymond et al., 2017) as care that ensures family members are given the opportunity to be present and supported during end-of-life care. All seven papers published since 2016 identified family-centred care as a nursing role in bereavement care (Coombs et al., 2016; Egerod et al., 2019; Egerod et al., 2018; Kalocsai et al., 2020; McAdam & Erikson, 2016; Naef et al., 2020; Walker & Deacon, 2016). Family-centred care was evidenced in some of these recent papers through interventions that included the use of an intensive care unit (ICU) diary for families to detail a patient's care in intensive care (Egerod et al., 2019), post-death meetings, handwritten condolence letters or cards (Egerod et al., 2018; McAdam & Erikson, 2016; Naef et al., 2020) and bereavement or follow-up programs (Egerod et al., 2019; Egerod et al., 2018; McAdam & Erikson, 2016). Relaxing visiting times, managing family expectations and grief reactions, providing empathetic gestures (including privacy and selective use of touch), listening, and providing information in simpler terms to enhance understanding were all elements of the nursing role in bereavement care (Walker & Deacon, 2016). The use of memory boxes, which included hand or footprints, locks of hair and photographs, was also identified as contributing to family-centred care (Coombs et al., 2016), with both the delivery of empathetic and emotional support for families (Kalocsai et al., 2020; Walker & Deacon, 2016). Viewing the body of the deceased with family was also described as a role of nurses in bereavement care that was family-centred care (Egerod et al., 2019; Egerod et al., 2018; Naef et al., 2020). Meeting the spiritual needs in the form of coordinating religious supports for both patients and families was also identified as a nursing role in bereavement care (Coombs et al., 2016; Egerod et al., 2019; Egerod et al., 2018; Naef et al., 2020; Walker & Deacon, 2016). Facilitating cultural practices for families after the death of patients was also identified in two of the papers (Coombs et al., 2016; Walker & Deacon, 2016).

Advocacy roles and professional development needs

No advocacy roles for nurses were identified as bereavement care in the more recent papers reviewed.

All, except two papers, identified the need for further education and training for nurses in acute care, to help them feel comfortable and/or to provide effective bereavement care to families (Coombs et al., 2016; Kalocsai et al., 2020; McAdam & Erikson, 2016; Naef et al., 2020; Walker & Deacon, 2016).

Timing of Bereavement Care

The timing of the delivery of bereavement care by nurses to families was unclear in the seven more recent papers reviewed. In four of the seven papers, it was identified that bereavement care was provided to families by nurses from the time of patient death and after patient death in acute care, commonly with follow up or bereavement programs to support families (Egerod et al., 2019; Egerod et al., 2018; McAdam & Erikson, 2016; Naef et al., 2020). In three papers, bereavement care was identified as occurring for families in anticipation of or leading up to patient death and shortly after death (Coombs et al., 2016; Kalocsai et al., 2020; Walker & Deacon, 2016). The actual extent and duration of bereavement care that nurses provided varied, and it was unclear whether bereavement care ceased when families left the hospital or continued afterwards. It was evident that the descriptions of bereavement care typically varied across all seven papers published since 2016 with no standardised practices to describe the nurse's roles in the provision of care. It was also noted that patient-centred care focused directly on emotional support for patients could not be identified in the recent papers, with nursing care roles being family-centred only in relation to psychosocial support.

Summary

The review of literature from 2016 to 2020 identified that a nurse's role in bereavement care is primarily family-centred. Acute care nurses have limited roles as patient and family advocates. Challenges existed for acute care nurses relating to the level of bereavement care provided, due to competing clinical workload demands. Limitations and barriers also existed, related to the acute care environment's lack of privacy and resources, noise levels and the need for further professional development of nurses in bereavement care. Although the review provided information about some of the roles of acute care nurses in the delivery of bereavement care in acute hospital settings, it remains unclear if a

rural/regional hospital setting impacts on how bereavement care is provided to dying patients and their families. It also remains unclear as to how bereavement care is delivered and the timing of its delivery over the course of end-of-life care, for both the patient/family. The systematic review and the review of more recent literature highlighted the knowledge gaps regarding the roles of nurses in the provision of bereavement care in hospitals, particularly within rural or regional health services and the need for further research in this area. The researcher has therefore incorporated a methodological approach to assist in the generation of further information in relation to these knowledge deficit areas, as will be further described in chapter three.

CHAPTER THREE – Methodology

Introduction

In this research study, the establishment of a clearer understanding of the roles that nurses undertake during the care of dying patients in acute non-metropolitan hospital was sought. A qualitative, constructivist paradigm was utilised following an Interpretive Descriptive methodology to accomplish the aim of this study. This chapter outlines the methods undertaken to accomplish the aim, including the research design, site selection, sampling, participant recruitment and the procedures used to collect and analyse the data. The ethical process and limitations relevant to this research design have also been detailed.

Design

The aim and research questions in this study include the description, exploration and understanding of the nursing roles in bereavement care in non-metropolitan hospitals. Questions concerning the competence and confidence of acute care nurses in the delivery of bereavement care, including the barriers that impact on the provision of bereavement care, were also investigated. Understanding how bereavement care is delivered required a methodology that enabled the nurses, as the key providers of care, to reflect and share their experience of caring for dying patients and their families. In doing this, the bereavement care roles that are identified can be better understood from both the study nurse's personal and professional perspectives, alongside the context of the regional hospital setting in which this care is provided.

Therefore, research inquiry undertaken through statistical references or numerical measurements, as used in quantitative methods, would not be an appropriate methodology to describe and understand the roles of nurses in the delivery of bereavement care. A qualitative approach however that allows for the generation of knowledge with extensive description and deeper contextual understanding (Polit & Beck, 2017; Tracy, 2013) was identified as the most effective method for accomplishing the aim of this study. This was also reinforced by the potential for the nurses as participants and providers of bereavement care, to be the narrative informers of the research which again is best achieved through methods of qualitative inquiry (Hulley, Cummings, Browner, Grady, & Newman, 2013). The qualitative

approach of this research was also guided by an Interpretive Descriptive methodology. Interpretive Description will be further described in this chapter, but it should be noted the background development as evidenced in chapter one, has outlined the theoretical foregrounding which was foundational in the overall development of the aim and research questions for this study.

Constructivism and interpretive description

Disciplined inquiry in nursing is generally performed with a view or perspective that follows a particular paradigm (Polit & Beck, 2017). Qualitative research that has a constructivist paradigm is relevant and well-suited to this project, because the voices and experiences of the participants are crucial to the understanding of the phenomenon of interest (Maxwell, 2016; Polit & Beck, 2017). A constructivist paradigm, sometimes called a naturalistic paradigm, can be defined as qualitative research which focuses on understanding a participant's view of reality, within the realms of a specific context setting (Polit & Beck, 2017). Constructivist research encourages the researcher to view and understand experiences through the participant's eyes and this research paradigm assumes that reality is multiple, subjective and mentally constructed by individuals (Aspers & Corte, 2019; Polit & Beck, 2017).

Researchers following a constructivist paradigm interact with those being researched, and the research findings are the product of this interaction, between the researcher and the participants (Polit & Beck, 2017). The constructivist paradigm assumes that reality is therefore not a fixed entity but, rather, a construction of the people participating in it, and emphasises the dynamic, holistic, and individual aspects of human life, which generates understanding and theoretically based conclusions (Creswell & Clarke, 2017; Polit & Beck, 2017). Constructivist studies generate rich, in-depth information that can clarify varied dimensions of a complicated phenomenon (Polit & Beck, 2017), such as the roles nurses have in the provision of bereavement care in non-metropolitan hospitals.

Thorne, and MacDonald-Emes (1997) developed the method of Interpretive Description (Thorne, 2016). Burdine, Thorne, and Sandhu (2021) describe Interpretive Description as "a qualitative research approach with epistemological roots in nursing science" (p.343). This qualitative methodology is applicable to the disciplinary domain of nursing because it can be applied to clinically specific problems

and seeks evidence to understand the problems, from a variety of related contexts (Thorne, 2016).

Qualitative researchers in nursing and other applied disciplines have used an Interpretive Descriptive framework successfully to help answer many contextually embedded questions (Thorne, 2016).

Interpretive Description was selected for use within this research to help generate a deeper understanding of nurses' experiences relating to the provision of bereavement care in the clinical context of an acute non-metropolitan hospital.

Using Interpretive Description the researcher sought to generate in-depth analysis of a clinical phenomenon for which depth and contextual understanding is beneficial, and seek not only to describe but to also provide an interpretative explanation for the findings (Thorne, Stephens, & Truant, 2016).

Interpretive Description is described by Thorne (2016) is an approach to generate credible and defensible new knowledge in a form that will be meaningful and relevant to the applied practice context. Therefore, it is intended that the findings of this research will not only describe the roles of nurses in the provision of bereavement care in non-metropolitan hospitals, but also provide an understanding of why bereavement care is performed this way by acute care nurses.

Thorne (2016) describes two elements that underpin an Interpretive Descriptive study: first, an actual practice goal and, second, an understanding of what we do and do not know, based on the available empirical evidence, from all relevant sources. Although no theoretical framework exists for Interpretive Description, the approach is anchored by the foundations of theoretical fore-structure, which encourages researchers to locate themselves within the "field and the theoretical world that surrounds it" p.6 (Thorne, 2008). Thorne (2016) describes several related concepts that are necessary when applying theoretical fore-structure, including locating theoretical allegiances to the study, locating themselves as the researcher within the relevant discipline and locating personal relationship with the ideas held concerning a study. Each element represents an intellectual exercise in which the researcher needs to engage, to ensure 'integrity of purpose' and to help confirm that the findings generated are developed through empirical contributions and the product of systematic inquiry (Thorne, 2013; 2016). This will be described further in the next section.

The application of Interpretive Description enables the researcher to identify and be clear about the practice or research goal which, for this research project, is to describe and understand the roles of nurses in the provision of bereavement care, in acute hospital settings. Interpretive Description calls on the researcher to incorporate and evaluate all of the evidence, from all sources, to understand the clinical phenomenon (Thorne, 2008). In this study, the empirical evidence primarily included the interviews with the study nurses, which represented not only the roles of nurses in the provision of bereavement care but also included information concerning the non-metropolitan regional acute care settings. Other information relating to how bereavement care was provided within the region and relevant bereavement theories was also necessary to integrate to better understand the nursing role.

Interpretive Descriptive studies enable not only the description of a clinical phenomenon but also an 'explanatory' interpretative analysis (Thorne, 2016). Research undertaken using this methodological framework explores the various features of a common issue, seeking understanding of the complexity and demonstrating a manner in which individual instances contribute to a general pattern or process of behaviour (Thorne, 2008; 2016). Seeking explanation and reasoning behind the processes and practices of bereavement care undertaken by acute care nurses in the context of a non-metropolitan hospital was necessary, including enquiry into barriers to delivery of this care and the study nurse's confidence and competence concerning this nursing role.

Theoretical framework

The initial stages of this Interpretive Descriptive study required the construction or 'theoretical scaffolding' that supported understanding of phenomenon of interest, and the development of the aim and research questions for this study. Within chapter one, a description of theoretical bereavement models and information concerning how bereavement care is provided in the context of the relevant regional setting has been provided. The personal connection to the research topic is also established by the researcher as a component of the required theoretical fore-structure. Chapter two also supports the enquiry into bereavement care identifying nursing roles in bereavement care in the context of acute non-metropolitan settings through a review of literature from 2005 to 2020. This work has provided the 'scaffolding' for the study and has helped to researcher to 'locate' themselves within the disciplinary

field and begin to understand the elements that impact on how and why (Thorne, 2016) nurses provide bereavement care in a particular fashion.

Trustworthiness and credibility

Various evaluative measures in support of trustworthiness and credibility have been applied to the design of this qualitative study. One prominent evaluative framework is that of Lincoln and Guba who identify four strategies to enhance the quality of the qualitative research (Polit & Beck, 2014). The four evaluative criteria include: credibility and confidence in the truth and the value of the data and its interpretation, dependability referring to the stability or the reliability of data over time, confirmability that refers to congruence between two or more people that the data is accurate, and transferability which refers to the extent at which the qualitative findings could be transferred to or are applicable to other settings or groups (Polit & Beck, 2014).

To increase the likelihood that the findings from this study would be credible and trustworthy, several techniques described by Polit & Beck (2014) were also employed in this research. This included using techniques such as 'prolonged engagement' in that sufficient time was devoted to collect in-depth and descriptive data in interviews over a time-period sufficient to ensure adequate data saturation, as well as ensuring the views of participants were adequately represented in the data. Data collection was therefore undertaken over a 12-month period, with interviews on average taking one hour to complete, with the possibility of re-interview, as per the participant information form, should more clarity be required by the participants in relation to their responses. This included techniques such as intensive listening, careful probing during the interview sessions and the use of open-ended questions. Two pilot interviews were recorded and scrutinised by the research team prior to the participant interview sessions to ensure the interview process would be effective. The interview sessions also were undertaken without a script with prompts used to lead discussion ensuring the interview was a more comfortable conversation. A relaxed interview has the capacity to maximise data collection, and the information exchange more fully reflecting the ideas and beliefs of the participants (Polit & Beck 104). In addition, the interview sessions were recorded and the verbatim transcribed exact to the audio recording. To ensure the information collected was accurate, the research team also confirmed the

transcription documents were a correct representation of the audio recorded for each interview session. On two occasions participants were also asked back for a second interview to clarify the interpretation of information they shared during the first interview session. This process reinforced and enhanced some of the areas in the data that required further clarity ensuring the information collected was accurate and reflected the views and perceptions of the study nurses.

The method of data triangulation which involved 'space & person triangulation' was also applied to this research to help strengthen the credibility of the data (Polit & Beck 2014). This involved ensuring that the recruited participants were from different hospital sites in the same region, with varied years of nursing experience and of different genders in the sample group in attempts to validate the data through multiple perspectives (Hulley et al., 2013). During analysis of the study findings 'investigator triangulation' was applied by the supervisors and the student researcher who all undertook the data analysis. An independent review of the different narrative text responses occurred through the review of data constituting each theme and the overarching themes to validate the different groups of data. This process also minimised the possibility of biased decisions and minimised personal interpretations of the data impacting on the results that may occur if the data analysis process was limited to a single investigator.

An audit trail was also instigated throughout the data analysis process which included systematic storage of the related finding documents via access to the Lab Archives platform through Monash University. A record of the progressive working documents that supported the concurrent data analysis which was occurring during data collection was also kept, including the open coding work of data to generate the themes and subthemes in relation to the aim and research questions. The NVivo 11 program was also utilised to support the qualitative analysis and existed as an audit trail in support of the qualitative analysis process. These methods ensured the possibility of replication of the finding analysis process which supports the credibility and trustworthiness of the research findings.

In addition, Thorne (2016) suggests that credibility must extend beyond the adherence to generic methodological frameworks, and that Interpretive Descriptive studies can apply several evaluative criteria to the output or product of the research. These alternative methods to support the credibility of

qualitative inquiry for Interpretive Descriptive studies are known as epistemological integrity, representative credibility, and analytic logic (Thorne, 2016). For the findings of the study to be credible the research process must reveal a research question that is consistent with the stated epistemological standpoint and the research questions posed and that the interpretation of data is logical in response to the question (Aspers & Corte, 2019).

Epistemological integrity was reinforced through the work of the theoretical fore-structure that helped to provide the framework for which the aim and research questions were developed. Analytic logic was also necessary and reinforced the need to follow a research process, develop an audit trail and provide reasoning and pathways that supporting data analysis. The analytic logic also forms part of the theoretical fore-structure that supports the interpretation and knowledge development relating to the research output or finding claims (Thorne, 2016). Interpretive authority is the requirement in that qualitative studies reveal truth external to the researcher's bias or own experience and that the research interpretations are fair and trustworthy (Thorne, 2013, 2016). This process was confirmed through the early exercise of writing a reflective piece concerning my own experience of bereavement care in the region and considering this information in the theoretical fore-structure of background development of the research in which my connection or relationship to the research question was identified, to identify my experience separately from the experiences of nurse participants in this study.

Site selection

Acute care nurse participants recruited to this study worked in the south-east region of Victoria. The region extends from the edge of Melbourne's metropolitan region in the west, eastwards to the New South Wales border, with the northern boundary formed by the edge of alpine country, with the coastline and Wilsons Promontory comprising its southern border (gippsland.com, 2015). Six local council areas (LCA) make up the regional area boundaries and they include Bass Coast, Baw Baw, East Gippsland, South Gippsland, Wellington and Latrobe (Australian Bureau of Statistics, 2020). The Australian Bureau of Statistics (2020) indicates a combined population of approximately 290,987, which includes populations of 37,445 in Bass Coast, 54,884 in Baw Baw, 47,725 in East Gippsland, 30,248 in South Gippsland, 44,770 in the Wellington Shire 44,770 and 75,915 in the Latrobe Shire.

The deaths within the region account for 2,857 persons per year in 2019, with the highest number in the greater regional area of Latrobe (810 deaths) which also has the highest population group for the region (Australian Bureau of Statistics, 2020). The largest hospital within the region accounts for 313 beds for treatment to account for population of 75,915 in total, followed by the second largest hospital within the region accounting for 99 beds per 54,888 populations. Both hospitals as earlier identified were selected as non-metropolitan hospital sites for inclusion based on their sizes, acute care beds, nursing staff and deaths in the region. Both hospitals provided acute care services with a mixture of in-patient medical/surgical and high acuity units. Neither of the hospitals had specific palliative care units. A total of approximately 740.9 FTE of nursing staff were employed at one hospital and a total of 329.19 FTE of nursing staff employed at the other participating hospital site (Latrobe Regional Hospital Annual Report, 2020; West Gippsland Healthcare Group, 2020). Participants were also recruited as attendants at the regional Acute Care Symposium, which was an approach providing greater outreach into the region and acute care nurses working at the three smaller hospitals within the region.

Sampling

This study sought participation from registered nurse participants who were employed in one of the non-metropolitan hospitals within the region and provided end-of-life care. Registered nurses who worked in an acute care setting in a non-metropolitan hospital and provided end-of-life care to dying patients and families were potential participants in this research project. This participant 'sample group' identified as best to describe the roles of acute care nurses in the provision of bereavement care were the registered nurses working within regional hospitals, that were providing end-of-life care. Enrolled nurses were not recruited into this study under the precedence that the roles performed during end-of-life care may be different to that of registered nurses, and the likelihood that registered nurses would be of higher number in acute care units of benefit to recruitment.

The inclusion criteria for participants in this study included being a registered nurse, having worked in an acute care, non-metropolitan hospital and having provided end-of-life care for patients. The exclusion criteria for participants in this study included having a palliative care speciality with a certificate, diploma, masters, or higher degree in palliative care nursing, working in a non-acute hospital setting or

with no experience in caring for a dying patient. It was thought that acute care nurses having specialty training in palliative care nursing would influence their roles in the delivery of bereavement care, so these candidates were not included in the overall sample.

Given the goal of this study was to provide a meaningful clinical description of bereavement care roles through the 'disciplinary lens' of an acute care nurse and following a qualitative approach, a smaller sample size was predicted (Thorne, 2016). It was initially anticipated that a total of 20 to 40 participant responses would ensure data saturation however Interpretive Description avoids using 'data saturation' as a justification for sample size based on inestimable variation in relation to participant experiences (Thorne, 2016). Data saturation for this study was actually occurring at the eighteenth interview and, after the completion of the twenty second interview, the researchers concluded that no new data were being identified and there was clear repetition of information being exchanged (Polit & Beck, 2014; Streubert & Carpenter, 2011); and no further interviews were undertaken.

Purposive sampling and snowballing were used in this study as the main method for sampling. Purposive sampling was necessary as a select health professional that being a 'registered nurse' working in acute care hospitals was identified as the necessary population group to include from the regional setting. Polit & Beck (2014) describe purposeful sampling as necessary when researchers select participants based on who will be the most informative for the purposes of describing a phenomenon. Snowballing was another strategy used in the sampling as the registered nurse participants provided an opportunity for referrals to other nursing colleagues in their hospitals. Strategies were therefore employed to capture a large number of potential nurse participants at the two larger hospital sites selected, but also from within the wider region through the acute care symposium event with supported greater outreach. This occurred through a detailed recruitment process as will be further discussed in this chapter under recruitment and consent. With other methods such as using internal promotion strategies within the hospitals through relevant Unit Managers working in acute areas who shared the project details through staff email distribution. The researcher also asked each participant after their interview session to share the study's research flyer and information regarding the project with other nurses who may be interested in the research. In addition, the research flyers were on display within relevant staff only

areas in tearooms and handover rooms within the hospitals, to promote interest and the effect of network sampling. The snowballing strategies proved beneficial in that clusters of staff from the same units were noted as participating. Two nurse participants also became strong promoters of the research within in-patient areas at separate hospital sites, which also allowed for effective snowball sampling within these areas. The researcher also presented this study's systematic literature review at the regional annual acute care symposium in November 2016 and promoted this research during the presentation as well as the necessary participant information to encourage participation. The attendants at the symposium as further detailed upcoming in this chapter, would have also received information regarding this study as a method for potential recruitment through email distribution from a member of the symposium committee prior to their attendance. This approach was also considered part of the purposive and snowballing sampling strategies used in this study and enabled a broader recruitment of acute care nurses within the region.

Nurse participants were recruited with acute care experience in medical, surgical, emergency, critical care, midwifery, renal and oncology units within the region. The participants had a varied range of nursing experience which ranged from 3-37 years in the acute care settings. Twenty-two participants overall volunteered to be part of this research study, most being female, and one male participant. Two of the participants agreed to be interviewed on a second occasion to clarify and expand on parts of the information they initially provided during the first interview session to ensure maximal data collection, clarity and expansion of key finding areas. Twelve participants were recruited as Hospital Nurse Participants, three participants recruited through the Health Alliance website and seven recruited through the Acute care symposium, these methods of recruitment will be further discussed.

Recruitment and consent

There were three potential participant samples for this research study. In accordance with the ethical approvals, participants were recruited from several sources. The participant samples consisted of nurses who were recruited from acute care hospitals in the region, nurses attending a rural symposium and nurses who were subscribers to the rural health alliance web site. A separate participant information

and consent form (PICF) was developed for each three participant sample groups, please refer to Appendix 2.

Hospitals

Flyers outlining details of the project and researcher contact information were posted on various staff-only notice boards / handover rooms within the two largest hospital sites in the region, to promote the project and recruit participants for this research. Location sites and contact for flyers distribution within the hospitals, were identified via the Hospital Research Ethics Committee review process. Please refer to Appendix 3 for the two different flyers used for the promotion of the study, with one produced for the recruitment of hospital nurse participants and one produced for recruitment of acute care symposium participants. The Nurse Unit Managers (NUMs) of the emergency, critical care, medical and surgical departments' sites were sent an email, which included a short summary about the project, the participant information and consent form. The researcher requested that the NUMs forward this email to all nursing staff working within their departments. Potential participants, who received the email from their NUM, could choose to indicate their willingness to participate in the project by email or making phone contact with the researcher. The researcher also attended a NUM hospital meeting at one of the hospital sites to promote awareness and interest in the research project and encourage staff participation. This was the largest participating hospital site with the greatest number of equivalent full time nursing staff, which was considered advantageous as a potential recruitment approach.

Acute care symposium

This study was also promoted through access to an electronic mail list for nurses who had previously registered to attend a regional acute care symposium. The annual symposium was a professional development event on the care of acutely ill patients in regional locations. The symposium, which is held annually, attracts on average 200 to 250 acute care nurses from the wider south-east region of Victoria annually.

A member of the symposium's organising committee forwarded an email with information about the project, including the participant information and consent form along with the contact details of the

researcher, to encourage participation. This promotional email was sent on two occasions by the member of the organising committee one month apart from the original distribution date.

The researcher also submitted an abstract to present the systematic review publication which had been accepted for publication in the Journal of Clinical Nursing in August 2016 (Raymond et al., 2017) at the November 2016, Acute Care Symposium. The abstract was accepted, and the researcher presented to the acute care nurses within the region to encourage interest and potentially further recruitment into the study. This approach further supported the emailed PICF and project information that the participants had already received regarding this study.

Health Alliance Website

A wider rural population of nurses was also targeted by means of promoting the research through a regional health alliance website. The collaborative, web-based organisation is a communication network for over twenty acute care and primary care service providers across the wider region in Victoria. Information concerning the project was posted on this website under 'news' with a link to the participant information and contact details of the researcher to also encourage participation. The researcher contacted the relevant Information Technology staff member at the relevant hospital sites to share the project details. The Information Technology department contact was identified through the Hospital Research Ethics Committee review process with relevant contact details shared with the researcher following ethics approval.

This information remained on the health alliance site for the duration of data collection to encourage opportunities for participant recruitment. The researcher was not a member of the Health Alliance Website during recruitment. Participant recruitment commenced via all of the three methods outlined in October 2016. By the end of December 2016, 25 individuals had returned PICF's and expressed interest in being interviewed,

Data collection

Interviews commenced on the 31st of October 2016 and 22 interviews had been completed by the 5th of May 2018. It should be noted that although 25 PICF's were returned to the researcher, one potential

participant did not meet the inclusion criteria given their palliative postgraduate qualifications and the two other potential participants, did not respond to contact made to schedule an interview with one declining at the point of scheduling an appointment for interview.

Data collection for this study involved semi-structured interviews with the registered nurses who had provided end-of-life care to patients in acute care non-metropolitan hospital settings. The interview sessions with each nurse participant took, on average, one hour to fully complete. The participating hospitals provided office space and/or vacant tutorial rooms to conduct the semi-structured interview sessions. The use of a private space for interview sessions minimised the risk of interruption. All interviews were held at a convenient time for the participants.

Information was sought about interviewing styles and techniques for effective interviewing sessions in preparation for the recruitment of participants. The researcher as earlier discussed performed two pilot interview sessions with nurses not otherwise eligible for the study but who had the relevant nursing experience, in preparation for the data collection. Each of these interview sessions were audio-recorded. Both interview sessions were critiqued by the research project supervisors, and this feedback was used to refine the researcher's approach to the interview questions and techniques employed.

During the study interviews, the researcher took measures to avoid formality and ensure each nurse participant was as relaxed as possible during the interview session to encourage maximum discussion and data collection (Josselson, 2013). Some of the interview techniques used to minimise formality included rehearsing the questions to ensure plain language was used and with a relaxed approach, guiding the interview session without a script, ensuring that morning or afternoon tea was offered to the participant during the session, and sitting at an angle adjacent to the researcher rather than directly opposite. Minimising formality allowed for the participants to feel more relaxed and comfortable which is necessary to help build rapport and open discussion during the sessions. No notes were taken during the session as the interviews were recorded, however some points were noted during the interview on paper to remind the researcher to come back to these areas for further discussion. Interviews commenced on the 31st of October 2016 and 24 interviews with 22 participants had been completed by the 5th of May 2018. As previously indicate, two participants were contacted for a second interview to

further extend the narrative around some of the key research concepts discussed. This allowed for further clarity and expansion on some of the issues discussed that the researcher felt needed deeper explanation. Consent for the second interview with the research participants was established through the initial PICF under item 3 (Appendix 2).

Semi-structured interviews

A semi-structured interview was considered the most effective method of data collection for this research study, to illicit the experiences of registered nurses in their provision of bereavement care. A semi-structured interview allowed the participants the freedom to express their own views in their own terms, unlike a structured or standardised interview which utilises a pre-set list of questions that dictates participant responses (Josselson, 2013).

Following a semi-structured interview technique also ensured that the flow of the discussion was guided by specific research statements without specifically structured questions, allowing for individuality in interpretation and an opportunity for story telling (Streubert & Carpenter, 2011). Again, no script was used, as the researcher remembered the research questions and guided discussion around these concepts. Please see Appendix 4 for the topics of discussion used to guide the interview sessions. The researcher often opened the interview asking for a participant to share an experience of end-of-life care and this clinical experience guided the subsequent interview discussion and focus. Prompts were used during the interview sessions by the researcher to help increase the potential for information exchange and flow and to promote clarity of dialogue in key conceptual areas (Josselson, 2013).

Individual semi-structured interview sessions were selected, rather than focus group sessions, to avoid the 'group think' process in which the stronger group members overpower discussion or influence verbalisation or opinions of other group members (Streubert & Carpenter, 2011). The complex nature of bereavement care, as experienced by the nurse participants, also needed to be expressed without influence from other participants and individually, so rich clinical experiences could be identified. During the interview, the researcher reinforced the principles that the project was focused on participant

experiences and there were no incorrect answers, as an attempt to avoid participants telling the researcher what they thought should be reported, rather than sharing the realities of their practice.

Ethical approval

Ethics approval was firstly obtained through submission of an on-line National Ethics Application Form for review by the relevant Hospital Research Ethics Committee at two of the larger acute non-metropolitan hospitals in the region. Hospital Research Ethics Committee ethical approval (Project No 2015-35) was obtained in July 2016, for both participating hospital sites. Following Hospital Research Ethics Committee approval, ethics approval was then sought through Monash University. Monash University ethics approval (Project Number 0540) was obtained in August 2016. Please see Appendix 5 for the Hospital Research Ethics Committee and Appendix 6 for Monash University ethics approval certificates.

Research that involves humans as participants can raise ethical concerns regarding inconvenience or risk of harm in pursuit of advancing scientific knowledge and research benefit to others (Hulley et al., 2013). Current guidelines for clinical research encompass three ethical principles that have been established to guide the safe research on humans and they are articulated as respect, beneficence and justice (National Health and Medical Research Council, 2018). Respect for the participants requires the investigator to obtain informed and voluntary consent with the right for the participant to discontinue participation at any-time. The principle of beneficence requires the scientific knowledge to be gained from the study outweighs the inconvenience and the risk experienced and if risk is a potential this is minimised. The third principle of justice requires that the benefits and the burdens that might be the direct result of participation are distributed fairly and provide for equitable access given any associated benefits for the research (Hulley et al., 2013).

The researcher firstly completed a Research Integrity module in June 2016, prior to ethics submission which was accessible for PhD students as part of Monash University coursework for students. The researcher also completed the requirements necessary for a Good Clinical Practice Certificate in November 2018 to support ethical research conduct. In addition, application of respect, benefit and

justice were applied to this study, and it was determined that these principles were maintained ensuring ethical research conduct. All the participants provided information and written consent and the data has been protected in a limited access data base and de-identified. It was in fact not anticipated that any participant would experience harm or physical discomfort during data collection sessions. If nursing participants were to become emotionally distressed during any of the interview sessions, appropriate referral to the hospitals Employment Assistance Program (EAP) was determined as the best arrangement for support and professional counselling. It was imperative that appropriate qualified staff, who were also not members of this research team were utilised as necessary in support of participants if the situation arose. No participants required the use of this intervention during or after any of the interview sessions. It should be noted that participation in the study was also entirely voluntary, and participants could refuse to answer any interview questions if they felt uncomfortable or distressed. Participation in this project was also justified by the potential of the research to enhance the quality of bereavement care to dying patients and their families within non-metropolitan hospitals. There were also perceived benefits to the nursing participants themselves, as the interview session could provide the opportunity to enhance role clarity of bereavement care through open discussion about the process and how it is delivered as part of end-of-life care with the interview session providing a chance for enhanced clinical reflection.

Data analysis

The first eight interview recordings were transcribed verbatim from the audio MP3 file into de-identified text by the researcher. Self-transcribing has been described as beneficial for improving technique as an interviewer, ensuring rich detail or description is kept in the transcript and to assist the researcher in identifying major themes and concepts that promote an intimate understanding of the verbatim (Corners, 2015). Streubert and Carpenter (2011) describe a qualitative researcher's position as never fixed but an on-going process of self-critique and self-appraisal, which can effectively occur during the process of data transcription.

Self-transcription also assisted the researcher to have a better understanding of the data and enabled early patterns and trends in the verbatim to be identified, leading the way for the process of thematic

analysis. The transcriptions of the remaining 14 interviews were subsequently completed by a professional transcriber. Each of the transcripts were checked against the audio for completeness and accuracy. All the transcriptions and audio recordings were reviewed multiple times by the researcher to ensure immersion in the data. The supervisors also had access to the audio recordings and the transcribed documents to ensure this process was completed accurately which also supported their engagement and understanding with the data. Each participant session was named after the order of the interview sessions, and this ensured the participant remained anonymous. For example, Interviewee 1, Interviewee 2 and so on to Interviewee 22. Interviewees 1 and 4 had two parts to their interview as these participants were called back for second round interview sessions. Therefore, although 24 interviews were completed two interviewees were interviewed twice, which meant a total of 22 participants, but 24 interview sessions were completed in total, for this study.

Early data analysis was occurring from the commencement of transcription by the researcher and, subsequently, during the period when interviews were undertaken and afterwards, which was foundational for the upcoming process of thematic analysis. Thematic analysis is commonly used to analyse narrative forms of data and has been described as a reliable, qualitative approach to analysis (Polit & Beck, 2014; Streubert & Carpenter, 2011; Vaismoradi & Turunen, 2013). Thematic analysis involves the search and identification of common themes in narrative data and is a method used for identifying, analysing and reporting patterns or frequencies that extend throughout qualitative data sets (Vaismoradi & Turunen, 2013).

The 22 transcripts for this research study were all subject to thematic analysis, with two major themes and related subthemes developed from the data. Several steps were followed in application of thematic analysis which firstly involved the researchers familiarising themselves with the data (Kiger & Varpio, 2020). The process of self-transcription as earlier discussed supported this process, including the application of NVivo 11 Plus (2020) which required accurate entry of all the transcripts into the program.

The second step, undertaken as part of the thematic analysis process, was to generate initial codes from the data (Kiger & Varpio, 2020). Using the NVivo 11 Plus (2020) program, text dialogue was organised, based on patterns and similarities in meaning, which also reflected any pertinent issues raised in the

data (Braun, Clarke, & Hayfield, 2019) in relation to the aim and research questions. The NVivo11 program supported the movement of text to identify similarities or dissimilarities in meaning, and provided the ability to reduce or expand concepts as required. The NVivo 11 program also enabled the representation of the codes via the allocation of labels, to also help identify commonalities or trends in the data.

Further discussion with supervisors and documentation of this process also occurred to support the process of how the codes were being developed from the data, which also provided an audit trail to ensure trustworthiness of the interpretation and analysis (Kiger & Varpio, 2020; Polit & Beck, 2017). The codes eventually became well defined and 'demarcated' so they did not overlap with other codes and could all fit logically within a larger group which supported a common and central idea or concept (Kiger & Varpio, 2020).

Theme development was linked to this process, in that the central idea of each theme became the organising concept of the coded data extracts (Braun et al., 2019). Themes were, therefore, developed through analysing, combining, comparing and, sometimes, mapping how codes related to one another (Kiger & Varpio, 2020). This process included the examination of the entire coded data, with the introduction of linking the overarching themes that defined the broader significance or meaning of the codes. Sub sequentially subthemes were also developed which defined the overarching themes.

Each theme was then reviewed to determine accuracy and relationship to the coded data, and this process led to the development of two distinct themes 'The doing' and 'The coping'. These themes and related subthemes were reviewed by the researcher and project supervisors to confirm that the existing trends and relationships within the data were true to the coding and subsequent development of overarching themes and subthemes. This process again ensured 'trustworthiness' via wider consultation within the research team (Polit & Beck, 2017). The 'reviewing of themes' and work to 'define and name themes' appropriately are in support of the fourth and fifth step, described as necessary for the process of thematic analysis (Kiger & Varpio, 2020).

Over several meetings the supervision team audited the process of thematic analysis discussing and confirming the themes and subthemes, describing, defining, and naming the themes developed by the researcher, against the coded data. Mind maps and diagrams were also developed during this data analysis process to validate the development and naming of the overarching themes and subthemes, from the qualitative data.

Limitations to the study design

Several potential limitations existed in relation to the study design for this project. Many acute care nurses may not have regarded themselves as potential participants in the study as they may not identify themselves as providers of bereavement care in hospitals. The flyers alone, without the PICF, may not have been descriptive enough to explain bereavement care as a nursing measure. A lack of identification with the research may have discouraged some nurses from participating in the project. To address this limitation, the researcher presented the study at the largest participating hospitals site to a group of Unit Managers and the Acute Rural Symposium to clarify the details about the research study and bereavement care and clarify and promote participation.

Additionally, nurses may have been reluctant to participate in the project if they felt that the quality of bereavement care they provide for patients is sub-standard. If nurses lack confidence in end-of-life care measures, then they may have been discouraged to participate in this project. During discussion with potential participants, the researcher reassured them that the project was not concerned with the appraisal of the measures performed during end-of-life care but rather with identifying the nurse roles or provisions of bereavement care for patients and families in acute care hospitals.

Summary

This research is situated within a constructivist paradigm, using an Interpretive Descriptive methodology to accomplish the aim of the study. This chapter outlined the recruitment and data collection processes. Twenty-two semi-structured interviews were completed with nurse participants who met the research inclusion criteria, with concurrent interview transcription and data analysis occurring. Thematic analysis enabled the identification of two major themes and related subthemes. These themes and subthemes

will be further discussed as part of chapters four and five that present the overall research findings for this study.

CHAPTER FOUR – ‘The Doing’

Introduction

Nurses in this study described how they cared for dying patients and their families in acute non-metropolitan hospital settings, during semi-structured interviews. Following data collection as described in Chapter three, each interview was fully transcribed from audio MP3 file to text. All the transcriptions and audio recordings were reviewed multiple times, to ensure immersion in the data. Open coding of the data supported the development of themes using the NVivo11 program. The themes and subthemes were reviewed by the investigator and supervisors to ensure accuracy, and the work of defining and naming of the themes occurred to enable accurate description.

In the analysis, the overarching themes and relevant sub-themes were separated into two distinct activities that nurses undertook to provide bereavement care. It was the ‘time’ that nurses spent with the patient/family that needed to be evaluated to identify what roles they performed as bereavement care. One group of themes represented the roles of nurses during end-of-life care which could impact on bereavement or the bereavement process for patients and their families. This group of themes is described as ‘The doing’ theme and related to the implementation of bereavement care during end-of-life care at the bedside.

The remaining group of themes described how acute care nurses coped with processed the impact of delivering end-of-life care and dealing with the reality of caring for dying patients in an acute care, non-metropolitan hospital. This group of themes is described as ‘The coping’ theme and related to the impact of care delivery and the personal reality relating to ‘space’, referring to the acute care environment, and ‘place’, referring to the non-metropolitan hospital location. The theme, ‘The doing’, is described in this chapter, Chapter 4, following an overview of the participants. The theme, ‘The coping’, is described in Chapter 5. The participant voices are presented as quotes in italics with the interview number noted in brackets at the end of each quote. When needed, the participant voice is explained by the researcher in square brackets.

Overview of participants

Twenty-two interviews with 20 acute care nurses were completed. As described in the previous chapter, the interviews were performed without a script, in which the researcher asked the participants to describe their experiences of caring for dying patients in acute care, non-metropolitan hospitals. Open-ended questions then built the dialogue around the roles that nurses undertook in the care of dying patients, with specific research statements helping to guide the flow of discussion, enable storytelling and ensure participants had the freedom to express their experiences.

The nurse participants in this study had from three to 47 years of nursing experience. None of the participants had any formal specialty palliative care training. The hospital settings that they were employed in were located approximately 92 to 143 km from a major Australian capital city. The nurses were caring for dying patients and their families, whilst working in acute care settings, inclusive of Emergency, Critical Care, Medical, Surgical, Renal, Oncology and Midwifery departments. One male and 21 female participants were part of the overall research sample. Table 4.1, below, summarises the research participant sample.

Table 4.1 Research Participant Sample

Interviewee	Interview Sessions	Years of Nursing Experience	Gender	Current Nursing Position
1	2	6	Female	Nurse Educator
2	1	10	Female	RN staff
3	1	35	Female	Unit Manager
4	2	16	Female	RN staff
5	1	32	Female	RN staff
6	1	4	Female	RN staff
7	1	3	Female	RN staff
8	1	26	Female	Nurse Specialist
9	1	5	Female	RN staff
10	1	7	Female	RN staff
11	1	22	Female	Unit Manager
12	1	23	Female	Education Manager
13	1	12	Female	RN staff
14	1	6	Male	RN staff
15	1	47	Female	Associate Unit Manager
16	1	7	Female	RN staff
17	1	37	Female	RN staff
18	1	11	Female	RN staff
19	1	8	Female	Nurse Educator
20	1	21	Female	RN staff
21	1	9	Female	Unit Manager
22	1	12	Female	RN staff
Total	Total			
22	24			

The doing

'The doing' describes how nurses in acute care non-metropolitan hospitals provide bereavement care to dying patients and families during provisions of end-of-life care. The nurses described the multiple and complex roles they performed during end-of-life care to actively meet the individual needs of dying patients and their families, with communication being a vital component to guide their care. Two large sub-themes of the 'The doing' theme included 'Meeting needs' and 'Communication guiding care'. Table 4.2, below, represents the many roles that the nurses performed as part of 'The doing'. These roles met the research definition of 'bereavement care' provided after the contents page in this thesis, and were what the study nurses spent their time doing with the patient/family to help them cope with death and dying.

Bereavement care was always delivered as part of end-of-life care, but the study nurses referred to end-of-life care more commonly than bereavement care. Bereavement was not a term frequently used when the study nurses described how they cared for patients and families, and it was for this reason that the investigator was unsure on some occasions, if the nurses knew they were providing bereavement care. Review of the findings also indicated that bereavement care was being delivered mainly a consequence to the delivery end-of-life care, and this was sometimes a reactive process that occurred in association with the provisions of end-of-life care, to patients and families. For example, when the study nurses were providing physical comfort care to patients, they were needing to also educate about the dying process which often led to family engagement in some of the care measures when appropriate.

Table 4.2 presents these roles under the relevant subthemes, 'Meeting needs' and 'Communication guiding care'. 'Meeting needs' has 5 smaller sub-themes that describe the roles of nurses in the provision of bereavement care. 'Communication guiding care' has 4 smaller sub-themes that describe how nurses communicate to facilitate bereavement care.

Table 4.2 'The doing' - bereavement care roles

Meeting Needs	Communication Guiding Care
Individualising care	Talking about death 'What happens now what happens next?'
Meeting the cultural and religious needs of patients and their families	Enlisting multidisciplinary support
Keeping dying patients comfortable	Supporting family expectations, 'How do we make them see?'
Defining care pathways as a useful resource rather than an illusion	Being an advocate to support patients and families
Providing after-death care for families	

Meeting needs

Nurses in this study spent considerable time trying to meet the many needs of dying patients and their families during end-of-life care. Making time to listen to concerns and understand the needs of patient and their families was an important contributor in support of their grief and bereavement process for families. The nurse participants described how they engaged in roles, such as individualising care, to suit the needs of dying patients and their families, addressing the cultural and religious requests of patients and their families, providing care to ensure dying patients were kept comfortable, utilising care pathways in the delivery of end-of-life care and continuing care for families after the death of patients, to meet their needs.

Individualising care

It was evident in the nurse's descriptions of their interactions that they perceived the needs of dying patients and their families as unique and varied and the study nurses provided individualised care, to accommodate such needs. Each nurse participant described a different story of how they provided care

for dying patients in acute care hospitals. This individualised approach to care, as described by the study nurses, was varied and delivered differently on each occasion, with no described common rules or methods followed.

The nurse participants explained that the process of death and dying for patients was always different; *“Death is like birth ... sometimes it’s easy and sometimes it’s hard and sometimes it’s long and sometimes it’s short”* (Interviewee 3). Therefore, the subsequent care of a dying patient also needed to evolve and change to accommodate the uniqueness of the person and their individual needs including that of family members as part of the dying process; *“...so they [family] feel like they’ve done their best they can, or the best they wanted to when they reflect back on it down the track. It’s being insightful and being able to see the small cues to be able to work from”* (Interviewee 11).

The provision of care for dying patients was described as something that:

“...needs to be individualised, it’s no one else’s experience except theirs. You don’t have a list per se, you can’t envision the obstacles that you are going to face or the conversations that you will have, or what is required because everyone is different. The family is so different as well.”

(Interviewee 1)

During the interviews, the nurse participants described very different experiences of end-of-life care and approaches to care delivery, based on dying patients or family needs; *“It’s always going to be different, what might go well with one family, with another family will not”* (Interviewee 18). Another participant described.

I have had family members that don’t want to talk about anything, so pretend that it is all ok and that is fine ...other questions that have come up about funeral preparations, what’s going to happen to the body when someone passes away ... I found that confronting to be having that conversation with that person that is dying in the room but that is how they were dealing with it ... others ask about medications and how they work other family members that I can recall just want something to stop the pain or make them comfortable. (Interviewee 1)

Nurse participants frequently recalled clinical examples, through storytelling, of how care was provided differently in attempts to meet the varied needs of dying patients and their families. This nurse participant reflected on the needs of young parents, whose baby had died unexpectedly at home:

We had a six-week-old baby die. I do remember them come in the early hours of the morning this little baby came in there was no signs of life, but we still did CPR the parents were very, very young. I think about 19 or 20... they were blaming each other at the time, they just didn't know what to do, they said, "Oh well we'll just go home," and we are like we need to contact your family, we need to bring people in for you, ring your parents. "NO, NO," they said, "We'll let them know in the morning," and we were like no you've just lost your little baby. I remember we were spending a lot of time with them. Being younger myself, they weren't really interested in listening to me, they needed older nurses, so thankfully the nursing coordinator was a little bit more older, senior, and the same as the nurse in charge...it took a lot of coaxing for them just to get them to ring their family...so I remember that situation, just thinking it was a real struggle to try and get them to want to call family in to have a support there. They just wanted to go home, it took a long time. We were just trying to sort out getting their family in and getting the right support services in for them, because they were so young... that was totally different, I've never been in that situation, and I haven't ever since you know, normally everyone's got all the right support services. Sometimes there's too many family members involved. (Interviewee 13)

This case, as described by the nurse participant, identifies the unique needs of the parents of a child in which individualised care needed to be provided in a different way to ensure an appropriate level of psychosocial support. Other examples of individualised care involved; allowing multiple family members screaming and wailing in grief at the bedside (Interviewee 8), assisting family members to lay with the dying patient in a hospital bed (Interviewee 18), taking hand prints of dying patients to family members (Interviewee 3, Interviewee 13), making time to sit and hold a dying patient's hand at their request (Interviewee 17), personalising the bedside with patient belongings, bringing in pets, allowing family members to stay overnight and sleeping with or close to the patient, giving family extended time alone with dying patients, listening to stories about the patient, being present with the family when they

reminisced about the patient's life, praying with the family and arranging for patients to go home for periods of time to fulfil final wishes (Interviewee 8, Interviewee 18, Interviewee 3, Interviewee 16, Interviewee 4, Interviewee 6).

The nurses explained that the approaches and methods they used in the delivery of individualised care were identified through spending time with both the patient and the family, getting to know what their wishes were and their understanding of the dying process and end-of-life care. This nurse participant explained, *"It's just exposure and getting to know what families and patient's want, because every situation is different, and if you can have an outcome, of what the families want and what the patient wants. I think that helps"* (Interviewee 10). Spending time and becoming more familiar with family members also allowed for the implementation of individualised care by nurses, as described by this nurse participant:

Thinking of ways that they can be involved in the care of their loved one to a degree that they're comfortable with, so there is a lot of deductive work about what is this person comfortable in doing, what do they feel about end-of-life in general themselves as well and then how we can best facilitate them being involved. (Interviewee 11)

Understanding the needs of patients and their families also encompassed the spiritual and cultural beliefs of patients and their families, with nurse participants also describing measures taken to meet these individual needs.

Cultural and religious needs of patients and families

Nurses in this study commonly identified the need to support patients and their families during end-of-life care with their cultural and spiritual requirements. The nurses commonly enquired with patients and families about a dying patient's *"spiritual concerns and contacting a priest"* (Interviewee 7).

Coordination of religious support was sometimes challenging, in terms of access and contacts to religious representatives, with requests for *"having increased availability for pastoral care"* (Interviewee

20). Some nurse participants indicated that religious support would also be initiated by the families; *“The family will get their own priest or pastor in, they’ll ask if that’s okay and they will bring them in and let us know”* (Interviewee 20). Providing sufficient spiritual and religious supports as further discussed in Chapter six is significant to an individual’s grief experience and for families also an important part of the bereavement process.

Acute care nurses in this study also discussed the need for being increasingly culturally sensitive and open to cultural differences and practices regarding death. Nurse participants indicated that culture and cultural needs for patients and their families were sometimes hard to identify; *“unless it’s visible or if they have been handed over that they are from another culture”* (Interviewee 6). End-of-life care, in some instances, could cause distress or conflict with cultural beliefs; *“we should have taken more notice, like the cultural aspects because she didn’t want us to wash the body or anything else afterwards”* (Interviewee 6).

Sometimes, supporting the cultural needs of families was challenging for acute care nurses who described it as necessary to work through with family members:

I think culture plays a really significant role in the care that you provide... Sometimes it can also be a bit of a barrier to, as well, some cultures where food is really important and a symbol of life and healthiness and so forth, developing an understanding that the person doesn’t need to eat or drink or that they can’t or that they don’t feel like, that kind of thing is very challenging, because all they want to do is feed, feed, feed. And the person could be, in my experience, at times they’ve been unconscious and yet the loved one still wants to feed them because it’s that nurturing... and that’s a very difficult. (Interviewee 1)

This quote demonstrates the importance of recognising the cultural beliefs and values of family members and highlights this nurse participant’s understanding of cultural differences and the need to respect them in order to provide bereavement care.

Language barriers for patients and families were also described as challenging for the acute care nurse at the bedside, with the use of hospital interpreters necessary, on occasions, to support the family and

the delivery of care, as illustrated in the following interview excerpts: *“You have to ask those questions. Is there any specifically that you want because communication might be an issue, so you might need to get an interpreter”* (Interviewee 17) and *“she [patient] could speak English, but English wasn’t her first language yeah, so it was a bit tricky”* (Interviewee 6).

The nurse participants described the positive impact of meeting religious and cultural requests on a family’s and patient’s grief: *“It gives them comfort because that’s what their belief is and it helps them go through the grieving process and what’s happening, and maybe accept it more”* (Interviewee 20).

Similarly, another nurse explained:

You can see it in the patients, they feel more relaxed, so I’ve seen patients that have been quite apprehensive and quite scared, understandably, about not knowing what to expect whether they’re religious or not, and they’ll request the priest to come in and then there’s almost this sense of calm and readiness, which is quite a beautiful thing to see. (Interviewee 19)

Nurses described how it was necessary to become aware of the cultural and religious beliefs of patients and their families and to identify how such beliefs impact on a family’s experience of death and dying. Being informed about religious and cultural beliefs enabled nurses to implement care to better meet the needs of dying patients and their families. Meeting needs also extended beyond spiritual and cultural needs, with the physical needs of patients also of high priority for nurses within this research.

Keeping dying patients comfortable

A significant role identified by nurse participants within this research was to keep dying patients comfortable and assess and manage any physical symptoms of dying. Managing a patient’s pain, minimising nausea, ensuring adequate mouth care and hygiene, and frequent repositioning were all measures of high priority to the study nurses, as such measures were considered necessary to minimise distress for patients and bereaved families. Through the provision of care to manage any physical symptoms of dying, nurse participants described maintaining a patient’s dignity, whilst ensuring families did not witness their significant other in an uncomfortable or unkept state, as illustrated by the following interview excerpts: *“ no one wants to see anyone suffer and if you can alleviate the pain and*

distress that people are feeling that can help, offering that to the family” (Interviewee 4), “ to be able to give good nursing care and support to the family and make someone feel comfortable and relaxed at the time is very important” (Interviewee 5), and “ preserving his dignity in the face of the family because if someone is going to die you try to preserve a positive picture of the person” (Interviewee 14).

Nurse participants usually opened the interview with this topic of discussion and talked about the significance of keeping dying patients comfortable and well presented. Nurses would involve medical staff to ensure an adequate level of care was being maintained. The nurse participants could also be very specific about the timing and type of care they were providing, which most frequently included turns, washes, mouth care and pain relief measures. Keeping patients comfortable was of high priority for the study nurses, as illustrated by the following account:

As the nurse you take on a lot of roles with the care of the dying patient in that you are continually doing assessments but it's not your traditional assessment for general patients, you are looking more at pain scale, more about comfort, maintain the moisture in the mouth and hygiene and all of those kinds of things you do for other patients but it's a bit more emphasised for those at end-of-life. I don't know if it means more, it's just it's all that you can do, it just kinds of takes priority I guess, there is a bit more meaning attached because you know it might be the last time you want to do that well and make sure they feel the most comfortable and dignified.
(Interviewee 1)

Care that was given to keep patients comfortable was, to an extent, shared with families who were sometimes willing and wanting to participate in the provision of care. This sometimes included turning patients and assisting with washes; *“if the family are comfortable, we are happy for them to step in this kind of lets them feel like they are doing something to help” (Interviewee 5).* This may also be highly significant to a family's bereavement and will be discussed further in Chapter six as part of 'facilitating a family presence' which contributes to the necessary 'grief work' required as part of some of published grief and bereavement models.

Sometimes, prompts to manage for patients their physical symptoms of dying were also identified, and care clarified using the care pathway as described by the study nurses.

Care pathways - an illusion or a useful resource

When nurses were caring for patients who were dying in acute care settings, end-of-life care pathways were commonly used. These care pathways were a paper resource that provided prompts to care delivery during the final stages of life for patients and their families. The end-of-life pathways were designed for use by the multidisciplinary team in support of holistic care, and structured with tick boxes and free text boxes to provide notes and signatures to confirm end-of-life care provisions have been attended to. The use of end-of-life care pathways were discussed more frequently by the nurses in this study who worked in less acute areas, such as medical and surgical departments, with emergency and critical care nurse participants referring a lot less to the care pathway resources.

The nurses either liked and praised or disliked and criticised the use of the care pathways. Overall, text responses were almost even, although more narrative existed to support the observation that acute care nurses found care pathways a useful tool to help prompt the delivery of end-of-life care for dying patients and their families. This participant talked about the benefit of using a care pathway in meeting the needs of the patient and family:

I think it's really good because it helps to remind you about going back to basics almost. Like to remember the pressure area care to remember to offer comfort measures like, would you like a drink of water, something to eat if that's appropriate that type of thing, giving those comfort measures and those simple things, but I actually think that those things really give the family heart you know they like to see you still come in and check and provide pressure area care, mouth care and give pain relief you know, it's simple to give a wash and that type of thing, they still believe that their family member is valuable and receiving the attention that they should receive rather than saying if you want anything just call out to me, and then walking away again.

(Interviewee 4)

Care pathways also ensured that the nurses had guidelines to advocate regarding the management of and control of any physical symptoms relating to death and dying, as illustrated below:

It just creates a common goal that we all know what we are looking for and there is this one kind of flow chart that talks about medication. So if you have got Dr's that are not used to dealing with this sort of thing you might know what you want in terms of medication what you think is appropriate...it's an objective way of explaining to them, these are the options and this is what we should be considering, it just clears things up and creates a common goal and it's a more unified approach. I just find that it's very easy to understand and the end-of-life process is just made better, I think. (Interviewee 2)

Care pathways were also described as useful tools for more junior or graduate nurses who are not as experienced in the care of dying patients and may, therefore, require prompts to support the delivery of care. Care pathways also existed as an information resource regarding patient wishes and goals of care, as one participant described:

I think that any care plan is actually useful for a graduate. I think it really helps provide some direction for them, especially if the rest of the ward is very busy and they don't have someone that can come and support them and answer their questions. I think that although it could be used as a very structured thing and might not be necessarily that beneficial at times, I think that in an inexperienced carer's role they can be really helpful and really useful. They also provide a means for asking some of those questions of the patient, and of the family, around what is it that they want and what their hopes are, and then being able to document so that hopefully that can get passed on from person to person rather than needing to keep asking. (Interviewee 12)

The responses that were critical of care pathways for the dying described the tool as an illusion of providing quality care for dying patients and families. Some nurse participants criticised the form as being too easy to tick and then forget the need to provide the care. They expressed concern that the prompts for care might be too superficial and not individual, specific, or descriptive enough to meet the

patient's and the family's needs. Pathways were also criticised as less relevant to meeting the needs of dying patients due to a lack of completion or use and the tool not being revisited or used, as follows:

I don't think it is reflective of, or flexible enough or maybe it's too broad, and so it's too easy to tick tick tick tick done that, but have you really done that...I don't think it promotes quality care in that it I think it can provide a bit of a scapegoat for the illusion of providing quality care in my experience because I used to audit them too, they weren't completed and you know if it's not documented it's not done ... but the documentation doesn't support or reflect things the care that needs to be undertaken or the individualised nature of the care. I feel like the questions are kind of like filtered throughout the first couple of pages and then it's kind of like once those two pages are done the initial assessment is done and then you go on to just your general daily care plan it's like those pages are never revisited (Interviewee 1)

Regardless of whether care pathways were liked or disliked by the nurses in this research, the care pathways were a resource commonly used by the study nurses to support the delivery of both end-of-life care and bereavement care for dying patients in acute care. Sometimes the nurse participants explained that the needs of families extended beyond what was identified on a care pathway and continued after the death of patients.

After-death care for families

Nurses continued to provide care for families in acute care, after the death of patients in hospitals. Supporting and spending time with families commonly occurred at the bedside and, on many occasions, occurred up until the time the patient's body had left the department.

Nurse participants indicated that the time spent with families was, dependent on the situation or individualised, based on how much time the family needed, and this varied from hours spent directly at the bedside to weeks and, as one participant described, continued to occur in the department, two years following a death in an intensive care unit:

It doesn't stop when a patient dies and then it depends on a family's needs as to how much as to how long that care goes on. Sometimes it might be a phone call a week later and then that's it.

But it depends on the family, and what they really need. Like I said this lady we were still meeting with us two years later, so it just depends [on the family]. (Interviewee 11)

Participants indicated that the time after the death of patients was the time for families to say a final goodbye to the patient and during this time, nurses commonly needed to be present to support and answer questions about the processes after death. The following nurse participant described why nurses are needed after the death of patients: *“Because they are asking questions, what do we do from here, who do we contact, what do we put them in, stuff like that, can we leave this, can we leave that”* (Interviewee 7). Care continued after death for families within acute care and, as described, nurses answered questions and supported families at the bedside. It was also identified that the extent of after-death care was dependent on the needs of families and the time they required, which varied between families.

As identified, nurses provided end-of-life care that was individualised to meet the needs of patients and their families. Cultural and religious requests were accommodated, and nurses ensured that any physical symptoms associated with death and dying were controlled. End-of-life care pathways were utilised in acute care, and care extended at the bedside, beyond the immediate death of patients. Throughout all the themes associated with ‘meeting needs’, a common factor amongst the findings was the significance of the role of communication, which helped to guide care and assist nurses to meet the individualised needs associated with end-of-life care.

Communication guiding care

This sub-theme to ‘The doing’ theme, describes the significance of the role of communication in guiding care for dying patients, as described by the acute care nurses within this research study. Nurse participants identified the needs of patients and their families through spending time and talking with families about death and the end-of-life process. Making time to listen to families helped nurses support, assess and understand what issues required attention and how to develop strategies and resources to meet these needs as part of end-of-life care.

This subtheme is inclusive of the bereavement care roles of the study nurses that constituted; talking about 'what happens now and what happens next', enlisting multidisciplinary support, enabling understanding and decision making, managing family expectations and conflict, including 'how do we make them see?', and being an advocate to support a patient and their family. Communication was a role frequently discussed by the nurse participants and is identified, throughout the theme of 'The doing', as a strategy to guide care and facilitate the delivery of bereavement care.

Talking about death – 'What happens now what happens next'

The nurses in this study described making time to talk with patients and families as a key role in end-of-life care. Explaining the dying process to families and enabling their understanding of the provision of end-of-life care occurred commonly through communication; *"You have to make sure that the family has got an understanding of the process what happens now what happens later on and just really having that open communication with them"* (Interviewee 10).

Nurse participants described allocating and making time to spend with families. During the time spent with families, nurses provided as much information as possible and assessed families' understanding of the dying process and end-of-life care through verbal and, sometimes, non-verbal communication, and listened to the responses and concerns of families, as described by one participant:

We are allocated patients at the start of the shift and I think that it is part of your role in the allocation of those patients, in your mind or your planner you will dedicate time to have these conversations...if you had a patient at end-of-life you are mentally making a note that you are going to need time for these difficult conversations depending where they are in their process of dying and the process of grief as well its put upon you to be involved in this with your patient allocation. The biggest thing is listening and being aware of the situation looking at body posture and faces and positioning of people and what they are doing and how they are responding to your questions and so forth but I think what contributes to success is asking questions and then listening to the responses and giving time for the responses and so I think by giving time.

(Interviewee 1)

The nurses not only talked and listened to families, but also educating families about death and the end-of-life process for the patients.

Usually, a lot is focused on the family and their understanding...a lot of the time there is education around what's happening, the symptoms and the experiences. They have a lot of questions, they are always asking what happens now, what happens next, and you need to make time to go through all of that. (Interviewee 6)

The nurse participants also attempted to identify a family's needs and how to meet these needs, as part of the end-of-life care provided. During the time spent with families, nurses also identified how the family were processing and adjusting to the impending death of their significant other, as shown by the following excerpt:

There's a lot of deductive work around what is this person comfortable in doing, what they feel about end-of-life in general themselves as well, and then how can we facilitate them being involved so that they feel like they've done the best they can, or the best they wanted to, when they reflect back on it down the track. It's being insightful and being able to see the small cues to be able to work from. I think understanding is the key and trying to understand the individuals involved is important. (Interviewee 12)

This level of assessment was identified by nurses spending time and talking to dying patients and asking them what they wanted and what mattered to them at this stage of their lives; for example:

The biggest thing is asking a patient, at any time of their admission, what matters to you. Like out of all of this, what matters? How does this impact on you as a person and your family and your life and your job and your hopes and your dreams and what you expect? How can we provide good bereavement care if I don't know what's important to you when you're alive and what's important to your family? So, we're providing bereavement care not for that person really, but anticipatory bereavement care on people approaching death for the family. Unless I know what's important to the person I'm caring about, how can I provide that to the family. (Interviewee 9)

Being an active communicator with patients and families enabled identification by the acute care nurses of the appropriate care for patients. A level of compassion and a deeper understanding of bereavement needs occurred through communicating with patients and their families. Communication was vital in assessing and delivering appropriate end-of-life and bereavement care, as described by the nurse participants. Communication also led to identification of needs that were best met by other multidisciplinary professionals.

Enlisting multidisciplinary support

A significant role of the acute care nurse was to enlist the skills of the wider multi-disciplinary team to support families throughout the dying process. Using the expertise of varied disciplines was a strategy that nurses undertook in attempts to provide additional support to families, meet their needs and enable a better understanding of and support for medical decision making.

Family meetings were one method of enlisting multidisciplinary support, and nurse participants indicated that they were usually the first to initiate or request such meetings. Family meetings were commonly held when it was identified that not all family members understood the current situation or there was a need to communicate changes in a patient's condition or clarify levels of care. For example, *"... this was the patient that was originally quite alert and deteriorated quite quickly and he had family members that understood what was happening and family members that didn't, so a family meeting needed to be had."* (Interviewee 1)

Doctors are commonly called on by nurses to talk with families and explain and clarify decisions, reinforcing end-of-life care provisions as part of family meetings. Nurse participants describe that, as part of end-of-life care, families need to be kept informed and this commonly occurs during regular family meetings. Doctors commonly lead discussion during family meetings, with direct care nurses and social workers frequently in attendance to provide support to family members (Interviewees, 1, 8 10, 11, 14, 16, 20,22). One example suggested that family members enabled common understanding,

If we think that the family require an update, mainly it's to get us all on the same page. This is what we're going for, this is what we believe is going to happen. This is everything that's been

done for this patient, we've exhausted every avenue, and to see if they're on the same page with what's going to happen and make a plan from there. And that's usually what the family meetings are for. Sometimes a family ask for it when they've got relatives coming from different places, so then instead of us telling one who tells another, who then rings us, they're all in one room. Everything's discussed and everything can be asked then and there. (Interviewee 20)

The nurses' roles during the meetings were to support families during and after the session. Nurses also prepared some families for meetings, by helping them to develop questions for the meeting, as follows:

...we spend a lot more time with the patient and family and we are asked a lot of questions and I sometimes say that's something you need to ask the doctor and I always say to family members to keep a piece of paper by your bedside because you'll have questions write them down and bring them, so you've got them there when we go for the meeting. (Interviewee 14)

Nurse participants described the need for doctors to be clear, during family meetings, about the decisions and requirements to withdraw treatment, so that all family members were informed and the care pathway was established with unanimous agreement; *"What made it right with one family was that they were all together with the decision-making from the get-go and the patient was with that, so the meeting was done in their room, and everyone was on board"* (Interviewee 10). Nurse participants believe that a family needs decisions based on the withdrawal of treatment to be initiated by the medical team, so that no responsibility is placed on family members (Interviewee 11, 15). They worked with medical staff to ensure clear communication with families and so that family members understood the decision to withdraw treatment was a medical condition as illustrated by the following example:

Some intensivists had this thing about getting sued and they were worried about the legal reasons more than patient-centred care and they would always put the decision on the family and those families would go away thinking they were the reason their loved one had died. So we had a lot of discussions and if they have a medical opinion they needed to give it and say that's what they want to do it's all about the use of words, so if you go in there and say this is what we think but we want you to make the decision that's a horrible thing, whereas if you go in and say

this is what we are going to do if you have any objections to that you need to tell us know and we can talk through it, then they don't have ownership of that decision, that's very important.

(Interviewee 11)

The following nurse participant understood the relationship between the decision of treatment withdrawal and a family's grief and described how it was necessary to protect families from this burden or ownership.

I think that personal experience tells me that there are opportunities for family to be more in touch with their loved one, if they are in the right head space. It might take somebody a long time to deal with it and straighten it out and make sense of it, but grief's very complex and it can get blocked... I do try and soften the things as in like try and make it so that somebody doesn't feel responsible for withdrawing, as in we made the decision, we had to make the decision to withdraw on this patient... they need to be relieved of that in some shape or form, if necessary, that it's been a medical decision. (Interviewee 15)

Acute care nurses commonly worked in a multidisciplinary approach to achieve the needs of patients and their families, although some of the acute care nurses believed that nurses had a 'lead' supportive role as the direct and most frequent care giver; as one nurse outlined:

The nurse's role is for that support, and they're the ones that help mum or dad or the family members through. I think we are the rock. I'm not degrading any other disciplines, but I think the nursing staff are with them [patient] twenty-four hours a day seven days a week. They see the majority of the family and the majority of the patient [nurse provides most of patient care] and they're the ones providing the medication to help them, for comfort, they're the ones that sit there with the family and hold the family's hand at night, they're the ones that are constantly offering that support. (Interviewee 21)

In the interviews, acute care nurses frequently talked about enlisting the support of other healthcare professionals to assist families during the provision of end-of-life care. Nurses described the need for the multidisciplinary support to employ additional skills, outside their scope of practice, to meet the needs

of and maximise support for families. Most frequently, the services of both medical and social workers were required by patients and families and referrals were initiated by nurse participants.

Social workers were called to support families, which mostly meant they were providing not only additional counselling, *“social workers are trying to provide support in many ways but the main one is around supporting the emotional effects for the patient and family”* (Interviewee 11) but were also helping to answer some of the families’ questions, *“social workers are really good at helping out with the family with questions”*(Interviewee 6) and assisting to provide additional resources to meet a family’s needs, *“trying to get resources in to help support him and his wife”* (Interviewee 12).

Nurses discussed utilising the skills of other specialist nurses ,such as *“community palliative nurses”* (Interviewee 12,10), more senior nurses *“nurse managers – ‘in charge’ or more senior nursing staff”* (Interviewee 1, 8,10), *“nurse practitioners other nurses working on medical wards nursing coordinators”* (Interviewee 13, Interviewee 20) or other multidisciplinary staff *“pastoral care /chaplaincy services”* (Interviewee 1,2,4,8,12,18) and *“speech therapists, dieticians”* (Interviewee 5,6,7), to support the provision of end-of-life care for the dying patient and their family within acute care.

Sometimes, even with the support of the wider multidisciplinary team, the nurses in this study still described challenges with meeting family expectations and enabling their understanding of end-of-life care and the dying process.

Family expectations - How do we make them see?

Nurses described how family members were often emotional and sometimes angry at the bedside. Communication by the study nurses was therefore required to help guide care and help make sense of family expectations relating to the dying process. Sometimes, family dynamics also complicated the provision of end-of-life care, with family conflict occurring at the bedside. Families were described as having expectations about how end-of-life care should be delivered within acute care hospitals. These expectations concerned the amount of time that nurses should be spending with the patient and the type of care that should be provided, which made end-of-life care, on many occasions, difficult to deliver. The nurse participants also felt that *“Sometimes it doesn’t matter what you say or what you do,*

it's not good enough, or you're not quite meeting their needs" (Interviewee 13). This is further supported by another nurse participant:

Families expect a lot from us and sometimes what they expect is unachievable. I think it's hard at times with them obviously grieving, they can portray that onto us. And obviously be angry about things that aren't done. Whether you know, they feel that their family member's not getting enough pain relief or whether they feel we're not caring for them as much as we could be, because we're not there all the time. (Interviewee 9)

Sometimes, nurses felt unable to provide care or encountered resistance from families in the delivery of care at the bedside. This conflict of care, as perceived by the nurses, was caused by them not meeting the family's expectations of care delivery, described as:

I have had patients that you are meant to do your pressure area care for, every 2 hours whatever when families are like NO just leave them and so you respond to that and you do that, even when you know what is best for the patient in terms of their skin integrity and needing to move for this particular person. It's not their desire for them to be moved so that's ok. I have responded to what they have wanted. (Interviewee 1)

And one of the relatives said can you please just give us some space. So that was awkward because I felt like you know I didn't want to go into the room, but from a nursing perspective I felt I wasn't doing the right thing for the patient. (Interviewee 17)

Families also have expectations regarding the clinical interventions that patients should be receiving, which are sometimes driven by the hope that a patient will improve or recover because they are being cared for in a hospital. Sometimes, families have, essentially, not accepted the end-stage diagnosis, as exemplified below:

They [family] have unrealistic expectations for a family member they feel that mum is going to miraculously get better not accepting the actual prognosis not understanding why you can't give multiple drugs, some people want blood tests all the time, want them to have oxygen on, you're

trying to explain that there is not value or why it's not worth the pain it might cause.

(Interviewee 5)

Nurses also expressed that families expected them to be able to predict the day/time of death for patients, which was often extremely difficult for nurses, as shown by some of their comments at the interviews: *"They want to know how long they're going to live for"* (Interviewee 10) and *"Family get angry when we keep calling them in and saying I think they are about to die and they don't die...families get angry that you didn't call them quick enough, that you called them too many times or you are not able to actually give them a time"* (Interviewee 5).

Sometimes, nurses interacted with angry family members at the bedside. This anger was described by the nurses as relating to the complex relationships within families and the issues that may exist between family members. These issues were often de-escalated by nurses at the bedside, as in the following example:

A lot of family issues come up. There might be fights about money, there might be fights about they don't want this person visiting or they don't want that one visiting, or they [other family members] just want to take her [dying patient] money and so you get all of those things come up. And sometimes we sit down just as a team with doctors and nurse and have that discussion with the family about working out who the Next of Kin is, just working through the family dynamics. We tend to prefer to just deal with direct family when they are in here and we make that clear to the family as well and often we find that is a relief for the family to put those barriers up for people that probably are inappropriate to be coming in. So, we leave it up to them, if they want some second cousin from somewhere to come in that's fine, providing it's their decision. So we help them make those decisions. It's hard to police who comes to visit and things but if they inform us if there's particular people they don't want in and if they've got good reasons for it, we certainly make every effort to make sure that doesn't happen. And just things like if there's conflict at the bedside, sometimes we have to ask families to step away from the bedside and it's important to remain impartial to any of it and set ground rules about what's not appropriate at the bedside and

we're an intensive care unit and it's not about your family or anything else, but this behaviour is inappropriate in this environment (Interview 11).

There is always conflict, but I think that this is the stresses on the family. I mean every family is different you know the younger brother may not speak to the elder sister, there's always family dynamics and we just try and adapt to what the family is, if there's arguing going on in the room, we ask them to leave. (Interviewee 21)

Some nurses describe the anger of family members at the bedside as related to grieving: *"You will be faced with managing aggressive situations as well because people are grieving, and different people react differently, they just don't know what to do"* (Interviewee 12). Commonly, nurses tried to de-escalate the situation by encouraging family members to take a break, go home for a shower or have a coffee and/or time away from the bedside (Interviewee 1, 5, 8, 10, 15, 20).

In other cases, the nurses interviewed indicated that the anger of the family had been a result of a lack of understanding, flagging that further communication was needed to illicit better understanding and identify further supports; for example, *"Probably the biggest challenge would be when, in a disagreement with the family you can see that they are not understanding of the situation...and how do we make them see"* (Interviewee 7) and *"Those are actually the biggest challenges, family members that don't accept the decisions being made"* (Interviewee 11). One participant also identified that, often, time is needed, *"when people haven't accepted the fact and even though it's been addressed, you know it takes people time to be able to process the decisions made"* (Interviewee 17).

Nurses described attempts to work with families, to try and meet their expectations and deal with conflict as the bedside. Sometimes, as described by nurses, they needed to be an advocate to direct care measures to support dying patients and their families.

Being an advocate to support patient and family

Acting as a patient advocate, by communicating with the multidisciplinary team to ensure patient needs were addressed was sometimes necessary to ensure changes were implemented or incorporated into care pathways.

I had a gentleman who was receiving dialysis and he decided that he didn't enjoy dialysis anymore and that all of his health problems and the pain that he was experiencing was quite awful, so he and I had a chat together one night shift and we talked about ... him not wanting to do dialysis anymore and I said to him 'well actually you're involved in this. You are the recipient, and you can say something'. So, I encouraged him to talk to the Doctors which he did, and he made a plan to stop dialysis. So, he made a plan to catch up with all of his family and friends and we made arrangements so that he could go home for a few days and then he wanted to come back to hospital to die where he knew all the staff. (Interviewee 4)

During end-of-life care, nurses described themselves acting as an advocate for both dying patients and their families. Nurses acted as a communication link for both the family's needs and the patient's needs, ensuring necessary information was fed back to medical teams for management or for enlisting multidisciplinary support to meet needs. Nurses ensured that both the patient and the family were fully informed and understood the plans for the provision of end-of-life care; for example:

The nurse's role would be just to say what their care needs are, maybe the pain management, that we've had to give them extra pain relief or they're deteriorated from yesterday, they can't get out of bed now, like we've tried to get them up and they've deteriorated quite rapidly.

(Interviewee 21)

It was also evident that, on many occasions, a nurse's role was to advocate for both the patient and the family, as part of end-of-life care. Nurses were most commonly needed to advocate for medical support, to ensure that physical symptoms experienced by dying patients were being appropriately managed to maintain acceptable levels of patient comfort, as illustrated by the following comments made by nurse participants: "You're also the patient advocate, if they have pain, you're the one that needs to be liaising with the medical team" (Interviewee 11) and "So, my role is number one advocate for the patient, you have to make sure that a patient is comfortable, that the patient is not struggling" (Interviewee 8).

On occasions, nurses advocated for patients, on their behalf, in discussions with medical staff regarding the reasoning behind and the need for treatment interventions, as illustrated below:

I need to make sure that if a doctor comes to me and says we are going to send them down for an ultrasound and they are unconscious and they [the patient] said to me two days ago that they had enough of life, and they knew that they were dying, I would advocate for that patient. 'Is this really the best thing'? and reiterate what the patient had said (Interviewee 4)

Sometimes, it was necessary for nurses to advocate on behalf of a patient with family members despite the family's demands to continue treatment:

You have to explain what's best for the patient at the time to the family again when you have a family meeting the doctor explains what's going on but I think you end up explaining it again and again and again, and part of that's being a patient advocate and part of that's just your job, as a nurse, to explain your care for a patient to a family (Interviewee 16)

A large part of a nurse's patient advocate role is about ensuring that the wishes of the patient were being upheld. Nurse participants indicated that it was imperative that nurses were *"advocating for the patient in regard to what they want and don't want when they are actively dying"* (Interviewee 1). Sometimes, this involved *"prompting doctors to ask or have end-of-life discussions"* (Interviewee 10), which commonly occurred in multidisciplinary team meetings with families.

Summary

Twenty-two nurse participants, 1 male and twenty-one females, working in a range of acute settings in non-metropolitan hospitals described how they care for dying patients and their families. All of the participants had no formal specialist palliative care training. Bereavement care roles were identified from the narratives and described as 'The doing'. 'The doing' described how nurses in acute care provided bereavement care by attempting to meet the many needs of dying patients and their families during end-of-life care.

The nurses in this study provided bereavement care at end-of-life through providing individualised to suit the needs of dying patients and their families, addressing the cultural and religious requests of patients and their families, providing care to ensure dying patients were kept comfortable, utilising care pathways in the delivery of end-of-life care and continuing care for families after the death of patients,

to meet their needs. They used communication to guide their care when talking about death with dying patients and their families, enlisting multidisciplinary support to meet the psychosocial needs of dying patients and their families, managing family expectations of care and being an advocate to support the needs of dying patient and their families.

Although 'The doing' work kept the nurses in this study busy, they were equally as busy coping with their experiences of caring for dying patients and managing the reality of 'space', the acute care environment, and 'place', the non-metropolitan location of the hospitals. The study nurses described that time was required to process the care delivered at the end of life. The impact of working in a regional acute care setting was also influential on the delivery of care. Hence, the next chapter, Chapter five, describes how the study nurses coped with the bereavement care measures they provided for dying patients and their families in acute care, non-metropolitan hospitals.

CHAPTER FIVE – ‘The Coping’

‘The coping’ theme describes how nurses in acute care coped with caring for patients during end-of-life and with the bereavement care they provide for patients and families during this time. Additionally, this chapter describes how the acute care nurses in this study coped with the reality of providing care in an acute care setting that is regional and non-metropolitan. ‘The coping’ element also influenced the way that bereavement care was delivered to families during end of life, which appeared also to be influenced by nurses’ personal and professional experiences of death and dying.

The data representing ‘The coping’ theme supports the notion that the nurses in this study were busy coping with care they provided for patients during end-of-life in addition to performing the provision of bereavement care, as described in ‘The doing’ theme. A significant amount of time and effort, as described by the nurse participants, was dedicated to processing the care delivered and the impact of working in a non-metropolitan acute care environment on the delivery of care at end of life. Two large subthemes were evident within the ‘The coping’ theme, which included making sense of dying and coping with our reality. Table 5.1 below represents the sub-themes for ‘The coping’ theme.

Table 5.1 ‘The coping’ – bereavement care roles

Making sense of dying	Coping with our reality
Becoming comfortable through experience	Rurality as a reality
Learn from role modelling and debriefing	A better space to provide care
Using coping mechanisms	End-of-life care against the grain – we are too busy keeping people alive
	Patient ratios and juggling time to spend with families

Making sense of dying

The nurses within this study required time to process the care and the impact of care they delivered to patients and families during end of life. The nurses described how their experiences and familiarity with the roles in end-of-life care impacted on how comfortable they felt in the provision of care. In addition, the skills used for care at the end of life were typically acquired through role modelling from more senior or experienced staff, and talking or debriefing with their nursing peers. The nurses also identified several coping mechanisms, highlighting the negative impact of care delivery. This subtheme is, therefore, representative of three smaller subthemes: becoming comfortable through experience, learning from role modelling, and debriefing and using coping mechanisms.

Becoming comfortable through experience

The nurse participants frequently discussed the need for experience in and exposure to the care of dying patients and their families, in order to feel comfortable and confident in the delivery of end-of-life care. The experience of death and dying was described by participants in both a personal and professional sense, with personal and professional types of exposure to death described as being highly beneficial in establishing a better understanding of the end-of-life process and influential in the delivery of bereavement care to patients and their families.

Some of the nurse participants discussed how the experience of the death of a person or family member impacted on the approach they followed or the way they delivered care at the end of life. In the course of the study, nurses drew on these personal experiences and adapted these as lessons learned through self-reflection, as follows:

In terms of providing end-of-life care that stems more so from my own personal experience of being involved with a relative who I was quite close that passed away, so I drew comparisons on what I kind of experienced for my aunty and the experiences that I wanted for patients and their families. (Interviewee 1)

Some nurse participants shared personal stories identifying issues and care provisions that they would try to eliminate from practice or care measures that they would try to implement in future instances, as in the examples below:

This is something really personal... my mother who died thirty years ago, she had cancer, and palliative care wasn't good back then, and I can remember when my mother was dying every breath that she took was a gasp and I'll never ever forget that. I wouldn't ever want anybody to go through that pain as a patient or family member. (Interviewee 17)

I nursed dad at home until he passed away. And what I thought that patients wanted, or what I thought that I wanted, when I look back on it. I think if I had a nurse that did that to me, that's not what I would want. And I know everyone's different, but you go in there and I suppose you just give them space. But you gauge that with what the families need and what I thought it was like and then you have your personal experience and then you come back to it, and you think... I can't believe I did that because that's not what I wanted. (Interviewee 10)

Personal experiences and exposure to death and dying of his parents and other relatives was also of benefit to this nurse participant (interviewee 14) who explained how it helped him to manage or feel more comfortable with the death of patients in acute care:

I think experience what I've seen...I witnessed, and I was there for, I was there when my father passed away and...there when mum passed away as well...So I had that experience, and I can remove myself a little bit from these things. But I think because I've witnessed death and I've had older relatives, I've had a lot of older relatives' die as well...I've been to their funerals and I've witnessed their decline and things like that...so I've experienced a little bit of life and with experience and a little bit of life you sort of, you see a bit of death as well...So I think that's helped, I think that has really helped me. (Interviewee 14)

The nurses felt strongly that professional experience in the care of dying patients and families was necessary for building confidence and competence in end-of-life care:

I think that it definitely comes with experience because at first, it's pretty confronting having to deal with a dying patient and relatives who are really emotional and having difficulty coming to terms, but you learn what works and what doesn't work. (Interviewee 17)

The participants frequently indicated that their prior experiences and exposure to death and dying enabled them to feel better about approaching families and managing care provisions for patients:

I used to find it I guess confronting and scary, and I used to feel afraid of it because I wasn't confident with it or what I was doing but I actually really enjoy it now. I think I have realised that I used to feel nervous with it, apprehensive I suppose. I just wasn't confident. I didn't have the knowledge in terms of medications because yes, I was familiar with the Dr's orders and those kinds of things but in terms of knowing I'm doing the best things for the patient, you want to know what you are doing is appropriate, but I know that I've done everything that I could possibly do asking them could we increase the drug. I don't think that dose is enough, so I actually feel that now I've got that little bit more confidence in this area I feel more equipped in this area (Interviewee 2)

Both personal and professional experiences of end-of-life care, as encountered by the nurses, helped them to process or make sense of dying, and this was influential on the roles they performed as part of the provision of end-of-life care:

But with that experience, is how you deliver your care you know what's important to you and as I said, you can't predict but you try and portray that experience or that education and experience you have onto the family. Sometimes I've found that people haven't coped with a situation because they haven't acknowledged their own part and moved past it. They've stayed where they were, and they can't move past that...It's not easy. Because all that experience will always be with you. I'm a very, very emotional person, I'm shocking, I'm a sook but I've become better as the years go on and you get better at it, you deal with it... and move on. (Interviewee 8)

Throughout the interview sessions, the nurse participants identified individual or significant cases and engaged in 'story telling' about the clinical experiences that had the greatest impact on them as nurses. On these occasions the participants reflected on the experience and what they learnt from the experience

and how they coped. This nurse participant described her processing of loss, and how death in one patient's situation was considered as a good outcome for a struggling patient:

My first layout was a child of eleven with thalassemia major, and I had been working, you know, prior days, so basically the nights were listening to this poor child, this is when I was not finished my training.... the last night I remember very clearly, because her laboured breathing was such that every breath was a groan. And the father was sitting there, and it went on for hours and hours and hours of this laboured breathing. She had a liver the size of, almost the size of her torso, it was just massive. The colour was a cross between it was just dirty grey, and finally she died. An eleven-year-old, racked with pain, or the appearance of pain, because she was unconscious, but she was breathing, but after she turned into an angel, she turned into this beautiful, pale, pain free angel. It was absolute blessing for that time, because there was nothing for her, it was just rotten, eleven years old! But it gave me a perspective about dying which has lived with me ever since, the passive impact of seeing that child die of something at the time which was incurable and have complete loss of pain, she's at rest...there was nothing better that could happen to that child at that time, cannot regret and that's probably, that's the one that stayed. It's the first one, it was a big one.

(Interviewee 15)

The study nurses provided many clinical accounts which were of significance to them and were related to the death of patients and the care they provided to families. Many of these accounts were remembered from years previously and despite that length of time, still influenced the nurses' practice. In some circumstances the study nurses described using their peers to help make sense of the situations and help process the event.

Learn from role modelling and debriefing

Nurses described the need to role model care from other staff members who they thought were providing effective end-of-life care. Staff identified as role models were other staff that the participants had observed delivering care at what was perceived as a high standard, and were commonly described as more senior staff members. Watching and learning the approaches and methods of communication was

described by the nurses within this research as highly beneficial: *“You can develop those skills from being part and role modelling. I think role modelling is very important especially with end-of-life care knowing how to have those conversations is really hard and I have learnt that through being role modelled to”* (Interviewee 1).

This nurse participant, Interviewee 2 described how she learnt to provide end-of-life care by watching more senior staff practice end-of-life care:

I’d say learning from other nurses, talking to Dr’s about it. Figuring out what worked and what doesn’t just listening to them and watching them have helped even things like with medications well if this medication isn’t working then knowing that sometimes you haven’t got the right drugs rather than keep giving it or is there something wrong with the site just the experience of doing it actually doing it...learning from other people other more senior colleagues. (Interviewee 2)

Most role models identified in the interviews were described as more senior or more experienced nurses. These nurses were also described as being more than happy to provide support or on-the-job training and guidance concerning end-of-life care. Most support was sourced within the immediate unit or departmental team:

Those nurses taught me a lot because those nurses were the more mature nurses who were very experienced and senior nurses and they sort of guided you and gave you information for your care of the patient throughout the day and I remember they used to come and say to you are you ok what’s going on do you know what your role is do you want me to know anything else and they would come on the ward round and have that discussion with you at the end of the ward round and then you were set up for the day really. (Interviewee 4)

Internal support from members in the wider team, in the form of formal and informal debriefing sessions, also assisted nurses with their end-of-life care roles, and overall, to help understand or make sense of dying and the related events that led to a patient’s death. Talking with other acute care nurses was described as highly beneficial to coping with the death of patients and the care provided to their families;

“Probably a lot of things that pass through social chit chat in the tearoom just a bit of a debrief. I think that’s how you pick up most of your information and support” (Interviewee 11).

This nurse participant discussed the need to debrief, to try and cope with the death of a patient in the critical care unit, by reflecting on the care provided on that occasion:

So, I had my little cry and then later on I spoke to our educator and had like a debrief with the educator and also with the nurse in charge who was on that day a couple of days later I also had a talk to them as well to debrief, just to make sure that we did everything at that time, and we did what we could. (Interviewee 9)

Informal debriefing and support that was department and team specific was also described as highly beneficial to acute care nurses:

I think that staff are great in supporting each other from anything that’s medically urgent happening to if they are in a palliative situation or post-death, I think we’re all very good in supporting each other as well as doctors. We all work very well together in our department, so I always feel like if I need help in any way it’s there, and I’ve always got someone that I can go and have a sook to, or if I know, look, I just need ten minutes to go and have a break myself because I’m just emotionally drained and physically as well as, you know, I am always looked after in that sense. (Interviewee 13)

The participant Interviewee 11, a nurse leader, also discussed her desire to look out for and support staff from “burn-out”, which she recognised may be associated with caring for dying patients and families for long periods of time; *“and if staff are struggling, if I can see that they are struggling, I’ll often re-allocate or just say to someone, make sure they don’t have that patient the next day” (Interviewee 11).*

Although formal support mechanisms were also identified by the nurse participants, with frequent reference made to the option of the Employee Assistance Program (EAP) throughout the transcripts. The nurses in this study more often described casual debriefs with other colleagues as the most preferred and sufficient method to support them.

But I know that if I don't cope okay, I can always debrief with someone. There is assistance programs here at the hospital but I've never had to use them. It's mainly just debriefing with others really, that I use. Because I know that if you bottle it up it's just not going to work so yes, debriefing. That's usually the supports that I use. But you do have an awareness of the supports that the hospital has, or you could go and speak to counsellors or things like that, but I haven't had to use them, but I'm not saying that I won't have to later on. But just always, shout out to someone if you're not coping or things like that. You know, debriefs that you do with your colleagues tend to suffice, because they were there too. (Interviewee 10)

But then you know, you just catch up with some nursing friends afterwards and you debrief, you talk about it and I know that I might be a bit funny for a week or two, and if it gets past that and I'm still thinking about it and not sleeping or whatever, then I'll go and see a professional, but you know, I know that it usually takes me about three weeks to process something like that. But usually, a debrief with the nursing girlfriends usually gets me through. (Interviewee 18)

There was evidence within the data to also suggest that acute care nurses did not always cope with the care of dying patients and their families with some clinical cases causing more emotional distress than others.

Using coping mechanisms

The acute care nurses within this research described caring for patients during end-of-life care as sometimes being emotionally challenging and “*taking its toll*” (Interviewee 4). A negative emotional response was common when nurses described the impact end-of-life care had on them as acute care nurses; for example:

Some days it's really full on. I suppose it depends how emotionally attached you get to them as well because obviously there's a lot of little factors that you relate to, like, in your own personal life and family that cling to you a bit more than other family. You just have to keep your professional wall up, I guess. Sometimes it can take its toll a little bit more than others. (Interview 7)

In some instances, and when nurse participants were having particularly bad shifts, they described end-of-life care as *“quite distressing”* (Interviewee 13), *“really difficult experience”* (Interviewee 1), *“really terrible”* (Interviewee 10), *“really upsetting”* (Interviewee 20) and *“pretty horrible”* (Interviewee 16). Nurse participants described the emotional reaction of ‘crying’ as a frequent response to how they dealt with some situations. Interviewee 20 describes the emotional toll of caring for both the patient and the family during a patient’s end of life: *“...I go home and cry, sometimes I just cry, and I know I’ve sat in meetings or with family and you tear up, because...when you see the heartache of some of these families... it can be really upsetting”* (Interviewee 20). Interviewee 9 also states, *“I went out the back and had a big cry because it was fairly sudden and traumatic. But it was yeah, very emotional”* (Interviewee 9).

The long-term, negative emotional effects of caring for dying patients was also described, as highlighted by this critical care nurse who explained her experiences as traumatic and depressing:

Yeah, it can be pretty horrible. I think I kind of touched on the fact that in CCU it’s a lot more I think almost traumatic, like, the whole thing. Like, we’re doing so much and then we’re not doing anything at all, and it can just feel really, like, deflated. It just can be depressing. You kind of feel like you’ve put everything you can into doing something for someone and then you just pull treatment, and you know why, but it’s not, it’s still not really a nice thing to have happen. So yeah, it can be really hard. Your kind of taking on everybody else’s grief because you’re also grieving for the fact that, you know, your human, you’re going to grieve for the fact you’re losing a patient and it’s a person, and the whole situation, and then you can’t really express that because the family, it’s their turn to do that. So, your kind of. I know myself when I’ve been upset in a situation, I’ve kind of, you just hold it all in until you can leave, and you’re supporting them and then you walk out and you go home, and you think okay now, now I can think about my own feelings and cry and have that moment to yourself. (Interviewee 16)

Other nurse participants provided examples during the interview sessions of how they distanced themselves, by trying to remain professional and not become too emotionally attached. This was done in an attempt to protect themselves and cope with the end-of-life situations they encountered in practice, although this approach was described as not always easy; *“They needed to shut everything off, go in and*

do the job and come out of the room so that they could cope with it" (Interviewee 12). This is elaborated by another nurse participant:

Some patients you can keep up that wall, but sometimes they really get you. I don't know why, but you just have a bit more, you like them a bit better, or you're fond of them, they remind you of something and sometimes you just get a little like. Some days it's hard. I think there's been one day I cried because I was just like oh my God, I was like a wreck and everyone was saying oh my God, what's going on, why's she crying. So, you do get a bit attached to them and like obviously the family...I think once you do it a few times it just becomes second nature, like, it's a part of life. As hard as that sounds. (Interviewee 7)

Commonly, the nurse participants described holding back emotions and trying not to show too much emotion; *"I do feel it's inappropriate if you get too emotional"* (Interviewee 8). Some nurse participants described holding a family's hands or giving family members a cuddle, as a gesture to show empathy (Interviewee 8, 17, 21). Other nurse participants spoke about the need to separate sympathy and empathy to protect themselves and meet the needs of families:

It's very hard to take your own emotions out of it whereas now, I can really separate what's work and what's outside work I suppose, I don't know if that's the right way to describe it but I think just not sympathising, it's that empathy but not sympathising I think is a difficult skill to learn. And even just to say those words, it's hard to explain what the difference is between those two things. One is to put yourself in their shoes I guess and understand what they're going through and not using language or body language or things that will make it worse for them. And if you sympathise, well you're the one that's bawling in a heap in the corner and that's not helpful to them either. (Interviewee 11)

In many situations, the nurses within this study shared their experiences and emotions with other staff members and learned or debriefed together, through different clinical events. Their professional and personal experiences of death and dying also impacted the way they provided care. The emotional burden of care was also evident in the findings, and the nurses needed time to adjust to a patient's death with

care 'taking its toll' on some occasions. The reality of the acute care environment and the non-metropolitan setting in which the nurse participants performed end-of-life care also impacted their coping with the provisions of bereavement care during the end-of-life care of dying patients.

Coping with our reality

The study nurses discussed the challenges of working within an acute non-metropolitan hospital and how these challenges were also significant to their 'coping' with the delivery of care at end-of-life. The acute care setting and a non-metropolitan location also fashioned the way that bereavement care could be delivered to both patients and their families. 'Coping with our reality' has the following subthemes: Rurality as a reality, A better space to provide care, End-of-life care against the grain – 'We are too busy keeping people alive', Patient ratios and juggling time to spend with families.

Rurality as a reality

The nurses interviewed perceived that caring for dying patients in a rural or regional location was associated with a reduction of resources and limited supports and referral pathways within the immediate or local area for patients and families. This was frustrating for the nurses in this study, but they coped with this reality by rationalising that it was the reality of caring for patients in a non-metropolitan or regionally setting; *"I don't think we have the resources to do the job well, for example allied health supports, after hours, specialists in palliative care that could come and review the patient, hospice facilities"* (Interviewee 1).

No hospice care centres were available at any of the hospitals or within regional proximity for dying patients and their families. No terminal or palliative care units existed at the participating hospitals, and patients commonly died in acute beds, referred to as 'palliative care beds', in medical departments. These beds, although still located in acute care units, differed given that they were single bedrooms (Interviewee 1,2, 5, 11, 16). All other resources for families of dying patients were shared with other family members within the acute care units. As one nurse participant stated:

*In **** [name of a metropolitan hospital] I know they've got hospices and things like that where there is a palliative care doctor and that patient can either go to the hospice which is not home but it's a more home-based environment, so you know, there's a hospice home where people go to be palliated with a doctor there, they can order things they need why just in the city? Give us a hospice! (Interviewee 8)*

Nurses also described a lack of specific resource availability and a lack of awareness about supports in the region to meet the cultural needs, particularly as the region's cultural mix was changing.

I think we're limited, we have the Koori Liaison, which is great, so that's good for our indigenous patients that identify as indigenous, and that's a very different culture in terms of end-of-life care as well, in terms of what you do a little bit differently, but I think as Gippsland's getting more and more multicultural, there's not the supports there, especially at end of life. There's lots of resources online, and we've got lots of brochures and so forth, and there's training that you can go to, but you have to be aware of it, so I think there's a lot of information online, but I think because it's so varied. I think you'd need something kind of general to be able to draw upon to direct you in the right spot for resources or information on how to care for that particular demographic when they're here. (Interviewee 19)

Some participants talked about larger metropolitan centres and departments specifically for dying patients in which additional patient requests and wishes could be fulfilled and families better supported and needs of both better met:

*I know down at the **** [name of a metropolitan hospital] they have a palliative care ward and some of the things they did for families and patients were amazing like it was just crazy. There were a few patients that renewed their vows and stuff like that just little stuff like that you wouldn't, you could never do here we just don't have the facilities to support or the money or anything like that. So, just fulfilling those little things; that would make patients and families happy. The metropolitan hospitals just have so much more support, there's never someone that*

can't give you a hand, there's enough resources, there's enough people to help you. (Interviewee 7)

One nurse participant described the need for a coordinator to assist with the end-of-life care needs of families within acute care, to ensure that resources were provided, or patients and their families were linked to support services during the patient's end-of-life care in hospitals and after death for families.

If there was one person in that role, they can be making those phone calls to social work, organising a priest...getting in and making sure that the family are looked after once they leave the department. To be honest, a lot of families leave and then that's it, we have nothing else to do with them and you just don't know how distressed they're going to be when they get home or what supports are in place. (Interviewee 18)

Support services for the management and review of patient care was also discussed by the nurses in the study and were considered less than ideal. They suggested that lack of referrals to palliative care and medical consultants also impacted on the care or ability to meet the needs of dying patients.

There was a team from the consortium, so they would come down, but it was only once a month, but I don't think they come anymore... but just having this access and this education and clinical supervision is so beneficial and important to us (Interviewee 1).

But services offered to families there's probably not many that are offered. If you were in a perfect world, you would have all the services available for 24/7 and there would be palliative trained nurses on every ward...there would be specific wards for specific areas for families...it would be easy to take family members home if that's what they wanted...there would be a service to support this (Interviewee 10).

The lack of available specialist medical review or palliative support services impacted, in some instances, on patient care and the management of a dying patient, with possibly associated delays in the implementation of care and sometimes inadequate comfort measures for dying patients. This nurse

participant, interviewee 7 described the need for nurses to plan issues for discussion with doctors regarding patient care needs, to avoid any delay in management:

The speed that things get done because you're chasing someone that miles away that doesn't want to come to your ward because that's not their area, so it gets a little bit hard you have to make sure you get everything done while they [doctors] are there and the weekends it's probably harder because there is only the one intern and on registrar sometimes it is impossible, it's a waiting game till Monday until all the teams are back and can make a decision. (Interviewee 7)

In most situations, deaths occurred over a short time frame, particularly in Critical Care and Emergency units. This often meant that the opportunity to arrange for patients to go home and die was mostly limited or extremely difficult to coordinate and nurses felt this should be an option to better support both the patients and family's bereavement. *"We liaise to try and make that happen. Unfortunately, sometimes it's just not possible because the patients are deteriorating quite quickly"* (Interviewee 21).

Nurses did not feel comfortable with this reality, as these participants explain:

Not being able to move someone from an intensive care unit to home to die is just unfair... I think there is a lot of brick walls for people regionally and that's unfortunate because I think if someone wants to die at home, they should be allowed...we should have the resources to make this happen. (Interviewee 8)

It should be so easy for family members to take patients home to die if that's what they want I was a nurse and had a good relationship with the GP so we could do that not every patient has that luxury and when they do have that luxury it takes days for that to be implemented and appropriate relationships between doctors at the hospital and GP's and hospitals, and a correct understanding of care more flexibility with palliative care services here. (Interviewee 10)

Some participants found that working in non-metropolitan areas also had advantages in the provision of end-of-life care to dying patients and their families. Nurse participants described what it was like living and working in non-metropolitan areas and how the setting could impact positively on grief and bereavement for patients and families.

The best parts of working in this hospital is that people are local we know people we have common interests and common friends and I think that makes people more relaxed and more comfortable and that makes me feel more fulfilled the best thing is the rapport we have with people just because we are in a small county hospital and we have got commonalities and repeat patients that we see so you get to know them quite well. (Interviewee 5)

Another participant described how non-metropolitan, or country, patients and families could be more accepting of death, which had a positive impact on the delivery of end-of-life care:

When I first came back to the country it was so different death and dying was so different here, then in the city. I know it sounds so silly but they really believe that technology and the medical intervention will save their loved one and I think that there is a real element of hope that is attached to that but I found people here are a bit more realistic or pragmatic maybe and I think that farming background people see the circle of life is that it ends in death but I really found that people coped with it better here in the country than they did in the city. (Interviewee 5)

Some nurse participants felt the opposite to other participants regarding the benefits of knowing patients and families as result of living in smaller populated, regional areas; *“It is more confronting when it’s in a small town and you know people, it is harder to accept sometimes”*. (Interviewee 18)

Overall, a reduction in resources and specialist medical services to support patients and their families during end of care, as well as the positive and negative impacts of nursing patients in smaller rural communities, were regarded rural realities, as described by the nurse participants in this study. The acute care hospital setting was also perceived as presenting more challenges to nurses providing care to dying patients in non-metropolitan settings that could impact on how patients and families coped with their grief relating to death and dying.

A better space to provide care

The acute care environment presented many challenges to the provision of end-of-life care for dying patients and families, as one nurse participant described, *“We’re trying to push the clinical, sterile, away. We’re trying to keep that away because we all kind of acknowledge that that’s not conducive to*

what you need...you would want a calm and comfortable environment for a patient that's dying"

(Interviewee 19).

The nurse participants frequently expressed there was a lack of space, privacy, and adequate resources to properly support families. The emergency department was a particularly difficult environment in which to care for dying patients, as one nurse participant explains:

We have no family room or anything like that in our department, so it's not like we could redirect families to a special room to sit, to make a cuppa, you literally have to tell them, sit in the waiting room, or sit in the cubicle. And then if someone is passing away or has passed away, a lot of families want to get together and talk, whether they're making decisions about the end-of-life process, or just supporting each other, they've either got to do it in public in the waiting room, in a cubicle where people can still hear, you know, curtains don't block, and they don't have a room. So, there's nowhere for them to really start that grieving process. If they want to cry, there's nowhere to do it. If that was me, I would go in the car, maybe people do that, but a lot of people will sit out in the waiting room and it's probably really hard for them to be sitting maybe as a group of five or six, if not more, in a waiting room that might already have about twenty people sitting in it, to try and talk. There's no privacy, there's nowhere to grieve. We need some sort of a room for families, for ones that are passing away or have passed away. We need a room that they don't have to leave the department.

(Interviewee 13)

In other acute care areas, the nurses in this study also identified a lack of privacy and space as impacting end-of-life care, which became a quite common finding. On many occasions, a single room was sought for dying patients, however, this was not always a possibility and patients often died in rooms with other patients close by, separated by curtains for visual but not auditory privacy. Nurses within this study found this less than ideal for families of the dying patient and for other family members of patients, as follows:

There's not enough privacy I think that all the time. We have curtains between bed spaces and obviously if a patient is palliated and they're not expected to pass away imminently, we will try

and arrange for them to go to a ward bed with a single bed or go to, we have one single room, but it's usually an isolation room for someone who is isolated for something. So, we can't always use it. But we try and do that but if they can't, or their death will be imminent to the point of, either turning off the ventilator or turning off whatever supports they have off or on, there's not always that option. So yeah, I find it's really uncomfortable for the other patients as well. I think some of them can sometimes be a bit traumatised by the fact that there's no privacy, they can hear everything going on. We had a family recently who, they were of a culture that was quite loud and very vocal, and the other patients were quite distressed by people crying loudly and it's uncomfortable for everyone. (Interviewee 16)

Resources to support families that were staying at the hospital for extended periods or sleeping at the bedside were also minimal in acute care settings, with a lack of bedding and space to accommodate families; the sentiment of nurses is exemplified in the statements of this participant:

In hospital it would be so nice to have something that allowed the family to stay and just to attend to the basic needs of extra people while they are here to have a shower, have some food, you know tea and coffee that type of thing. (Interviewee 4)

Other nurse participants described the sleeping arrangements for family members at the hospital as less than ideal, as follows:

It's not ideal, but they can stay. I've seen people sitting on a chair with their head on the bed sleeping...and having a couple of couches around the place is good... I know for me personally in other situations, I've found a recliner chair and put it in the room for a family member to sleep on. (Interviewee 18)

Oh, it's tight, to say the least. I think we've only got three or four of the fold out beds so sometimes it's just not enough. You'll have relatives that you give chairs, which I guess we don't accommodate, we're not equipped to accommodate for a lot of family but sometimes. So, it gets a bit hard. We try our best to pull beds and stuff from everywhere if we do need them, like the

fold out couches but sometimes we have had relatives that sleep in a chair and stuff like that before, which would be so uncomfortable. (Interviewee 7)

The nurse participants in this study described the need for more resources within hospitals. Having more resources available to make the clinical environment more comfortable for patients and families during end-of-life care was described as essential. A comfortable environment that better accommodated patients and families at end-of-life, also supported a more positive experience of death and dying, in which individualised needs could be better met, and care overall better supported both the patient and family's grief.

Obviously enough facilities to help the patient get across to a shower if they're still at a point. We all know that if you've been sick and in bed for a couple of days, you get up and have a shower and you feel one hundred per cent better. It hasn't actually changed your health, but it's made you feel a lot better about yourself. Things like being able to wash patients' hair if they are confined to bed. Little things like that really make a big difference in a patient's life, and I think in the family's life, too, because those little things make them feel like the person's being cared for better. (Interviewee 12)

Resource wise, there is not always the fans or the CD player doesn't work so we don't always have the facilities to be able to respond to their needs with whatever music they may have that's a challenge, blankets, pillows those kind of resources are quite difficult to come by sometimes and food as well finding food sometimes in the middle of the night as well ice-creams or drinks if they are on thickened fluids that kind of thing can be a challenge. (Interviewee 1)

The general, acute care environment was also described as not ideal for supporting families; *"there's a lot happening in an ED, it's noisy, you know there's an intensity in the atmosphere sometimes, and I don't think that's conducive for family to be saying their goodbyes and they don't have privacy (Interview 18) and "It's just very clinical sometimes. Like it's not an enjoyable place sometimes, it's loud and it's noisy, and they don't get any rest" (Interviewee 7).*

Nurses within the study were often concerned about the clinical nature of the environment and attempted to personalise the bedspace as much as they could. Some nurse participants encouraged families to bring in personal belongings, such as pillows and blankets or doonas, sleepwear and pictures (Interviewee 18, 19, 11, 12), in an attempt to make the environment feel less clinical. Another nurse participant describes how she attempted to adjust her environment to best support families:

I think when patients are in for longer, people can and would bring in lots of photos of the family and they'd bring in blankets, like, nice colourful blankets or. Sometimes they would ask can we bring in music a couple of the patients we've turned the bed so they're facing out the window. We only have a courtyard that it faces but when we are not monitoring them, there's no reason that the bed has to be a certain way we've done it in our private room, and I did it the other day for a patient. That way, also, the patient's not seeing you kind of going past them all the time and it's all busy, busy, busy and things are going on. You can shut the curtain and they're facing out to the window and can see a bit of sunshine and so that's something that help's families, I think. Kind of block out what else is going on. (Interviewee 16)

It was evident that the acute care environment was perceived as less than ideal to nurse dying patients and their families and, although, many attempts were made to maintain privacy, it was evident that more resources were needed to allow families of patients to feel more comfortable at the bedside. Families were perceived as needing adequate space and privacy so they could grieve and be in the company of other family members to attend to religious/spiritual needs with patients and engage in other end-of-life and individualised care measures. Having adequate resources, space and a place to gather for extended periods was also considered significant for the patient's grief and the bereavement process for families. Nurses therefore attempted to buffer the clinical nature of the environment, allowing and encouraging belongings of patients to be brought in and used at the bedside of dying patients to create a more relaxed setting. The acute care environment, as described by the participants, encompassed the clinical or sterile nature of acute care and the study nurses managed this as part of end-of-life and consequentially bereavement care.

End-of-life care against the grain – we are too busy keeping people alive

Commonly, nurse participants expressed that end-of-life care was essentially 'against the grain' or an opposite extreme to the goals and outcomes for patients in acute care. Nurse participants explained that, within acute care, health professionals were aiming to treat people and restore health; for example, *"Treating patients is the goal for nurses coming to work...we are most of the time about making people better and sending them home"* (Interviewee 6) and *"Death and dying is taboo...because we are in health, we are trying to make people better or they come in to get better and go home, so that notion that they come in here and that they don't go back home again is a challenge"* (Interviewee 1).

The belief that acute care settings were designed for treatment with intent to restore health for patients was more commonly identified in the interviews with nurse participants from speciality areas. Critical care and emergency nurses, in this research, frequently discussed the need to move dying patients to other, less acute, wards to die; *"If you think you've got the time to get them to a ward bed, then you know, we will transfer to the ward...as soon as possible"* (Interviewee 18).

One nurse participant discussed this view and why it is appropriate to do such a transfer in the emergency department and this seemed related to the culture and also the acuity in terms of place of death for patients and their families.

I think they [nursing staff] are afraid to have people die in Emergency. I think they [nursing staff] don't see that as part of their role. Like some of the girls will come on shift and say, oooh saving lives today you know, and I think that's how they [nursing staff] see that role, they've come to work to save lives ... and it's a culture thing...so I've noticed in Emergency everyone's like people don't die in Emergency and often they will try and move heaven and earth to get people up to a ward if they are dying. (Interviewee 4)

The nurse participants suggested that having dying patients mixed with acute care patients was difficult to manage. The nurse participants indicated that the varying levels of care and meeting the differing needs for a mix of patients was exhausting, with subsequent potential negative effects on other patients, as follows:

The negatives to providing palliative care in an acute medical ward is that we never have enough time you never have enough time to give, or the right amount of time you rush straight from looking after someone who has got an infectious disease or an infarct or something else and then turn around and be compassionate and empathetic to a person that's dying and their family and to be able to give the correct amount of quality time is an astronomical struggle and very very draining and difficult so that's the worst aspect of having palliative care patients on an acute medical ward. I really think it needs to be separate from an acute area. (Interviewee 5)

You almost feel like the other people that you're caring for are selfish sometimes, because they'll be like, oh, my pillow's, I'm not very comfortable, and you'll be like look just be grateful you're alive, you know...so you need to remember that the person in here's got a sore foot, the next one next door's got tummy pain, the next one's passed away, the next one's got a broken arm...you've got to adjust to that, and that's what we do as nurses because as soon as someone leaves a cubicle you've got somebody else in there, so you just have to adjust to whatever you're looking after and hope that it doesn't affect you. (Interviewee 13)

It was also identified that nurses within this study felt that being in an acute hospital setting had some impact on families expecting positive outcomes or prognosis. This was explained by patients in acute care receiving initial treatment measures, for short periods, as a 'trial response' before full withdrawal of treatment occurred. This 'trial response' treatment was part of the nature of acute care, with one participant describing the point of end-of-life care as, "*against the grain, we are too busy keeping people alive*" (Interview 16). The opposite extremes of care are aptly identified in this quote, "*often it goes from spending every second trying to keep them alive to all of a sudden, bang, they're palliative now and then they are dead within a very short period*" (Interviewee 11). This sentiment was elaborated further by another participant:

Often you are there at the turning point...you are looking after them with the view of getting them well and returning them to their previous level of function and getting them home to their family or wherever they have come from but sometimes I think that the difficulty comes when you are trying all these things and you have offered them at the beginning of the illness or the

medical team have offered them at the beginning of the illness and then they don't do well. I find that the care during the day or throughout your shift is about the back and forth and unfortunately sometimes as you go back to the family and as you are in the room each time it becomes apparent that they [patients] are not winning and that the patient is not doing as well and so its slowly getting the family used to that and its quite terrifying for them because it happens so quickly to them and in the back of your mind you have been thinking this may not all go well we haven't prepared them for that at the beginning because there hasn't been the time for that discussion. The discussion has been about in the event of this what would you like us to do, ok let's try antibiotics, let's try Inotropes, let's try these measures and then how do you come back from that when that doesn't work for a family. I find that that's really hard. (Interviewee 4)

Nurses suggested that the trial response to treatment often led to a shorter period of end-of life care. Shorter periods of time to provide end-of-life care to patients and families also made it difficult for nurses to bond and develop the necessary rapport with family members to prepare for the impending death of a significant other (Interviewee 14); *"So, it might take you two days to get someone to understand that this person is dying right beside you...so time for the family is huge and is impossible to measure, to predict how much you need to give for a person and that's one of the worst things"* (Interviewee 5). Similarly, another participant commented:

I think compared to having that time on the wards when you might be with a patient for several days or the family has known for a long time, and you've stepped in but they are fully prepared and understanding the situation. Compared to Critical Care where it was just like, we're doing everything, to not doing anything at all, in a very short space of time and the family's shock of course, because they had only found out that morning that their family member isn't well and by that evening the family member might have passed away. (Interviewee 16)

The acute care setting was described by the nurses within this study as an environment associated with providing treatment for patients. Nurses described trial periods of therapy and withdrawal of treatment, which were often associated with shorter periods of end-of-life care for patients and families that were challenging. Having a mix of patients receiving both end-of-life care and full treatment measures was

also challenging for nurses, and this had further implications on patient ratios and time spent with patients and families. These factors combined, impacted on how the nurses felt about providing end-of-life care and consequentially bereavement care to dying patients and their families in acute care environments.

Nurse-to-patient ratios and juggling time to spend with families

The allocation of nurse-to-patient ratios in acute care settings was described as challenging and often meant that nurses had difficulty ensuring they spent enough time with dying patients and their families to provide bereavement care. Within the interview sessions, nurses frequently described the challenges of meeting the care demands for acute care patients and for dying patients and their families; *“Within an acute care setting where you’ve got other patients that you’ve still got to manage, you’re trying to juggle your time a lot”* (Interviewee 12). The majority of nurse participants provided descriptive accounts of challenging clinical situations, where they found it difficult to prioritise both care for critically ill patients and the bereavement care they believed was appropriate for other dying patient’s family members in addition to support of inexperienced staff.

So, there is plenty of times where different situations bring conflicts of what is needed to be done at that time. I have felt like I haven’t given the care that the family or loved one needed or if it’s the family member that has needed lots and lots of attention and you have got someone who is acutely unwell and you have a student nurse who has never dealt with someone who is dying before so your trying to support them mentally that’s really challenging and I don’t feel like I’ve done a good job and that’s really hard, really hard. (Interviewee 1)

Nurses within this study felt distressed about not providing enough care to patients and their families due to conflicting patient and clinical demands; *“You can feel incredibly pulled emotionally because you want to provide that emotional support and care, but you are so busy doing other tasks and looking after other patients, for me personally I can feel quite torn. So, I dislike that”* (Interviewee 18).

Nurse-to-patient ratios were sometimes described by the nurses as unbalanced, based on the needs of patients and their families, especially when the nurses cared for both patients receiving full treatment

measures and patients receiving care at the end of their lives. Most ratios, as described by the nurse participants, resulted in the nurses being time poor; *“I guess better ratios so you could spend...physically spend more time with that patient”* (Interviewee 6). Overall, nurse-to-patient ratios varied but were mostly described as from one nurse to every three patients (ratio 1:3) to a ratio of one nurse to four patients (1:4) (Interviewees 5, 6, 9, 18,20), depending on the complexity of patients, but always with a mix of both acute patients and patients receiving end-of-life care. This was a situation which the nurses described as less than ideal, as follows:

On this ward it's difficult because sometimes you might have 1 or 2 palliative patients with other quite acute patients. The patient allocation can be hard it really depends on how it's allocated and what the other patients are like as to how well you feel you can do. I do remember an instance recently where I had a patient...I can't remember what she had, but she wasn't the palliative one. Yet she was kind of making complaints about where was I why wasn't I here with her and I was actually caring for 2 other palliative patients at the same time and so that was really difficult because I didn't feel neglectful of her at all it's just that she didn't have as many needs compared to the other patients so she wasn't seeing me because I didn't need to do anything in particular at that time and I had intended to get back to her but I guess the difficulty is in caring for the palliative and the other medical or acute patients the hard part is that you can't be in both places and you want you spend the time with the palliative ones. I found that shift particularly difficult because of that and I felt personally effected because I was frustrated. I felt conflicted because I felt that if only you knew what I was doing next door you know. I felt that was really difficult, so I wanted to spend the time with that patient the palliative one. I guess that was really hard. (Interviewee 2)

Nurses believed that ideal bereavement care involved consistent carers. Therefore, shift changes also affected the care of patients and their families, and sometimes resulted in a reduction of time with a lack of consistency, as exemplified by one nurse who recounted, *“Consistency of carers as well, so that relationships could be built up between the patient and the carer as well as the partner and the carer, which isn't always easy to do with shift-working staff either”* (Interviewee 12).

In some cases, new admissions and the need for empty beds to admit new patients impacted on the urgency to remove deceased patients quickly from wards. This impacted the time that families could spend with the deceased patient, including the acute care nurses after the death of their significant other which was also less than ideal for bereavement care, as one nurse described:

Look, it all depends on what's coming in I have been hurried up in the past, come on we've got someone that needs to come around, you need to bag that patient up...you'd like to give the family another half an hour, but you say we've really got to move.... If you, can you leave them. You can't do much about it because it's such an acute area (Interviewee 8).

Similar experiences were shared by another nurse:

Hopefully you're not pressed for beds, and you're not pressed for time, which is another issue that comes into that, so you feel like you're forcing the family out and then wrapping the body and getting it out and then filling the bed again. Which unfortunately does happen at times (Interviewee 9).

The need to free up beds to accommodate new admissions, who could fill beds previously occupied by deceased patients, was not looked on favourably, as this nurse manager, Interviewee 5 describes. In this situation both acute care nurses and families were described as being emotionally impacted by arrangements in support of patient throughput within the acute care setting.

I will try my hardest not to admit a patient into a deceased persons bed in the same shift the next shift fine but not the same shift the nurse has had to look after someone that's died in that room, I feel that it is completely inappropriate to admit straight into that room. I think there should be a law that says that we don't ever have to admit straight into that room and that no nurse should ever have to do that. I think it's mean, cruel, and traumatic [referring to acute care nurses and families] (Interviewee 5)

Summary

Caring for dying patients in non-metropolitan hospitals requires acute care nurses to cope with both end-of-life care and with the bereavement care they provide for patients and families during this time. Acute care nurses within this study attempted to cope with the delivery of care through their own professional experiences, debriefing with peers and the use of coping mechanisms. It also required the nurses in this study to cope with the reality of caring for patients in a non-metropolitan hospital that lacked space and privacy and had a culture of practice that was treatment focused and primarily aimed to restore the health of patients. Varying levels of patient-to-nurse ratios, shift changes and the need to keep beds occupied with patients were described as challenging by the nurse participants, and impacted on the available time the nurses could spend providing bereavement care to patients and their families.

Chapter SIX – Discussion

Introduction

The purpose of this qualitative, interpretive, descriptive study was to investigate the roles of registered nurses in the provision of bereavement care to dying patients and their families in acute non-metropolitan hospitals. In this study, 24 semi-structured, in-depth interviews were completed and analysed using thematic analysis, providing new insights into bereavement care, an under-researched role of acute care nurses in non-metropolitan hospitals. This chapter includes a discussion of the study's three key research findings: communication to facilitate bereavement care, creating positive memories for families as bereavement care, and nurses coping with the delivery of end-of-life care. Interpretation of the study's findings occurred using relevant research and literature about the provision of bereavement care, including practice guidelines about quality palliative care and end-of-life care pathways in acute care settings. Confidence and competence as perceived by the study nurses in the delivery of end-of-life care and the needs and clinical barriers that impacted on the care of patients and their families during the final stages of life were also included into the interpretation of the results.

Bereavement care, as defined in Chapter One of this thesis and for the purposes of this study, refers to the provision of care in hospitals, which may impact the bereavement process of patients and their families. Bereavement applies to a process whereby the patient attempts to cope with grief as a consequence to facing death, or the family attempt to cope with grief as a consequence of death anticipation or the death of a significant other. The loss experienced, including the related grief experience is, therefore, different (Boerner et al., 2016; Hall, 2014) for the patient, and for each individual family member. For patients, bereavement occurs as they face the reality of impending death, and for families this occurs in anticipation of loss and after the death of their significant other, as the family member adapts to living with this loss in their lives (Allard et al., 2020; Overton & Cottone, 2016). Bereavement care in hospitals can include the process of preparing families for a patient's death, psychosocial support for both patients and their family, referral to multidisciplinary services and the performance of clinical interventions to maintain the comfort of a dying patient (Buckley et al., 2015; Walker & Deacon, 2016). The strategies used to provide grief care or support, as outlined in the

literature, were recognised as similar to the bereavement care strategies used by the nurses in this study and these terms have been included as part of the research definition of bereavement care, and maybe used interchangeably through this chapter.

The study's definitions were used as a 'lens' through which the findings were examined to identify the roles of nurses in the provision of bereavement care during end-of-life care in non-metropolitan hospitals. It was further recognised that some of the role's nurses undertook as bereavement care, were targeted specifically towards the 'grief' experience for patients and their families. The term 'grief' is derived from the Latin 'gravare', meaning "burden" or "to weigh down" (Boerner et al., 2016), and refers to the experience of a number of emotional, cognitive, psychological, physical, behavioural, and spiritual reactions to one's loss (Boerner et al., 2016; Hall, 2014). The nurses in this study, therefore, provided bereavement care addressing the different reactions of grief, as a result of the impending or actual death, through the delivery of person-centred care which varied to meet both the patient's and the family's needs or grief experience.

The study findings have identified that acute care nurses in rural health settings provided bereavement care to both patients and their families during care at the end of life, and this continued for short periods for family members after the death of patients. Bereavement care was provided, sometimes, as a consequence of the delivery of end-of-life care and the nurses often had limited awareness that they were providing it. Bereavement care was delivered through meeting the needs of both the dying patient and their family during end-of-life care, and communication was the necessary tool used to guide this care. In addition, the nurse participants required time to reflect on the delivery of end-of-life care and, consequently, the bereavement care they provided to dying patients and their families.

The stories of their care reflected how important the nurses in this study believed their role was for providing support and guidance to family members during end-of-life care, and how they worked to create the best possible experience of death and dying for patient and their families in rural hospitals. In this study, the metaphor of a 'trekking leader' is used to help describe the roles of the nurses in their provision of bereavement care during end-of-life care. The application of this metaphor to the study's findings will be further described, along with the key themes of using communication to facilitate

bereavement care and creating positive memories for families as part of bereavement care. The importance of self-care for enabling the nurses to cope with the delivery of end-of-life care, including the identification of bereavement care in the work of end-of-life care, will also be discussed in terms of the nursing roles that facilitated the delivery of bereavement care.

Leading the Trek on an End-of-Life Journey

Trekking is defined by Gwynn & Laugesen (2020), as “a long arduous journey” and refers to spending multiple days to reach a desired destination in a wild, natural environment (p. 1000). Trekking requires both physical and mental commitment to sustain the activities required to reach the set destination. Trekking journeys usually occur in groups and challenge natural landscapes or terrains with, for example, mountains, forests, or rugged coast lines. Small amounts of essential belongings are packed into backpacks and carried by trekkers to support their journey. Some of the basic essential trekking items to help sustain the trek include food, water and warm/waterproof clothing (Bikat Adventures, 2021). The remaining items are typically very different for each person, with efficient packing described as an ‘art’ very difficult to properly master (Tasmania Expeditions, 2021). The basic essential and individual items required for backpack belongings are reflective of the individual journey that each trekker undertakes, based on their own very different needs that arise in response to the environment and the larger trekking experience.

All trekking expeditions have a leader who helps support the wider group and navigates the journey in typically adverse or challenging environmental conditions. The trekking leader is the one usually with the most experience and understanding of the environment, with the required skills to lead the group to the destination point (Asawalikar, 2019). This often involves coordinating multiple tasks and responsibilities for other trekkers and so the experience, although arduous, is as positive and rewarding as possible (Enoksen & Lynch, 2018). Some of the roles that trekking leaders perform are to path find, work as part of the team to support the wider group, and listen to understand the different perspectives of the trekkers and their needs throughout the journey (Lee, 2021). Having the skills to practice effective communication as a trek leader is described as essential, including the skills of listening, engaging all

group members and being able to instruct and inform clearly (Asawalikar, 2019). In addition, it has also been described as vital that trekking leaders maintain adequate levels of self-care to remain capable of performing their role (Asawalikar, 2019). An example of a self-care measure was described by a trekking leader in the Malaysian Borneo, who practiced self-reflection through diary writing as a means of coping, enabling daily time to reflect and problem solve throughout the journey (Lee, 2021). Trekking, and the role of the trek leader, provides a metaphor for understanding end-of-life care and the roles that acute care nurses have in bereavement care for patients and families as they journey towards 'death' in non-metropolitan hospitals.

The nurses in this study described how they supported and helped navigate both patients and their families through the journey of end-of-life care within the setting of an acute non-metropolitan hospital. The bereavement care provided by the nurses occurred throughout the end-of-life care journey. This journey was described from the perspectives of the nurses as being difficult for patients and their families to endure, with the experience being quite different for each person. The nurses described many different roles they undertook to meet the individual needs of patients and their families, and how these needs always varied and were rarely the same. This was evident throughout the data, in which the participants described cases to highlight individualised needs of patients and families and the consequent care provided, with no two cases being identical or with the same combination of bereavement care described. In the sense of the trekking metaphor, patients and their families undertook their very own and individual trek, making their own paths as part of the wider group (multidisciplinary team) responding to the challenges faced along the end-of-life journey. It should also be noted that, although the direction and destination were the same for the patient/family group, the route taken was always unique and suited to the individual patient and family member. Hence, often the nurse as the 'trekking leader' did not know the best path to walk, which meant the study nurses often stayed close to the patient/family, listening to their needs, and shining a light on issues as they arose, to problem solve and progress the journey.

The end-of-life journey, therefore, seemed to be a process which enabled the patient and family to start to 'make sense' or 'find meaning' in the situation they were faced. Neimeyer's (2012) constructivist

theory of bereavement, identified in chapter 1, conceptualises that the loss of a significant other can challenge the validity and core beliefs of an individual and how they feel connected within the world. According to Neimeyer (2012) this requires meaning reconstruction or the development of a new self-narrative to accommodate the impact of this change. However, the process of 'meaning making' would take a long time and essentially would be still occurring for families when they leave the care of the hospital and well after the patient dies. Nevertheless, it is suggested that, based on the study's findings, the study nurses supported some of the early 'meaning making' processes in several ways for the patient and family, along the course of the end-of-life journey. Mostly this occurred by the study nurses making time to simply 'listen' to the patient but particularly assisting family members who were grappling with the impact of the death on themselves. It was through these conversations that a family member's grief became evident to the nurses, and this was attributed to how the family member's world was starting to look with death as the 'loss' was factored into their lives. It was these conversations with patients and families that often enabled nurses to identify interventions that could be delivered as part of end-of-life care as measures to help support their grief work. An example of this was how the study nurses often coordinated the implementation of cultural and spiritual practices, including religious supports, which were significant for patients and their families. The study nurses explained that the patient and family found comfort in being able to engage in their pre-established beliefs during end-of-life care that were based on their culture, religion and spirituality. This was believed to be bereavement care because it was in alignment with the 'grief work' required in bereavement models, such as Neimeyer (2013). Neimeyer (2013) discusses this concept as 'assimilating', in which the bereaved individual takes comfort in grounding themselves in existing pre-loss beliefs and self-narratives concerning their religion and spirituality and seek social connections with those having similar values or beliefs to help 'make sense' and drive meaning into the situation. Although the study nurses were not necessarily conscious of Neimeyer's concept of assimilation or the theoretical underpinnings that support bereavement as a process, the deliberate efforts to ensure the cultural and religious needs were being addressed for patient and families constituted bereavement care. Through the study nurses listening to concerns and addressing the different needs at the request of patients and families, this supported small steps being taken forward along the trekking path for patients/families as

part of their end-of-life and bereavement journey. As earlier discussed, given the complexities of bereavement, as per the different theoretical models that describe grief experience and the bereavement process, the trekking journey was interpreted as continuing well after the death of patients and outside of the hospital for the family, as they continued to adapt to the loss of their significant other in their lives.

The nurse participants also communicated to enhance description and understanding of the clinical condition of patients with families. This was done through multidisciplinary team meetings that were often held with families and occurred through talking about the process of death and dying and applying this information to the dying patient's condition. This work by the study nurses as trekking leaders made it apparent that death was becoming the reality for patients and families to face. Attempting to accept the reality of loss and that the significant other is not coming home again is one task that Worden (2018) describes is part of four tasks required as 'grief work' for a bereaved individual, and relates to a need to come to terms with the death and realise the impossibility of reunion. The reality of this task was that it takes some time for this to occur (Worden, 2018) for families and probably well beyond the death of the patient. The study nurses as trekking leaders, however, were identified as supporting this task through their repetitive explanations of the reasons behind care measures, explaining the processes concerning death/dying and their continual attempts to engage families in the dying process and the clinical care for patients along the end-of-life journey.

Bereavement care involved talking about the dying process and the care required as a means of preparation for death and, similar to the role of a trekking leader, included the nurses coordinating multiple interventions along the journey, to create the best possible experience within the acute rural setting. The study nurses described that, in many cases, the patient and their family were unprepared and unaware of the end-of-life journey that they were to face, particularly during the initial stages of care. In the early management phase, 'active treatment' or 'trial of life' measures were often implemented to identify the direction or necessary course to take, based on a patient's response. It was often the case that full treatment and patient recovery were expected, so end-of-life care became a complete change in direction or an opposite trajectory path for patients and their families. A significant

difference here, with respect to the trekking metaphor, is that the patient/family group did not choose the journey or destination 'death'; in fact, an opposite trajectory path was the most preferred destination. This is also true for the nurses in this study, who, as 'trekking leaders' working in acute care, often had a strong focus on active and short-term treatment with intent to restore health (World Health Organization, 2015), particularly those working in emergency and critical care units. Therefore, the study nurse as 'trekking leader' and the patient/family group reluctantly commenced their end-of-life journeys, unlike other trekking expeditions in which trekkers actively choose their destination and the journey they undertake.

The study nurses indicated that this reluctance often meant there was limited time to plan for the journey, and themselves, patients and their families were unprepared, physically, and mentally, for the arduous end-of-life journey. In relation to the trekking metaphor, this meant that essentials in backpacks to support the trekking expedition were usually limited, and patients and their families were under-resourced to undertake the journey, with essentially no time to prepare. Reluctance on behalf of the acute care nurse sometimes attributed to the attitudes of some of study nurses particularly in the higher acuity areas such as the Emergency and Critical Care Units. These study nurses believed that 'death was taboo' or that 'people did not die in ED' with care at end-of-life being 'against the grain' or of opposite extremes to the goals and outcomes for patients in acute care and were keen to move patients and their families out of these environments.

The nurses commonly described the point that the patient commenced on the end-of-life care pathway as signalling the commencement of the journey for a patient and their family. It was at this time that the nurses were identified as also implementing bereavement care measures, as part of end-of-life care. Bereavement care was also occurring as a consequence to the provision of end-of-life care without the study nurses always recognising that they were providing it. During this period, some of the study nurses began using the end-of-life care pathway (known as the Pathway for Improving the Care of the Dying (PICD) developed by Jackson, Mooney, and Campbell (2009) as a resource, akin to a rough navigation guide to the required destination. The nurses' narratives reflected the reality that patients and their families required person-centred care, with varying personalities, cultures, spiritual beliefs and, often,

previous experience of death impacting their needs and the different paths they took during the end-of-life journey. Person-centred care was thought to be a suitable approach to take, in terms of how grief is understood and given that the bereavement process is heavily influenced by the personality traits of that individual that have been customised around their culture, their beliefs and upbringing, including social mediators, gender and any concurrent stressors that may be impacting on that person (Doka & Martin, 2011; Worden, 2018). The nurses, like the 'trekking leader', used their communication skills to identify needs relating to their grief and bereavement and then provided person-centred care along the journey to suit the patient or family member. Providing person-centred care to meet the needs of patients and families created what the nurses believed were positive experiences of end-of-life care. In addition, the study nurses called upon other health professional disciplines to better meet these needs, and they, too, became part of the trekking group and end-of-life journey.

Provisions of care that were motivated by the nurses help family members to create positive memories will be further discussed but confirmed that although the study nurses were not always aware, parts of the end-of-life care they provided often constituted bereavement care. For example, some bereavement models that conceptualise the need for 'continuing bonds' (Klass, Silverman, & Nickman, 1996) and the task-based grief model (Worden, 2009) call for the bereaved individual to find a way to connect and remember the deceased in a positive way. The work of the study nurses in their efforts of attempting to create positive memories during end-of-life care for families may be supported by this idea. Families, after the death of patients may be able to reflect on the care they received during end-of-life care in positive way because the care was tailored to their beliefs/requests and was dignified care that ensured patient comfort which was the motivation of the study nurses.

For some of the study nurses who had previous personal and professional experiences with death and dying, the trek was more familiar, with their experience providing valuable insight into journey undertakings. For the study nurses who had less experience and were required to lead the end-of-life journey, a greater amount of support was sourced from the wider acute care team to join the group and trekking journey. Like the role of the trekking leader, the need for self-care was important and the nurses in this study required time to process and make sense of the end-of-life journey, so that they

could perform their role. The findings of this study support the notion that 'coping' work is how nurses find their strength to lead the trek and deal with the adversities through what is described as a difficult journey. The nurses in this study described how, when they were not able to endure the end-of-life journey, the expedition became jeopardised. The inability to cope with the demands of the 'journey' often meant the study nurses became disengaged with the patient/family group, which subsequently impacted on bereavement care and the ability to create positive memories during the end-of-life journey. This was identified in the results as study nurses needing to distant themselves and not get too emotionally attached to the patient and family in an attempt to cope. Communication was one of the key bereavement care roles that nurses provided during end-of-life care and will be further discussed as part of the end-of-life trekking journey for patients and their families with application to literature and relevant bereavement models.

Communication during end-of-life care

One of this study's key findings related to the reported communication employed by nurses in acute care, non-metropolitan hospitals, with both patients and their families and the wider multidisciplinary team during end-of-life care. Within this study's findings, communication was identified as a facilitator of bereavement care with ineffective communication having a negative impact on its delivery during care at end-of-life. Communicating made it possible for the nurses in this study to find out what mattered to the patient/family as recipients of care during the final stages of life. Communication was used as a tool to provide a deeper understanding of death/dying to the patient/family and used to engage the wider multidisciplinary team into the care provided at end-of-life, which was perceived to be of benefit to the patient/family by the study nurses. Communication, therefore, will be further discussed as a nursing bereavement care measure and as part of a multidisciplinary team approach. In addition, discussion concerning the existing barriers to communication as a bereavement care measure, as perceived by the study nurses will also be outlined.

Communication to facilitate bereavement care

O'Toole (2016) defines effective communication as a developed skill in face-face and non-face-to-face communication, which occurs “when people send, receive and successfully understand messages” (p 7).

Through communication which also included the study nurses identifying non-verbal information through body language, facial expressions, and gestures from patient/family they could assess how the provision of end-of-life care was being received. Communication enabled the nurse, as the ‘trekking leader’, to stay engaged with the patient/family group and understand their needs as they progressed through the journey of end-of-life care.

Communication has been described as an essential ‘core’ skill for any health professional (Higgs, McAllister, & Sefton, 2012), however, its use by acute care nurses in this study, to support both end-of-life care and the delivery of bereavement care to patients and their families, was identified as being absolutely crucial. In fact, if communication was ineffective or severely limited, the nurses believed that this could jeopardise the entire end-of-life experience which therefore would also impact on the quality of bereavement care provided to patients and their families by the nurses.

The nurses in this study reported that communication with patients and their families occurred both verbally, with discussions and information exchanged, and by active listening, whereby needs were also identified to support the delivery of end-of-life care. Communication with patients and their families also occurred non-verbally, in which the nurses assessed body language and described providing comfort, just through being present with patients and their families at the bedside. In addition, touch, through embrace and hand holding, was also identified in the findings as being used by the nurses, as a supportive and comforting gesture.

Active listening was an approach used by the study nurses to help identify needs for patients and families as recognised within the study findings. Active listening is different to listening in that the listener responds according to the verbal and non-verbal messages received in a manner that displays, understanding, interest and acceptance (O'Toole, 2016). Active listening is something that the nurses in this study performed to ascertain the needs of the patient and their families. Nurses can use active

listening, according to Anderson and DesSouza (2021), to 'open up' conversations about death, with techniques such as paraphrasing or vocal mediation to encourage people to voice their concerns and feelings (McCabe & Timmins, 2013) in order for specific needs and patient wishes to be factored into care provisions. Active listening has been described as the 'core' of grief care (Silloway, Glover, Coleman, & Kittleson, 2018), given that this technique provides an 'invitation' for patient and families to talk about death and therefore allows clinicians to have deeper insight into an individual's grief experience (Meichsner, O'Connor, Skritskaya, & Shear, 2020).

Communication in the form of active-listening was necessary to help support patients and their families deal with their bereavement and the overall end-of-life journey. This is reinforced by Bach and Grant (2015) who indicate that nurses who use active listening techniques will enhance families to voice their concerns and feelings in support of spiritual care and 'open-up' conversations regarding death.

Communication was seen as tool used by the nurses in this study to provide comfort, convey empathy and, more importantly, try to understand what both the patient and the family required, as part of the end-of-life process and to better reflect their individual grief experience.

Sometimes the study nurses described silence occurring during their patient/family interactions. It was unsure if the study nurses knew about the significance of 'silence' as a technique in relation to bereavement care and spirituality, given they mainly remarked that silence allowed for patient and families to express their feelings. These feelings the nurse participants described as any type of emotion including their grief, but after deeper analysis of the findings this may have also been spiritual pain for the patient/family. In a descriptive hermeneutic analysis of the meaning of silence at end-of-life care, Bassett, Bingley, and Brearley (2018) describe silence contributing to spiritual care as a way of being with another person to provide companionship, deepening the intimacy and connection and acting as medium for communication, when words fail. In addition, silence was described as a means of creating a 'caregiving space' that a bereaved person may find helpful or healing (Bassett et al., 2018). Providing comfort through silence is therefore a valuable tool to enhance spiritual care (Harrad, Consentino, Kearsley, & Sulla, 2019) given this intervention allows for the focus to be on 'critical thinking' in which

talking would get in the way of an individual experiencing and analysing their deep thoughts and feelings concerning the situation and their perceived losses (Dube, 2019).

Spirituality and religion are strongly related to an individual's grief experience and have been described as important constructs associated with bereavement (Damianakis & Marziali, 2012). The relationship between grief and spirituality/religion is that both provide a 'soul connection' or a 'meaning to life' for individuals (Doka, 2011) which calls for a deep interpretation and application of their belief into their 'being' as a person. Therefore, spirituality and religion can also be important coping mechanisms for bereaved individuals (Becker, Wright, & Schmit, 2017). Spirituality has been described as the inner essence of who we are as a person, our individuality and what allows us to feel connected with the world we live in (Doka, 2011; Nelson-Becker, 2013). Religion has been described as a communal or collective approach to thinking which binds people together through beliefs, practices, or rituals (Doka, 2011; Nelson-Becker, 2013).

As a result of grief concerning the anticipated death of a patient, families sometimes encounter spiritual turmoil or chaos and become challenged or start to question or doubt their own spiritual and/or religious beliefs (Doka, 2011). For example, a bereaved individual may start to question their own belief or faith and alienate themselves from sources that were once spiritual strength, questioning why the dying process is occurring, or feeling a sense of 'moral guilt' and that the death is somehow associated with their moral failing or sin for which they are being punished for (Doka, 2011). For others, the chaos could be managed in an opposite way, in that both spiritual and religious beliefs now allow a greater sense of meaning; hence, with death leading to fulfilling some purpose or being part of a wider plan, it may also offer a belief that the deceased will be safe or happy or supports the possibility of a continuing connection or reunion (Doka, 2011). Rituals may be also something that are necessary to families as they cope with grief, reflecting their specific culture spirituality and religious beliefs relating to death (Anderson & DesSouza, 2021). Research concerning cancer-bereaved 'young adults' by Lovgren et al. (2017), through survey analysis of 174 participants, identified that engaging in spiritual and religious beliefs activities was associated with an enhanced coping of painful grief. Results within the Lovgren et

al. (2017) study highlight that religion and spirituality provided comfort through the belief of meeting that person again, or that the person was in a safe place or with God.

Religion and spiritual needs for patients and their families are essentially very complex and encompass the need for an understanding of many different cultural, religious, and spiritual customs (Anderson & DesSouza, 2021) of which the nurses in this study did not fully understand. The study nurses, however, managed this knowledge gap through conversation and investigating a patient's and families cultural religious and or spiritual beliefs and making referrals to appropriate religious or spiritual advisors. It was identified that, although the study nurses did not have all the answers or solutions for patients/families, they often made time just to 'listen' to families talk about their feelings and concerns, and this was highly significant to their bereavement and the bereavement process.

Through their use of communication strategies, the nurses, as the trek leaders in this study, could 'shine a light' on needs and identify a way forward for the patient and their family during their end-of-life journey. Communication was pivotal to establishing a potential trekking path, based on the needs of the patient/family and in response to the dying process. Communication was used by the nurses in this study and the wider multidisciplinary team to assist patients and their families to better understand death and the dying process and was a means of offering comfort during periods of grief.

Communication was, therefore, a key bereavement care role and facilitator for other end-of-life measures because it supported the grief experience for patients and their families and allowed for the identification of the needs to suit.

Bereavement theories, like those of Martin and Doka (2000) who describe adaptive grieving styles, also identify the benefits of communicating to help express one's feelings concerning death and dying.

Martin & Doka's (2000) theory on adaptive grieving styles identify that some individuals are in fact 'intuitive grievers' who adapt to loss in their lives through crying and expressing their painful feelings with other people. Intuitive grievers are described as needing to seek out others who have had similar loss experiences and talk to them about the details of their experience. The study nurses who along the course of the end-of-life journey provided support through communication were also providing 'grief

care' or 'grief support' by providing the patients/families with opportunities to discuss and express their feelings.

In this research, the nurse's communication also helped to facilitate understanding concerning end-of-life care and the dying process, which the nurses described as necessary to properly prepare both patients and their families for impending death. In a descriptive phenomenological study of 13 critical care nurses in United Kingdom (UK) hospital settings, Arbour and Wiegand (2014) similarly described nurses communicating to educate families regarding provisions of end-of-life care. Arbour and Wiegand (2014) described education occurring as part of everyday nursing interactions with families, which was necessary to enhance their preparedness for death. Other research studies have also identified the importance of communication during end-of-life care, to answer questions regarding what occurs during the dying process (Hendricks-Ferguson et al., 2014; Walker & Deacon, 2016) and to keep families engaged and up-to-date regarding the end-of-life process (Sullivan, Silva, & Meeker, 2015). Likewise, the nurses in this study reported spending time communicating by answering questions and providing explanations to both patients and their families at an early stage and frequently during and after the death of patients.

Communication was used to prepare and enhance understanding of the dying process and the many interventions performed as end-of-life care for patients and their families. This was considered a part of bereavement care as, through informing and educating, the nurses believed they were making patients and families feel more comfortable with the required care provisions and providing enough information to facilitate their understanding, thereby helping families prepare for patient death. In addition, communication was a strategy for enhancing the experience of end-of-life care, as it also facilitated enhanced levels of comfort and connection with the patient/family group and provided them with an opportunity to express their feelings.

In this study, although the level of communication was not measured or assessed, the nurses reported that communication was an important part of end-of-life care. One of the noticeable differences in the results of this study, compared to other research studies, was that communication was considered important and occupied a significant amount of a nurse's attention during end-of-life care, within the

acute rural hospital settings. This finding, with respect to the role of nurse communication in end-of-life care, contrasted with other research papers, in which nurse communication has been described as limited or much less required for delivering quality care (Bloomfield, O'Neill, & Gillett, 2015; Brighton & Bristowe, 2016; Shannon, Long-Sutehall, & Coombs, 2011). In a mixed method study by Nedjat-Haiem et al. (2017) that was conducted in two hospitals in Los Angeles and California, and took into account the perspectives of 25 nurses engaging with patients and their families in end-of-life, communication was poorly rated by nurses, themselves. The results of that study indicate that over half of nurses (64.5 %) take little ownership of communication, with under a quarter (13%) of nurses in the study claiming that end-of-life care discussions were not within their role to perform with patients and their families (Nedjat-Haiem et al., 2017). A mixed method study undertaken by Caswell et al. (2015), involving non-participant observation, semi structured interviews, and review of case notes in four acute wards in an English University teaching hospital involving 32 staff and 13 bereaved family members, also found communication to be ineffective for carers who felt unsure about what was happening to their relative and were distressed by the experience of their relative's end-of-life care (Caswell et al., 2015).

However, no research papers were found that examined communication as a specific bereavement care role of acute care nurses in non-metropolitan settings or link this role to grief or bereavement care. It was, therefore, unclear whether there was a relationship between the nurse's readiness to use communication to facilitate bereavement care in non-metropolitan hospitals compared to metropolitan settings. Also limited in previous research papers was the approaches used by nurses, and if the communication approach encompassed both the patient and the family together or individually as identified in this study. Better clarity concerning exactly what information is exchanged and at what stages of the end-of-life process communication is occurring with the patient and their family would provide greater understanding of the nurse's bereavement care role.

Communicating with the wider multidisciplinary team to deliver bereavement care

The nurses in this study often acted in advocacy roles to help ensure the patient's and their family's needs were being met during end-of-life care. This occurred mostly with other health professionals, as

part of a multidisciplinary team approach. Likewise, this practice was supported in other research papers where the researchers identified nurses acting in advocacy roles on behalf of patients and their families, by communicating both a patient's and a family's wishes and highlighting their needs in the process (Brooks, Manias, & Nicholson, 2017; Hussin et al., 2018b; Ito, Tsubaki, Fujimoto, & Sakaguchi, 2020; Minton, Isaacson, Varilek, Stadick, & O'Connell-Persaud, 2017). The systematic review conducted earlier in this study (as reported in Chapter Two) of the roles of acute care nurses in the delivery of bereavement care in hospitals also describes nurses working in advocacy roles (Raymond et al., 2017). In the systematic review, nurses were described as communicating, on behalf of patients and their families, with the wider multidisciplinary team to influence decisions regarding care (Raymond et al., 2017). Similarly, in this study, communication ensured that patients and their families were recipients of appropriate care, according to the needs expressed by the patients and their families; communication facilitated reviews to track how these care measures were being received. In addition, communication in this study was used to help respond to many of the behaviours which may have been associated with grief, occurring in anticipation of the death and as part of the bereavement process, that was being experienced by patients and their families.

The findings of this study also identified that, on occasions, the study nurses sought opportunities to broaden the scope of psychosocial support for patient and families through the multidisciplinary team. Seeking multidisciplinary support sometimes resulted in additional family meetings with medical staff or counselling with social workers, during which questions were answered and information shared with family members regarding patient prognosis, physical changes, and the stages of the dying process. The nurse participants also worked with other members of the nursing team, on occasions, particularly if they were novice nurses or when they thought additional support was required to best inform patients and their families regarding the provision of end-of-life care.

The nurse participants believed that multidisciplinary referral brought new skills and expertise to manage both the patient's and the family's needs. The nurses sometimes identified their own scope of practice to highlight this need, particularly when medical consultation was required for the comfort of a patient or when more complex psychosocial support was required from social workers. Several other

research papers also identify the collaborative approach acute care nurses tend to have with the wider multidisciplinary team to enhance psychosocial support (Anderson, Bloch, Armstrong, Stone, & Low, 2019; Buckley et al., 2015) as well as medical support for dying patients and their families during end-of-life care in hospitals (Brooks et al., 2017; Walker & Deacon, 2016). Breen and O'Connor (2013) however claimed that family members were often left with inadequate bereavement support and that multidisciplinary meetings were only focused on the provisions of information, sharing concerns and plans for care rather than provisions of bereavement care. The patients and families in receipt of the care described by the nurses may have had a different view of the care received, but it was beyond the scope of this study to identify that.

The nurses in this study did, however, describe seeking multidisciplinary support and frequently facilitating referral to other health professionals and related supports during end-of-life care, based on the level of needs of patients and their families and, particularly when they felt their own nursing experience and related nursing skill were lacking. However, there were sometimes barriers to this approach, with the nurse participants also reporting a lack of accessibility to multidisciplinary supports in comparison to their experiences in metropolitan hospitals, along with reduced availability of medical coverage and reduced options for specialist referral services. A lack of available health workforce has also been described as a barrier to the provision of multidisciplinary support by people living in remote and very remote areas, according to the Australian Medical Association (2021), including the availability of doctors (McGrail, Humphreys, Joyce, Scott, & Kalb, 2011; Weinhold & Gurtner, 2018). The incidence of medical accessibility is something that has also been identified as a problem, internationally, for rural and regional areas, particularly in the United States of America (USA), Canada and the UK (Weinhold & Gurtner, 2018). Accessibility to multidisciplinary services, based on the results of this study, was necessary to best support the acute care nurses in their communication roles during end-of-life care.

Barriers to communication as bereavement care

Given the complexity of effective communication as earlier discussed in support of 'grief care/support' which involved active listening and developing a therapeutic relationship with patients and families, the study nurses required adequate time during end-of-life care to facilitate this. In this study, the acute

care nurses believed that insufficient time spent communicating with patients and their families would impact negatively on their overall experience and the journey of end-of-life care. Anderson et al. (2019) describe effective communication between healthcare professionals and families of patients nearing end-of-life as vital, to ensure a 'good death', and the findings of this study also support the role of communication in enabling a better end-of-life experience. Likewise, Liaschenko, O'Conner-Von and Peden-McAlpine (2009) describe the lasting, negative impact of ineffective communication with health care professionals during end-of-life as something that becomes "morally troubling" (p. 225) for families, resulting in regrets about the care a patient received which impacts on their grief experience. When communication was insufficient, the nurse participants advised that this also precipitated displays of anger and anguish by families at the bedside, due to what the nurses described as a lack of understanding about what was happening to patients and generally feeling unsupported.

There is, however, evidence that nurses often considered communicating with patients and families concerning death and dying as challenging and or very confronting task (Brighton & Bristowe, 2016; Calvin, Kite-Powell, & Hickey, 2007; Hendricks-Ferguson et al., 2014; Nedjat-Haiem et al., 2017).

Evidence in some papers also refers to a need for additional training to support acute care nurses in this role (Anderson et al., 2019; Shannon et al., 2011) and, in particular, nursing students (Bloomfield et al., 2015). Several studies also show that nurses feel unprepared for communicating with dying patients and their families (Colley, 2016; Ek et al., 2014; Glover, Garvan, Nealis, Citty, & Derrico, 2017; Lippe, Volker, Jones, & Carter, 2017). In this study, the nurses did not directly indicate that they felt uncomfortable or lacked competence communicating with patients and their families.

The nurses in this study also described their workload in acute care as a barrier to the amount of available time they had to spend with dying patients and their families in acute care, non-metropolitan hospitals. No comparisons were made by the study nurses regarding differences in the time available in non-metropolitan hospitals compared to metropolitan hospitals in the delivery of end-of-life care, so it was not clear if this finding related to location. However, nursing allocations which involved nursing patients during their final stages of life as well as patients that were receiving full and active treatment, to promote recovery and discharge, created for the nurses what they described as a heavy and

unpredictable workload. The study nurses also described feelings of guilt and, sometimes, distress when they had not had enough time during their shifts to talk with family members or provide all the necessary end-of-life care measures for patients. The literature review by McCourt, Power and Glackin (2020), on the experiences of registered nurses providing end-of-life care to patients in the acute care hospital, reinforced the finding that lack of time is a barrier to provisions of end-of-life which included communicating with patient/family. This was attributed to the busyness of acute care wards and dictated by the demands of other, acutely ill patients for provision of care (Mccourt et al., 2020). A lack of time to talk to patients and their families during end-of-life care was also identified in a descriptive, cross-sectional survey of over one thousand (n=1320) registered nurses working in Lithuanian hospitals, with insufficient time attributed to patient demands in the acute care environment (Blazeviciene, Laurs, & Newland, 2020).

Previous studies also refer to limited time availability impacting the delivery of quality end-of-life care to both patients and their families in acute care hospital settings (Beckstrand, Collette, Callister, & Luthy, 2012; Decker, Lee, & Morphet, 2015; Kongsuwan et al., 2016; Marck et al., 2014; McCallum, Jackson, Walthall, & Aveyard, 2018). Following a cross-sectional survey, using an online questionnaire of 115 nurses from two University-affiliated acute and psychiatric hospitals in Switzerland, lack of time was identified by 45.9% of participants as a reason for limited engagement and provision of bereavement care (Naef et al., 2020). The Australian nurse participants in a study by Decker et al. (2015) described death in the emergency department as less than optimal due to insufficient time available to be with patients and families to provide end-of-life care during and after death due to competing patient demands in the unit.

In summary, communication was a significant bereavement care role for acute care nurses in this study undertaken in non-metropolitan settings. Application of the 'trekking' metaphor supports the importance of communication, similarly, as a means of identifying individualised needs, facilitating engagement, and informing how a journey was being perceived. Communication in this study was targeted at both the patients and their families throughout their end-of-life care journey and continued for only short periods after death for family members. Lack of time due to workload demands in the

acute care settings to enhance opportunities to spend time communicating with patient/family, was some of the perceived barriers for the nurses in this study. The study nurse's attempts to facilitate opportunities for communication in support of active listening and being present with patients and families to provide levels of emotional support provides evidence of 'grief work' and can be related to some theoretical models that have been used to define grief and the bereavement process.

Creating positive memories for families as bereavement care

The nurses in this study described their efforts to ensure that the end-of-life journey for patients and their families in rural hospital settings, although 'arduous', was a positive experience. This was achieved through attempts to make the patient and the family feel as comfortable as possible in the hospital setting. This included keeping dying patients comfortable and well-presented, and manipulating and sometimes personalising the bedside space to create a more relaxed environment for families to be in. The nurse participants also engaged the families in the end-of-life journey, encouraging them to stay for extended periods and participate in patient care, which they thought would help the family to process and prepare for patient death. In addition, they delivered care that is individualised to meet the different needs of patients and their families, with this care occurring for families for only for short periods after the death. End-of-life care pathways were a 'rough guide' followed by the nurse participants, but the medical decision to use the end-of-life care pathway always signalled the commencement of the end-of-life journey for the nurse, the patient, and their family.

Creating positive memories was a key bereavement care role of acute care nurses working in the non-metropolitan hospitals in this study, which aimed to reduce the burden and distress for both patients and families associated with the end-of-life journey. Further discussion of creating positive memories for families will occur, specifically in relation to person-centred care, include discussion about the provision of emotional support and facilitating a family presence as part of bereavement care. In addition, the bereavement care after death for families will be discussed, including the barriers that impacted on the creation of positive memories.

Providing person-centred care as bereavement care

The Pathways for Improving the Care of the Dying (PICD), developed by Jackson et al. (2009), were utilised at the study sites by the acute care nurses in this study. The PICD provided the nurses with a series of prompts, guidelines and algorithms to support end-of-life care, based on five major domains: patient comfort, communication with family/carers and other multidisciplinary team members, support for psychosocial spiritual/cultural requirements, written information for families/carers, and care after death (Jackson et al., 2009). Although the acute care nurses in this study discussed the use of the end-of-life care pathways during and after the death of patients in hospitals, this resource was not always used and was less used in higher acuity areas, such the emergency department or critical care unit. It was however unclear if this was a common practice in other Australian emergency and critical care units or something unique to a rural hospital setting.

The lack of use of the PICD was sometimes attributed by the emergency and critical care nurse participants to a perceived lack of need, due to short time periods to death (sometimes hours) or rapid patient transfers to other units for end-of-life care. The recommendation of the PICD, however, always signalled to the nurses that it was time to commence the 'end-of-life' journey for patients and their families which also encompassed bereavement care. The results of this study highlighted that lack of use of the PICD was also attributed to the individualised needs of patients being not well represented in standardised PICD pathways, which has also been supported in other studies (Baier & Buechsel, 2012; Sleeman & Collis, 2013). Nevertheless, the PICD pathways became a 'rough guide' used by the nurse participants to help prompt interventions and navigate the patients' and families' end-of-life journeys in rural hospital settings.

Bereavement care in this study was delivered by means of providing care that was individualised to meet the needs of dying patients and their families during end-of-life care. Sometimes person-centred care related to meeting the cultural and religious needs as earlier discussed or other special interests or habits, of significance to both the patient and their family. Although needs varied, what was consistent throughout the narratives was that the roles performed by the nurses were adjusted in their delivery to become patient- and family-centred at acknowledged times. This finding is contradicted by Reyniers,

Houttekier, Cohen, Pasma, and Deliens (2014), who used a qualitative study design to examine acute care settings as a place of death. They concluded that the acute hospital setting is not properly adjusted to the needs of dying patients and their families, given that, in many cases, the hospital is a place for routine care (Reyniers et al., 2014). This was not the case for the rural nurses in this study who mostly described manipulating the bedside environment and routine care measures to better suit patients and their families.

Providing care that was individualised to meet the different needs of the patient/family during end-of-life care was undertaken with the motivation behind this care being the ambition of creating the 'best death' possible for the patient and their family. This was a similar finding in qualitative research by Becker et al. (2017), who collected data from 49 nurses on four adult inpatient units to analyse nurse perceptions of distressing death and dying well. Becker et al. (2017) in this study found that provisions of person-centred care such as the provision of spiritual support, ensuring the presence of 'loved ones' at the bedside were some of the means of creating the 'best death' possible. It was also the belief of the nurses in this study that providing care that suited the different values and beliefs of patients and their families would create a more positive experience or end-of-life 'journey to patient death' in the rural hospitals. It was, however, unclear, due to a lack published research regarding bereavement care in non-metropolitan settings, if this was a trend for all rural nurses during end-of-life care. This was, nevertheless, a strong and common theme identified throughout the study data and a key motivator to why the rural nurses approached care during end of life that was patient- and family-centred. In order for person-centred care to be identified, the study nurses needed to spend time with patients/families. Making time to be present and get to know patients and their families was an approach undertaken by the study nurses for the identification of individualised needs that reflected what mattered to patients and their families. In this study the nurses also believed that spending time engaging with patients and families was necessary to build a trusting relationship in which as earlier discussed, the physical, emotional, spiritual, and cultural needs could also be best identified. In a qualitative study of 15 acute care oncology nurses and 10 bereaved family members, Chan, Lee, and Chan (2012) investigated the perceptions and experiences of nurses and bereaved family members towards bereavement care. Chan

et al. (2012) claimed that nurses making themselves available to be present with patient/family to provide support was crucial to build trusting relationships and enabled the nurses to get important information in support of end-of-life care. Becker et al. (2017) also identified that when acute care nurses made themselves available to be with patients and families it assisted them to understand what they were going through with a 'presence' demonstrating both caring and compassion. Spending time with patients and their families identifying what mattered to them was often followed up by the nurses in this study through the provision of person-centred care or by voicing these requests, on behalf of patients and their families, to the necessary health professionals, to meet their needs. The study findings also provided evidence that the nurse participants during time spend with both the patient/family provided care that suited the needs of patients/families relating to their grief experience as provision of bereavement care.

Providing emotional support to dying patients and families

During the bereavement process, individuals are not only described as being in a state of spiritual turmoil but also, because of the related grief experience during the end-of-life period, in intrapersonal and interpersonal emotional turmoil (Coombs, 2015). It is also known that many individuals may experience anticipatory grief or grief-related symptoms prior to the death of a significant person (Rogalla 2020). Grief refers to the emotional experience of psychological, behavioural, social and physical reactions to one's loss (Boerner et al., 2016). Therefore, the care provided to support the grief of patients and their families was delivered by the nurse participants differently for each patient and each family member. It should also be again noted that following the interpretation of this study's findings and relevant bereavement literature, both 'grief support' and 'grief care' were believed to hold similar meaning, with both measures constituting the delivery of bereavement care to patients and families during end-of-life care.

The Australian National Palliative Care Standards (National Palliative Care Standards, 2018) describes bereavement care as 'grief support', contained within Standard Six. Standard Six encompasses providing families with access to bereavement support, as well as the coordination of bereavement support at

designated timeframes after a death (National Palliative Care Standards, 2018). In addition, the National Palliative Care Standards also provides information about loss and grief as part of preparing families for the impending death and ensuring families have an adequate understanding of the dying process (National Palliative Care Standards, 2018). Providing bereavement care specific to behaviours and emotions associated with grief, for both the patient and their families, was clearly identified by the nurse participants in this study. Bereavement care also occurred during the early stage of end-of-life care for patients and continued throughout end-of-life care for families, even after death and whilst patients still occupied beds within the acute care units. This was an important contrast with the National Palliative Standards (2018) regarding grief support, in that the nurses regarded patients, as recipients of grief support in acute rural hospitals not just family members.

It should also be noted that, although 'grief support' within the National Palliative Care Standards (2018) is described as a requirement for 'families and carers' after death, the nurse participants mostly provided this care to families prior to death and during end-of-life care in non-metropolitan hospitals. In fact, the nurses were unaware of coordination of, or referral to support and services for families once patients were discharged and families had left the hospital, despite there being a palliative care consortium and referral options within the region. Cooper et al. (2019) confirm that 'grief support' also occurs for families whilst in emergency departments and can be a positive provision of care after death, providing opportunities for extended psychosocial support. However, arrangement for ongoing grief support for families after death, was not a role that the nurse participants in this study undertook in the provision of bereavement care.

The nurse participants were supporting both patients and their family's grief experience by addressing the emotional, spiritual and, sometimes, psychosocial needs as well as attempting to minimise circumstances that could intensify their grief. Hussin et al. (2018a) describe how acute care nurses are in tune with the emotional and psychological effects of death on families and work to assist families to cope with their emotional distress and bereavement during end-of-life care (Hussin et al., 2018a; Iranmanesh & Banazadeh, 2014; Wakanako, 2016). Being responsive to the emotional and spiritual needs of patient and families was also applicable to the nurses in this study, who described addressing

the many behaviours associated with grief that occurred whilst caring for patients and families in non-metropolitan hospitals, during their final stages of life.

Examples in the findings identified that the study nurses were providing bereavement care in response to the different behaviours and characteristics displayed by patients and their families during the end-of-life journey. Bereavement care for patients and families, therefore, needed to be individualised by the nurses because grief is such a unique phenomenon experienced differently by each person (Hall, 2014; Hall et al., 2012; Neimeyer et al., 2012). In relation to the trekking metaphor, this was why patients and families, although having a common destination, could not follow identical routes but, rather, had to 'walk their own path' during the end-of-life journey. Therefore, the nurses in this study can be aptly regarded as 'trekking leaders', who metaphorically walked alongside the patient and their family to provide support in response to their behaviour and their abilities to cope with grief and the many adversities associated with the end-of-life journey.

Unpredictable behaviours that are varied and dynamic (Baier & Buechsel, 2012; Boerner et al., 2016) as well as those including rumination about the deceased, painful longing (Stroebe & Schut, 1999) feelings of disbelief, an urge to deny the truth of the news, yearning and pining, which includes pangs of grief, anxiety, anger, bitterness, irritability, self-reproach, disorganisation and despair (Boerner et al., 2016; Hall, 2014) are common grief related responses. The nurses in this study described similar behaviours; this included families expressing high levels of emotion, having difficulty processing or understanding the information the nurses provided, and displaying levels of frustration, anger and denial.

Other behaviours were described by the study nurses as being less emotive and task orientated, which required the provision of information to support arrangements relating to the impending death. The nurse participants responded to these behaviours, through spending time talking to patients, reiterating care measures, and explaining the dying process and upcoming arrangements. Such approaches were therefore used to help address issues or concerns and to alleviate some of the associated emotions. In the Arbour and Wiegand (2014) study, critical care nurses also provided family support during end-of-life care by offering reassurance and emotional support as patients moved closer towards death. Being present to offer comfort was also used as an approach by the nurses in this study to console and

support both patients and their families. Noome et al. (2016) in an integrative review of nursing roles during end-of-life care in the intensive care units in England, Holland and Germany which included 20 relevant research studies, concluded that nursing care for families during end-of-life care consists mostly of emotional support, with family members often expressing their ideas and moral feelings about death during end-of-life care.

The approach of the study nurses in providing emotional support that is individualised to suit the different ways that grief was expressed during end-of-life care occurred mostly for family members, and this work also aligns with some of the interventions in grief and bereavement models. The work of Stroebe et al. (2010) describe that, individuals in bereavement will be alternating between two different types of coping; loss orientated, and restoration orientated coping during the bereavement process. While engaged in loss-orientated coping, the grief work associated involves dealing with intrusive thoughts concerning death and the negative emotions that are attached to this thinking, whilst in restoration-orientated work the activity is concerning restoration and constructive management of the related death issues. The study nurses through their narratives, were seen to be supporting families with their 'grief work' which as per the study findings was predominantly 'loss orientated'. On occasions examples of 'restoration orientated' grief work were provided by the study nurses which was purely informative, and process based and involved facilitating the necessary end-of-life arrangements for the family. It should be noted that this bereavement care was only relevant to family members who were facing the loss of a significant other and describes the work of learning to live with loss and growing around grief (Stroebe et al., 2010).

The theory supporting adaptive grieving styles by Martin & Doka (2000) could also be applied here in that an instrumental griever, is less likely to display emotion and attempts to actively manage their grief through a focus on problem solving and the management of related death issues. Instrumental grievers are therefore less likely to display emotions and may prefer information regarding process and lifestyle adjustments that may need to be accommodated (Martin & Doka, 2000). Whether this was the case, or some individuals chose to manage their grief focusing more heavily on the practical side of death rather expressing strong grief emotions is not known, because everyone's grief experience is different, and

relates to differences in personality, culture, socialisation, temperament, and relationships with the dying person (Doka & Martin, 2011; Doka & Martin, 2021). Within the findings of this study some behaviours of family members as described by the study nurses were similar to those described as instrumental grievers, reinforcing the need for the nurses to provide care that differed between individuals to meet their different needs.

The work of the study nurses is also consistent with the second task within the grief model developed by Worden (2009) in that a bereaved individual needs to address and analyse some of the pain associated with their loss. For example, Worden (2009) indicates that acknowledgment of the pain including fear, guilt, shame, loneliness, and sadness is necessary as part of the bereavement process. Therefore, by the study nurses supporting this type of 'grief work' of families through being present, listening and providing them with the opportunity to express their feelings, was considered as significant role that the study nurses undertook as bereavement care.

Although the bereavement care provided by the study nurses was sometimes in alignment with the 'grief work' that the family may have been undertaking as part of the bereavement process, the care was identified as on-the spot grief care or grief support to patients and families, and for short periods of time during the end stage of life for patients in hospitals. In addition, given, that there are no limits on the extent of the bereavement process, for families the period of end-of-life care was possibly only the very beginning of their journey, which would mean the bulk of the bereavement work would be occurring for families, after a patient's death, and when families leave the care of the hospital. Grief care/support which constituted bereavement care for families was also described by the study nurses as being very different for each family member, which Overton and Cottone (2016) describe is due to each family member anticipating and processing loss related to death, differently.

Bereavement care in the form of grief care/support was also different based on the individual's experience of grief and perception of loss. For example, the patient's grief was perceived to be heavily subjective of them facing the reality of impending death. For a family, their grief was related to their perceptions of loss in anticipation to death of their significant other, and how they would adapt to this loss in their lives. The study nurses during end-of-life care were more often providing bereavement care

to families, given the acute nature and short time frames to death for patients as described in the narratives and the fact, that no bereavement care was described as occurring before patients were commenced on end-of-life pathways. This often meant that there was limited capacity due to short time frames to death to provide direct bereavement care to patients. However, bereavement care was identified in the results as being provided on some occasions directly to patients, who were still conscious, and had made their own decision to stop active medical treatment. This approach denies patients and families the benefits of early integration of palliative care for patients with advanced disease trajectory, as suggested by Hudson, Collins, Boughey and Philip (2021). They describe early palliative intervention as enabling a greater focus on holistic care (physical, emotional, existential and social) and quality of life for the patient and their family Hudson et al. (2021). Nevertheless, bereavement care for families, was supported by the acute care nurses in this study engaging and empowering families in the provision of person-centred care for patients within the hospital setting.

Facilitating a family presence as bereavement care

In this study, keeping dying patients comfortable was often undertaken with the intent to support not only the family but also the patient's grief. The nurse participants often did this by using end-of-life care pathways as a resource, to ensure the basic needs of patients and, subsequently, their families were being met. Nurse participants were sensitive to how the dying patient was being 'presented' to families. The nurses indicated that, if dying patients looked unkempt or appeared in distress or uncomfortable during end-of-life care, this impacted negatively on a patient's dignity and a family's experiences and memories of the death. Creating clinical situations and scenes that would be perceived as a positive memory for patient/family was often the motivation for the nurse participants who ensured, at a minimum, measures were implemented for peaceful and dignified deaths. Similarly, in other studies, acute care nurses prioritised care to manage distressing symptoms of dying, to ensure dignity for patients and create positive memories for family members (Arbour & Wiegand, 2014; Bach, Ploeg, & Black, 2009; Becker et al., 2017; Beckstrand & Kirchhoff, 2005; Efstathiou & Walker, 2014; Efstathiou, Walker, Metcalfe, & Vanderspank-Wright, 2018; Fauri, Ettner, & Kovacs, 2000; Fridh, Forsberg, & Bergbom, 2009; Walker & Deacon, 2016). Yoshiyasa, Michihiro, Fujimoto, and Sakaguchi (2020) also

found that acute care nurses in Japan believed facilitating dying without suffering was a priority and was paramount to ensuring the quality of death in emergency care settings. In this study, families were also encouraged to participate in various comfort care measures for dying patients, to help create positive memories and experiences. It was also acknowledged that family engagement in the delivery of comfort care measures may have had the potential to create positive memories for patients also.

Encouraging a family presence at the bedside and, when appropriate, involving family members in aspects of care for dying patients, was a deliberate intervention of the acute care nurses in this study. Participants described that this inclusion in end-of-life care helped the family to feel closer to the patient, which was considered highly therapeutic and of great benefit for patients and families in bereavement. Nurses described encouraging families to contribute to the patient's care whilst reminiscing, sharing memories, talking, and touching the patient by hand holding and washing. This was how the nurse as the 'trekking leader' kept the patient and family engaged in the end-of-life journey, as the 'trekking' was the activity undertaken towards the destination of death.

This finding is also identified in other studies, whereby nurses encourage and empower family members and, in some cases, the parents of dying children in acute care settings, to participate in physical or comfort care measures for dying patients (Bloomer, Endacott, Copnell, & O'Connor, 2015; Donnelly & Dickson, 2012). In a phenomenological study of self-described nursing roles during the care of dying patients, Arbour and Wiegand (2014), also claimed that "facilitating family involvement made the patient's death easier for family members and helped provide positive memories" (p 215). Noome et al. (2016) and Kisorio and Langley (2016) also describe how involving families in direct care, and providing them the opportunity to perform their own routines or practices with the patient, had a positive impact on their levels of distress, which helped families cope with the dying patient in ICU. Facilitating a family presence and engaging families in nursing practice at the bedside was identified in this study as an important component of bereavement care, with the nurse participants describing that this helped families process the situation and accept the reality of impending death; so much so, that the study participants always tried to manage the time and space to facilitate this opportunity in the 'acute care' setting for patients and families. In a systematic review of parent-focused bereavement interventions,

Kochen et al. (2020) observed that those parents who participated in end-of-life care for their child had time to process and adjust gradually to the fact that the child was dying. Similarly, in research identifying the perspectives from bereaved families on improving end-of-life care in neonatal intensive care units Baughcum et al. (2017) also described family inclusion in patient care at the bedside as having a positive impact on their coping and became valuable memory making activities.

For patients, creation of positive memories by the study nurses may have been the coordination of specific activities at the patient's request prior death. Supporting requested arrangements which sometimes involved ensuring cessation of certain treatment or going home for periods of time to be with wider families and friends. In addition, the study nurses enabled families to stay for extended periods at the bedside at the request of the patient and it was their belief that this intervention brought comfort to the patient. It was these interventions that supported the nurse's belief that they were providing care that would be perceived as positive by the patient and had the potential to create positive memories also for the family. However, the impact of the care was not measured in this research and the perception was that of the study nurses and not that of patients and families.

Bereavement models that describe the process of individuals adjusting to loss as a result of death of a significant other in their lives, call on the bereaved individuals as a means of coping to identify positive memories or try to connect in a positive way with the deceased. The approach of the nurses working to create positive memories for families may assist with the required 'grief work' as per models such as (Worden, 2018) which call for the bereaved individual to be able to reconnect and remember, reminiscing in a positive way concerning the deceased.

Other research papers support those positive experiences during end-of-life care may impact on the bereavement experienced for families. Cronin, Arnstein and Flanagan (2015) used a qualitative descriptive approach identified the perceived needs of family members while their loved ones were receiving end-of-life care in an acute oncology general medical/surgical unit. Their study determined that a nurse's attention and time spent addressing the unique needs of patients and families offered comfort as well as a nursing presence providing one-on-one time with families provided reassurance and a sense of working together, including attention to the environment to provide privacy and

personalising the space with home belongings (Cronin et al., 2015). These interventions, like those that the nurses in this study provided, were described by Cronin et al. (2015) as being positive for families and supporting their grief and bereavement. Riegel, Randall, and Buckley (2021) in research to establish 'memory making' in health professionals during end-of-life care in an adult intensive care unit surveyed 75 registered nurses about interventions that were attributed as memory making for families which were viewed by the participants as creating positive memories during care at end-of-life. The following were identified as per as tangible keepsakes such as; hand or footprints, locks of hair but also non-tangible such as allowing patients to spend unlimited time with the patient, asking the families questions about the patient and reminiscing about their life, being present at the time of death to support, talking to the family about death and dying, supporting with end-of-life rituals and comforts for families (Riegel et al., 2021). Similar to the work of the nurses in this study considerable effort was devoted to making the end-of-life experience as positive as possible and this work is valuable and beneficial to some of the necessary grief work that occurs as part of the bereavement process particularly concerned around the need for positive memories and having a connection with the deceased.

Providing bereavement care to families after the death of patients

The nurse participants described the need to provide after-death care not only in the form of psychosocial care, as earlier discussed, but also as practical measures for families. Commonly, this care occurred for some hours after the death of patients, with nurse participants continuing to provide bereavement support during this time to family members. Despite this need, after death-care in this study was not factored into patient allocations and/or nurse-to-patient ratio planning and was not highlighted as a provision guided by the end-of-life care pathways for dying patients. The end-of-life 'trekking' journey, from the perspectives of the study nurses was essentially complete once patient death occurred, although the trek for families was likely to continue well after the 'destination death' without the nurse as 'trekking leader'. This idea was supported by the bereavement theory, that one learns to build their life around loss and grief during the process of bereavement, which has no timeframes (Eisma et al., 2021; Hall, 2014). This was also confirmed by nurse's descriptions of some

family members returning to the hospital to seek ongoing or after-death care, sometimes years after end-of-life care was received.

It should also be noted that the PICD domain that outlines care after death had the least amount of description to support care provisions, with much of the information attributed to patient comfort measures and algorithms to reinforce this (Jackson et al., 2009; Sleeman & Collis, 2013). Similarly, the nurse participants prioritised end-of-life care in this fashion, with a focus on comfort care measures for the patients and did not specify the exact care provisions implemented after death or reference the use of end-of-life care pathways as resources to prompt this care delivery. In many cases, nurse participants described that, after death, it was difficult to make time to remain with families and allow family members adequate time to stay with patients, due to the demands of the acute care environment in which other patients still required attention. Providing care to manage several patients simultaneously, including caring for the bereaved family members, proved especially challenging for the acute care nurses in this study. This challenge has also been described as the 'busyness' of acute care nurses, which impacts on their available time to spend time with families (Beckstrand et al., 2012; Hogan, Bourbonnais, Brajtman, Phillips, & Wilson, 2016; McCourt et al., 2020; Walker & Deacon, 2016).

There were also limited findings in this study regarding the support of family members with long-term bereavement or their referral by the nurses to community or outpatient services. As indicated earlier in this chapter, once family members left the hospital, the nurse participants were unclear about what multidisciplinary supports or resources were available to families and if any further contact was made by the hospital as follow up. There were also inconsistencies in the provision of information packs and/or brochures concerning regional grief and bereavement services. Lack of referral or resource support for bereavement is a concern, given that death in acute care settings is, commonly more traumatic or sudden and can predisposes the family to prolonged or complicated grief (Hall, 2014; Neimeyer & Burke, 2012; Shear, 2015).

The need for, and benefit of, bereavement care and support programs for families following the death of patients in hospitals is supported by other studies. In a study exploring nursing interventions for person-centred bereavement care in adult critical care settings in the UK, Walker and Deacon (2016)

identified the need for bereavement follow-up service for families, “to provide explanations, resolve questioning, offer counselling and afford closure” (p.43). Donovan, Wakefield, Russell, and Cohn (2015) undertook a mixed-method study of hospital-based bereavement programs, noting that these programs helped families feel cared for, reduced isolation and improved coping. Formal bereavement programs and after-care services have also been described in the literature as a positive measure that supports bereaved family members after the death of patients in acute care (Arbour & Wiegand, 2014; Holdsworth, 2015; Kurian et al., 2014; Stilos, Ford, & Chakraborty, 2020; Williams, Harris, Randall, Nichols, & Brown, 2003; Wilson et al., 2017). However, in this study, the nurses did not identify any informal or formal bereavement care programs for families of dying patients offered by their employers or in their communities when they spoke about the care of dying patients in rural hospitals.

Inconsistencies in practice and/or limited implementation of bereavement supports for families after the death of patients in hospitals is also identified in the literature. In the systematic review of the roles and responsibilities of acute care nurses in the provision of bereavement care in hospitals, that preceded this study, Raymond et al. (2017) identified inconsistencies in the duration of post-death care for families and how bereavement care was provided by nurses for families after the death of patients. More recent evidence continues to highlight this problem in practice, with inconsistent and limited bereavement care for families occurring in hospitals after the death of patients (Coombs et al., 2016; Efstathiou et al., 2018; McAdam & Erikson, 2016; Pringle, Bridget, & Buchanan, 2016).

In summary, bereavement care was provided through the nurse participants’ attempts to create positive memories for patients and their families during end-of-life care. Bereavement care was individualised to meet the emotional needs and other needs specific to the values and beliefs of patients and their families. Encouraging a family presence and managing the comfort measures of dying patients was important to the nurse participants and necessary to create positive memories. Bereavement care provided by the study nurses for families continued for only short periods of time after death, while patients were still present in acute care inpatient settings. PICD pathways were used merely as a rough guide to help navigate patients and their families through the end-of-life care journey. Barriers to creating positive memories were also identified in this the study, based around the acquisition of skills,

and will be further discussed in relation to the perceived competence and competence of the nurse participants who provided care to dying patients and their families in rural health settings.

Developing skills for creating positive memories as bereavement care

Skill acquisition was described as a potential barrier to the ability of rural nurses to create positive memories for patients and their families during end-of-life care. Although competence and confidence were not formally measured in this research, nurses were asked how they developed skills to deliver care to dying patients and their families in acute regional hospitals. Participants recognised and described the development of their confidence and the acquisition of skills through professional experience in care at the end of life and through personal exposure to death and dying. In relation to the trekking metaphor, if the nurse, as the 'trekking leader,' had previous experience of caring for patients, relatives or friends who had died, they believed that this provided better insight into the journey undertakings, along with greater familiarity to undertake the trek with the patient and their family.

Other studies have also identified that experience in the delivery of end-of-life care impacts positively on the confidence levels of nurses in the provision of end-of-life care to patients and their families in hospital settings (Hansen, Goodell, Dehaven, & Smith, 2009; Walker & Deacon, 2016). Including lower levels of anxiety and discomfort experienced during the care of dying patients of increased age and years of clinical experience (Arbour & Wiegand, 2014; Kurian et al., 2014). Griffiths (2019), in an international literature review on death anxiety and nurses' attitudes on how fear of death impacts nurses caring for patients at end of life, also found that less experienced nurses reported a stronger fear of death, and increased years of work experience mediated the impact of death anxiety. Similarly, Gamino and Ritter (2011), who define death competence as a "specialised skill in tolerating and managing a client's problems relating to dying, death and bereavement" (p 29-30), describe levels of competence improving through both formal training and the practical provision of psychosocial support in end-of life care. Miller-Lewis, Lewis, Tieman, Rawlings and Sanderson (2021) also describe that bereavement experience and experience caring for the dying was associated with greater death competence and that understanding of factors associated with death competence may help or prevent burnout as well as who may benefit from additional training and support.

The nurses in this study also frequently provided accounts from earlier periods in their careers when they felt underprepared to deliver end-of-life care. During the interviews, the nurses outlined clinical situations as junior nurses when they felt overwhelmed and inadequately equipped to deliver care to dying patients and their families. Similarly, in a qualitative study of nurses' experiences of caring for dying patients, Andersson et al. (2016) described the frustration felt by acute care nurses regarding their lack of knowledge and skills at the beginning of their careers. Ample similar evidence supports the need for more education and training to prepare acute care nurses for the delivery of care at the end of life (Andersson et al., 2016; Beckstrand et al., 2012; Colley, 2016; Croxon et al., 2018; Crump, Schaffer, & Schulte, 2010; Glover et al., 2017).

Personal experience in death and dying were also described by the study participants as helping them to feel more comfortable and confident in providing end-of-life care and bereavement care to families. Thompson, McClement, and Daeninck (2006) discuss nurses' using personal experience to support how they learn to care for dying patients. The nurses in this study provided similar descriptions, sharing stories about relatives who had died and how that experience shaped their opinions and fashioned how they interacted and provided care to patients and their families. In some narratives, the nurses highlighted specific interventions that they performed after being recipients of end-of-life care as a family member themselves. This mostly included spending time with patients and their families to create 'positive memories', trying to meet their individualised needs during end-of-life care, and providing opportunities for family members to stay with the dying patient, which was the result of their experience as a care recipient. Other nurses described that exposure to death in a personal experience had made them more realistic and somewhat better accustomed to the dying process and, hence, more positive about looking after dying patients and families.

The nurses in this study also described the need to role model and receive support from more senior staff members during the early stages of their careers. This mentoring enabled them to gain experience and develop the necessary skills required to feel more comfortable in the delivery of end-of-life care. The nurses explained that they learnt many of their skills through observation and role modelling of other staff who provided care at the end of life. Literature also supports that acute care nurses learn

how to deliver both end-of-life and bereavement care on the job, through role modelling and mentoring from their peers (Andersson et al., 2016; Arbour & Wiegand, 2014; Coombs et al., 2016; Croxon et al., 2018; Hendricks-Ferguson et al., 2014).

Experienced nurses, or those who were employed in management roles, described 'looking out for' junior staff members and checking on them to ensure they were comfortable when providing end-of-life care. These nurses also described acting as advocates for junior staff, helping facilitate further medical management or multidisciplinary referral, which in turn facilitated quality care. However, in a qualitative study on graduated nurses' perspectives on performing end-of-life care in Australian hospitals and community centres, Croxon et al. (2018) found conflicting evidence between the expectations of inexperienced nurses and their more experienced peers. In that study, Croxon et al. (2018) found that, although graduate nurses expected more experienced staff to guide their actions, the responsibility was frequently theirs alone, with little support provided by their peers on many occasions. A systematic review and qualitative meta-synthesis also described graduate nurses being largely unsupported and feeling left alone to cope with patient death (Zheng, Lee, & Bloomer, 2018). Hopkinson, Hallet, and Luker (2003) similarly reported that support from senior nurses for graduates caring for dying patients and their families was seldom and rare. This was therefore a contradictory study finding in that more experienced nurses described their role in supporting more junior nurses with the provisions of end-of-life and bereavement care, in this non-metropolitan study.

A potential barrier identified from the perceived levels of competence and confidence of the nurses in this study relates to the need for a mix of senior and junior staff working together to ensure the delivery of quality end-of-life and bereavement care for patients and their families. This was the case in this study, as often junior staff needed help with many of the bereavement care roles that occurred during end-of-life care. Appropriate skills or staffing mixes would therefore be necessary within rural hospitals to ensure novice nurses are supported during the delivery of bereavement care, whilst gaining the required professional experience and related skills. Andersson et al. (2016), in a qualitative study of nurses with less than two years of experience caring for dying patients in a surgical ward, claim that nursing education is basic and novice nurses need to develop their skills in end-of-life care alongside

other well-trained colleagues. It should also be noted that, as previously discussed, the PICD was not always used in high acuity care areas and, as a resource, was also criticised by the nurse participants as not always capturing the required person-centred care necessary for patients and their families; hence, indicating this tool alone would be insufficient to support novice nurses.

The lack of availability of medical services to support the comfort needs for dying patients was a potential barrier the creation of positive memories for patients and their families. Nurses in the study were frustrated with what they perceived as limited medical supports available within their health services, which sometimes impacted on referral for palliative care review and availability of medical staff to assist in keeping patients comfortable. The nurses indicated that, sometimes, the management of patient comfort was not well achieved because, on occasions, medical staff lacked training or the ability to consult more senior staff to support complex decisions about medications or referrals for patients. Evidence exists that rural Australia is experiencing a chronic medical workforce shortage (McGrail et al., 2011) with an inability to attract and retain sufficient numbers of doctors and specialists in many hospitals, which impacts on accessibility to and sustainability of quality medical care for rural health services (Australian Medical Association, 2021).

In this study, the provision for families of multidisciplinary support for bereavement services, during and following death, was also limited, which also impacted on the potential to create positive memories. The study nurses indicated that all resources and supports mostly ended abruptly for families following the death of patients and ended entirely once a patient left the acute care inpatient setting. Nurse participants were also unsure whether any follow-up with family members occurred or if sympathy cards were sent from the hospital to the next of kin. Some nurse participants indicated that they provided family members with information brochures or packs regarding bereavement services; this, however, was not a common occurrence. The nurse participants did not speak of any formal bereavement support groups or programs available for families. There was also no evidence of the nurses facilitating referrals for families for ongoing support or bereavement services, despite, as earlier indicated, these services existing in the region.

Sustaining the provisions of bereavement care during end-of-life care

The need for self-care was important for the nurses in this study to be able to 'weather the storm' or manage the adversities associated with the end-of-life journey for patients and their families.

Application of the 'trekking leader' metaphor highlights similarity in the strategies for self-care, as the nurses were required to sustain the activities necessary to complete the trek or end-of-life journey with the patient and their family. The findings of this study provided examples of how rural nurses made time to reflect on the end-of-life care they provided and used coping strategies to help them do this. When the study nurses found end-of-life care for patient and families overwhelming, the associated emotional burden led to disengagement with the patient/family group and, therefore, with the provision of bereavement care. Although it was evident that the nurses in this study were providing bereavement care, this often happened as a consequence to the delivery of end-of-life care and mostly occurred without recognition. A lack of awareness of their bereavement care role may have also impacted on their cognisance of their needs for support to engage in end-of-life and bereavement care.

In this section, the impact that delivering end-of-life care had on the nurse participants and how they managed to cope in the acute rural hospital setting is highlighted. The need for the nurses to better identify the roles they play in the delivery of bereavement care during end-of-life care will also be further discussed. The impact of delivering end-of-life care and the need for the study nurses to better identify with the roles undertaken as bereavement care, were understood to be potential barriers to the delivery of quality bereavement care in the non-metropolitan hospitals in this study.

Self-care measures to support the delivery of bereavement care

The provision of end-of-life care to dying patients and their families did not occur without emotional consequence for the rural nurses in this study. Often, the nurses described their difficulty caring for patients and families, with some experiences being worse than others due to the traumatic nature of the death or when clinical events triggered memories of family or friends who had previously died. Several narratives emerging from the interviews reinforced the notion that the journey of end-of-life care is emotionally difficult for nurses, particularly during the earlier stages of their careers. Other research studies describe acute care nurses feeling emotionally stressed throughout the provision of

care to dying patients and their families, associated with their perceptions of inadequate quality of care provided (Dong et al., 2016; Hussin et al., 2018b) and pressures to 'get it right' for patients and their families during end-of-life care (Nurse & Price, 2017). This was also the case when they perceived environmental and resource limitations impacted on the quality of care provided by acute care nurses (Liu & Chiang, 2017; Wolf et al., 2015). In a qualitative study of oncology nurses in Hong Kong, Chan et al. (2013) described the 15 nurses involved in the study as also 'suffering' while taking care of dying patients, explaining that bereavement care was emotionally taxing.

Nurses in this study identified concern for new nurses who they felt were particularly at risk of not coping with the care of dying patients. Previous research has described novice nurses having higher stress levels than expert nurses with claims that difficulty coping with the care of dying patients has been associated with lack of professional experience in junior nurses (Hinderer, 2012; Whittaker, Gillum, & Kelly, 2018). High levels of death anxiety for nurses also exist in anticipation of caring for dying patients and their families, with less emotional discomfort occurring for nurses of increased age and years of nursing experience (Arbour & Wiegand, 2014; Kurian et al., 2014). In an international literature review on death anxiety and nurses' attitudes on how fear of death and dying impacts nurses caring for patients at end of life, Griffiths (2019) also found less experienced nurses reported a stronger fear of death, with increased years of work mediating the impact of death anxiety.

Gamino and Ritter (2011) define death competence for all practitioners working with the dying and bereaved as having the necessary expertise in tolerating and managing problems relating to dying, death and bereavement. Gamino and Ritter (2011) explain that levels of death competence are facilitated through both formal training and the practical provision of psychosocial support in end-of life care. None of the nurses in this study had acquired any formal training in palliative care and based on their narratives, their death competence could only be identified through their professional and personal experiences of death, which was commonly less for the novice nurses in the study. It should also be noted that a lack of knowledge about death and 'death literacy', may have impacted on how the nurses felt about providing care to dying patients and their families. Death literacy has been described as the outcome of people's experiences of and learnings about death and dying which is context specific and

the ability to put this knowledge into practice to strengthen one's capacity for caring (Noonan, Horsfall, Leonard, & Rosener, 2016). Although the death literacy of the nurse participants was not assessed in this study, nurse participants' knowledge of bereavement services and referral pathways outside of the context of the hospital setting, to facilitate ongoing support for bereaved family members, was limited. Death literacy, as described, is directly proportionally to experience of and learnings about death, which would, again, have implications for novice nurses in terms of both quality care and the ability to sustain the provisions of bereavement care during end-of-life care.

Despite the intervening years, vivid examples of first experiences of end-of-life care were also shared by the study nurses and were consistently described as being the most overwhelming or challenging experiences to endure in their careers. However, research evidence also supports that, even nurses with several years of experience, have the collective weight of distressing experiences relating to care of dying patients, which can lead to stress and burnout over time (Guo & Zheng, 2019). This finding is in accordance with other studies that report a high incidence of job burnout and traumatic stress generally occurring amongst acute care nurses working with dying patients in hospitals (Beck, 2011; Frey, Robinson, Wong, & Gott, 2018; Oginska-Bulik & Michalska, 2020; Whittaker et al., 2018).

The rural nurses in this study found the delivery of bereavement care emotionally difficult to maintain, particularly when patient or their families were described as overwhelmed by grief, openly vocalising (crying and wailing) at the bedside. The nurse participants carried this distress, which often made it challenging for them to perform their responsibilities as 'trekking leaders' and provide the end-of-life care required. Sometimes the distress they faced became too difficult to endure, with some of the nurse participants separating themselves both physically and emotionally from the situation and the patient or the family. Like this study, other end-of-life care studies concerning oncology nurses have also shown that these acute care nurses often cope by applying avoidance and dissociative behaviours during highly stressful clinical situations (Kovacs, Kovacs, & Hegedus, 2010; Phillips & Volker, 2020; Wenzel, Shaha, Klimmek, & Krumm, 2011). There were also concerns for other patients and families who were being subject to this family's emotional distress within the same location, but pressure to allow families to express their grief, which became a moral dilemma for the nurses in this study.

Moral distress for the study nurses also related to managing workloads in acute care settings, which influenced the time available to spend with both dying patients and their families, as previously discussed. Deaths that also occurred in a short time following rapid clinical deterioration or after withdrawal of treatment or 'trial of life' were the cases described by the nurse participants as having the most impact or being the most morally troubling. Other cases, in which the symptom control for dying patients was inadequate, also had a negative impact on the study nurses. Moral distress has been identified in an ethnographic study of critical care nurses in Indiana and Michigan as relating to specific components of the care of dying patients and their families (Whittaker et al., 2018). In this study, Whittaker et al. (2018) describe cases that were traumatic or related to extended 'trial of life' periods, including situations in which dying patients were not kept comfortable and insufficient nurse to patient ratios were impacting on the time to deliver care, as similar causes for emotional burden or distress in nurses. Therefore, the need for additional support to recognise the complexity of bereavement care and manage the consequences of the emotional and moral distress that arises in response to its delivery by acute care nurses is essential.

In some cases, the nurse participants discussed that care of certain patients and families triggered memories of their own personal experiences of friends or family members who died. Sometimes patients and their families were described as having similar traits or being in similar circumstances to the nurse's 'important person' who had died. Similarities and memories triggered some nurse participants to be highly emotional and fragile in the delivery of care. In these situations, these nurses, also, described trying to distance themselves from the situation and the triggers that precipitated connections to personal experiences of death and dying, in an attempt to cope. Acute care nurses distancing themselves from clinical situations as a method of protecting themselves is also evident in other research papers (Hinderer, 2012; Stayt, 2010). The study nurses also discussed protective mechanisms in their behaviour at work, which included distancing themselves on occasions and trying to avoid becoming emotionally attached with patients and their family members. Andersson et al. (2016) similarly describe nurses caring for the dying as "using different strategies to balance their closeness of distance and empathy to protect themselves from emotional stress" (p. 148). Learning about alternative

coping mechanisms rather than distancing themselves to avoid becoming emotionally attached would be beneficial for not only the acute care nurses in this study but also for the patients and their families, as recipients of the end-of-life care.

It was identified, in this study, that some of the nurses who were employed in management roles took it upon themselves to monitor the wellbeing of other staff who may have been caring for the same dying patient and their family over several consecutive shifts. In these cases, the managers initiated the shuffling of patient allocations to other nursing staff to help manage the emotional burden associated with providing end-of-life care for patients and their families. Attia, Abd-Elaziz, and Kandeel (2012) also confirm that intensive care nurses draw on experience and support from one another to manage and sustain the delivery of end-of-life care to patients and their families.

Bereavement theory describes how the process can be triggered through reminders of the deceased (Dunne, 2004) and that bereavement, as a process, is how individuals learn to live and integrate loss into their lives (Hall, 2014). It is, therefore, likely that the nurse participants who described becoming overwhelmed with emotions due to reminders of previously known deceased people, may be, themselves, engaging in the bereavement process. The bereavement process, as described in Chapter One, identifies how bereaved individuals are intermittently active in 'loss orientated work' (Boerner et al., 2016; Stroebe & Schut, 1999). Loss orientated work has been described by Stroebe and Schut (1999) as 'grief work' or work dealing with and processing loss. Therefore, the nurses in this study may have, under certain circumstances and in relation to certain triggers or clinical incidents, needed to undertake their own 'grief work', which would result in them bringing their own grief and associated psychological responses to the patient's and the family's end-of-life journey. Under these circumstances, the level of bereavement care and engagement of nurses with the end-of-life process may be compromised. These findings were interpreted as a need for the acute care nurses to develop a richer understanding of grief and the bereavement process, to better equip them to acknowledge their own feelings and integrate personal coping strategies in support of their own bereavement. An understanding of bereavement and the options for engagement in bereavement programs or follow-up services may help to alleviate some of the stressors for acute care nurses during end-of-life care, and also support their own delivery of

bereavement care in the practice setting (Bloomer & O'Connor, 2012; Hinderer, 2012; LeBrocq, Charles, Chan, & Buchanan, 2003).

The findings reveal many accounts of challenging clinical situations where, as a result of their involvement nurses and other staff were impacted emotionally. Nevertheless, most participants described the need to withhold emotions at work, to function in a professional manner, even though this was not always possible. Nurse participants described the need to cry with their colleagues during or at the end of shifts, on the way home from work or at home when they reflected on clinical incidents. In many cases, the nurse participants needed to reflect and make sense of the dying process and the end-of-life journey, and this activity became significant to their coping. The nurse participants often provided recollections of clinical events that were meaningful for them during their careers, describing what they learnt from the situations and how these events shaped their understanding and influenced their coping. Previous professional and personal experience relating to death and dying was always described by nurses as beneficial, which supported their preparation for and coping with the provision of end-of-life care. It was apparent that, if the nurse as the 'trekking leader' had previously engaged in an end-of-life care journey, personally and professionally, this experience provided valuable insight (Andersson et al., 2016; Walker & Deacon, 2016) into the journey, including the undertakings and the preparation for burden of care.

The nurse participants described methods of coping with the delivery of care at the end of life, which mostly encompassed reflective practice and informal debriefing with their peers. Although the nurse participants were aware of employee assistance programs (EAP), these were not utilised by the nurses in this study. The nurses preferred to engage with other colleagues, with the majority using other nurses, to debrief with, in which discussion concerning care for dying patients and their families could occur. The use of informal support from nursing peers is also evident in other research papers and is described as a useful approach for nurses to seek comfort and manage grief related to their care of patients and families during the end of life (Kobler, 2014; Shariff et al., 2017; Shorter & Stayt, 2010).

Senior staff were also identified by the nurse participants as good resources for debriefing and role modelling, including nursing educators and other experienced staff nurses. The nurse participants

believed that other peers could relate better and were familiar with the clinical events that necessitated a discussion, which was appreciated and valued as effective debriefing in the recounts as by the nurse participants. This was also the main reason attributed to the lack of usage of the existing EAP service, in which external supports were considered unable to relate to existing clinical practices and rural care settings. Some nurse participants met with other nurses to debrief outside of working hours. Support was also provided from family members of the nurse participants, as identified throughout the findings.

Strong evidence emerged in the study regarding the emotional impact and emotional burden carried by the nurse participants relating to the provision of end-of-life care in rural health settings. The informal support mechanisms that were sought, such as the coping mechanisms through debriefing with nursing peers and with family and friends, were considered unbalanced and limited given the extent of distress expressed by a number of participants and concerns for their peers. Carvajal et al. (2019), in a scoping review of the barriers perceived by registered nurses to the provision of person-centred care at the end of life, also identified the emotional cost to nurses when caring for dying patients and the lack of coping strategies utilised during and after a patient's death. Other research, in hospitals of Sweden, South Africa, the UK and the USA, also cite the limited evidence of coping strategies and uptake of formal supports for acute care nurses who deliver end-of-life care (Andersson et al., 2016; Efstathiou & Clifford, 2011; Johansson & Lindahl, 2010; King & Thomas, 2013; Kisorio & Langley, 2016). The need for ongoing strategies to maximise and ensure the uptake of both informal and formal supports is, needed to ensure the psychological welfare of acute care nurses who are caring for dying patients in rural hospitals. Extra peer support and wellbeing monitoring may also be necessary for novice nurses who may be more sensitive to the experience of end-of-life care, given their lack of professional exposure.

Recognising the bereavement care in end-of-life care

As discussed, when the nurses in this study were not able to cope with the delivery of end-of-life care, they would disengage from the patient and their family, and the delivery of bereavement care became jeopardised. Similarly, bereavement care for patients and their families may also potentially be compromised when the nurse participants did not recognise the bereavement care in the end-of-life care they were providing. The need for the nurses to better identify their roles in bereavement care and

to have greater clarity and understanding of bereavement care, including the bereavement process, and how this will potentially enhance the delivery of bereavement care to dying patients and their families in rural hospitals, will now be discussed.

The results of this study establish that the nurse participants provided bereavement care to patients and families as a consequence to the delivery of end-of-life care, which occurred concurrently. Although the nurse participants did not use the term 'bereavement care' or 'grief care/support' to describe the care they were providing to both patients and their families, bereavement care was clearly identified in the study's findings with some identification of their work in the 'grief work' described in some theoretical models that define the bereavement process. Bereavement care or grief care/support as a term, was also rarely used in the language of the nurses' narratives to define their engagement with dying patients and their family members. The research participants also did not use bereavement care or grief care/support as a term to separate specific care measures from the overall provisions of end-of-life care for patients and families. It was for these reasons that it was unclear whether the nurse participants knew that the care they were providing would be significant to a patient's bereavement or the bereavement process for families. The level of understanding regarding bereavement care was also uncertain, based on the narratives.

This lack of recognition by the nurse participants of the delivery of bereavement care was a key study finding and may be related to a theoretical knowledge gap concerning the roles of acute care nurses in bereavement care, including with respect to how bereavement care is inextricably described within the overall provisions of end-of-life care in many research papers (Caswell et al., 2015; Noome et al., 2016; Stilos et al., 2020; Wolf et al., 2015). Chapter two provides the results of an Australian and international review of the literature, from 2016 to 2020, which identified limited published research, with only 14 studies meeting the inclusion criteria for research studies concerning nursing bereavement care in acute hospitals and nursing roles in bereavement care concerning adult death. No studies could be sourced that were applicable to nursing roles in bereavement care in rural hospital settings. This review of the literature highlights a significant knowledge gap concerning the role clarity of acute care nurses,

particularly rural nurses, in the delivery of bereavement care during end-of-life care for patients and their families.

Another key finding from this research is that bereavement care was provided to patients and families concurrently with end-of-life care. The nurse participants, therefore, did not separate bereavement care from the overall provisions of end-of-life care because, in practice, it was not delivered separately. This may account for why several roles that the nurses performed in the delivery of bereavement care were similarly identified as roles they performed in end-of-life care. For example, the bereavement care roles identified by the nurses in this study, such as enlisting multidisciplinary resources to support patient and families, communicating with patient and families about death and the dying process, and meeting the different cultural and religious needs for patients and their families, are identified in other research papers as end-of-life care roles (Arbour & Wiegand, 2014; Bailey, Murphy, & Porock, 2011; Beckstrand et al., 2012; Boyd, Merkh, Rutledge, & Randall, 2011; Caswell et al., 2015; Hussin et al., 2018a; Minton et al., 2017; Noome et al., 2016; Stilos et al., 2020; Thacker, 2008; Walker & Deacon, 2016; Wolf et al., 2015). The findings of this study confirm that there is a strong overlap in the delivery of bereavement care and end-of-life care provision. However, certain roles were significant contributors to bereavement care, and these included those roles targeted at grief experience and the implementation of person-centred care to create positive memories, as described by the nurse participants.

The lack of recognition for the delivery of bereavement care by the nurses in this study may be related to the study nurses' levels of understanding regarding bereavement. Although the level of confidence and competence in the delivery of bereavement care was not measured in this study, the nurses did provide some insights that required skills were learnt over time through personal and professional experiences with death and dying. Some nurses also indicated that additional training regarding the care of dying patients in acute care would be beneficial. Similarly, Andersson et al. (2016) described, in a qualitative study of nurses' experiences of caring for dying patients, the frustration of acute care nurses regarding their lack of knowledge and skills at the beginning of their careers. Ample evidence of this also exists in literature, supporting the need for more education and training to prepare acute care nurses for the delivery of care at the end of life (Beckstrand et al., 2012; Colley, 2016; Croxon et al., 2018;

Crump et al., 2010; Glover et al., 2017). Increased training in the assessment of spiritual care needs has also been described as necessary to support delivery in practice (Minton et al., 2017). Kurian et al. (2014), in a research study involving 110 nurses in four intensive care units in Texas, identified that 46% of the nurses indicated that they had not received sufficient education and training to deliver bereavement care within the clinical setting.

The results of this study also highlight that the nurse participants lacked understanding of the bereavement process for patients and family members and the potential impact of this process on nurse-family relationships. Issues the nurse participants described included difficulty making families understand specific clinical situations and prognosis, provisions of care perceived as not 'good enough' by family members, difficulty meeting family expectations, and the incidence of conflict at the bedside, may be behaviours associated with family members experiencing bereavement, and exist as manifestations of grief associated with the bereavement process. Psychological responses relating to loss, such as anxiety, anger, denial, disbelief and grief, commonly impact the bereaved individual's behaviour and often compromise their ability to process information (Buckley et al., 2015; Dunne, 2004). The nurse participants described these behaviours for both patients and their families, but they did not associate such behaviours directly with grief, bereavement, or the bereavement process. Mostly, these behaviours were identified as challenges that the nurses needed to work through with patients or family members, with little explanation provided to their cause.

The language used by the participants throughout the interviews also identified a lack of understanding concerning the type of care patients were receiving during the end of life. During the interviews, the nurse participants commonly used the terms 'palliative' and 'end-of-life' care interchangeably, often describing the end stages of care for dying patients as 'palliative' or using the term 'palliative care' to describe the process of end-of-life care. Participants also described the time that withdrawal of treatment measures occurred as the time patients became 'palliative' patients or in need of 'palliative care'. End-of-life care is defined as care for people as they approach the final stage of life, with palliative care referring to people who are living with a fatal condition (Australian Commission on Safety and Quality in Health Care 2018). The use of such language incorrectly, to define patients and the type of

care being delivered, was extremely common throughout the interviews. This signified a potential knowledge gap or lack of understanding of the needs of people living with life limiting illness versus those approaching the final stages of life. Palliative Care Australia (2019) describe end of life as the final days or weeks of life in which a patient is rapidly approaching death and as a time when the needs of patients and their families are at the highest. It is, therefore, imperative that acute care nurses have a good understanding of the difference between palliative and end-of-life care and how the needs may change for both dying patients and their families. Again early palliative intervention to provide enhanced quality of life and meet the holistic needs of patients as the progress towards death is important (Hudson et al., 2021) and not well demonstrated by the nurses in this study. Hussin et al. (2018a), in their study of nurses' perceptions of with end-of-life care, also highlighted that, overall, the 553 nurses who completed a cross-sectional questionnaire demonstrated a low level of knowledge about end-of-life care and what this period of care involved for both dying patients and their families. Failure to understand palliative care needs early in the course of illness, before imminent death, may cause a lack of referral to appropriate services to support quality of life. This may also be compounded by a lack of knowledge about referral pathways and community services, which appeared to be the case for the nurses in this study, who were mostly unsure of external supports for families, particularly after the death of patients.

Summary

The metaphor of a 'trekking leader' was used to help describe the roles of the nurse participants in the provision of bereavement care during end-of-life care in this rural health study. End-of-life care was the trekking journey that the nurses walked with the patient/family. The journey was arduous for both the nurse participants and, as they described for the patients and their families. Nurses invited multidisciplinary professionals to join the trekking group in support of bereavement care during the expedition. Communication was the key to success, as described by the nurses, as this enabled the identification of person-centred care needs and the tracking of how the patient and the family group were travelling in response to the care measures implemented. Throughout the delivery of bereavement

care, the nurses created what they believed were opportunities for positive memories, by responding to care needs that were both patient- and family-centred. Bereavement care continued during the end-of-life journey and, mostly, for short periods once the 'destination death' was reached. End-of-life care pathways were used as rough navigation guides by the study nurses, and previous experience, personally and professionally, provided insight into the end-of-life trek, which enabled them to feel more comfortable as the 'trekking leader', but also failed to address individualised needs. If the nurses were not able to manage the emotional burdens associated with the end-of-life journey, bereavement care and the ability to perform as a 'trekking leader' became compromised, due to disengagement from the trekking group. The bereavement care of the study nurses was sometimes reflected with the 'grief work' described in a number of different published bereavement models.

CHAPTER SEVEN – Conclusions and Recommendations

Thesis overview

This interpretive, descriptive study aimed to identify the bereavement care roles of acute care nurses during the delivery of end-of-life care in rural hospitals. The background of this thesis described how the death of a significant person and the bereavement process associated with this loss is one of life's greatest stressors, with potential adversities, such as a decline in physical and mental health, including an increased risk of mortality, for the bereaved individual. The background also highlighted the complexity of bereavement through models that describe grief and the bereavement process. As previously stated, with over half of all deaths per year occurring in hospitals, acute care nurses are at the frontline of providing end-of-life care and bereavement care to families with increased risk of complicated grief given the nature of many acute care deaths.

Bereavement care is a complex nursing role that requires the acquisition of skills to enable the delivery of effective psychosocial care for patients and their families, as well as appropriate referral to specialised multidisciplinary services and the ability to deliver clinical interventions to meet the comfort needs of dying patients. The bereavement care provided to dying patients was different for each family member based on differences in grief and how their losses through death, were being interpreted. Patients facing the reality of death therefore had different bereavement needs in comparison to family members, and the study nurses needed to provide care to suit. Bereavement care and its potential significance to the bereavement process for patients as recipients of end-of-life care, and families, both in death anticipation and after the death of patients, is complex. Despite this, bereavement care for nurses is not well defined in Australia or elsewhere in the world, with no research defining the bereavement care roles of nurses in rural hospital settings. A published systematic review undertaken for 2006-2015 and more recent review of literature undertaken for 2016-2020 established a baseline understanding of bereavement care and the roles that nurses undertake in hospitals. Bereavement care was defined in the background and this definition was used as a bereavement care 'lens' to further examine the study's findings and identify the bereavement care roles of nurses in this rural health study.

A constructivist paradigm and interpretive description methodology was used to understand how the nurse's provided bereavement care in acute-metropolitan hospitals, and bereavement care was identified within their narrative descriptions, of how they provided care to dying patients. This approach was anchored by the foundations of theoretical fore-structure through methodology of interpretive description which required the incorporation and evaluation of all related evidence concerning the delivery of bereavement care by nurses in the context of an acute rural hospital setting. In this study, the empirical evidence was provided by 24 in-depth, semi-structured interviews with rural and regional nurses, in which the nurses working in non-metropolitan acute care settings, described the roles of nurses in the provision of bereavement care.

The interviews were transcribed applying thematic analysis, using the NVivo 11 Plus (2020) program, which supported open coding of the data to generate two major themes, the 'coping' and the 'doing'. The thematic analysis process supported the identification of nursing roles that constituted two major areas of work for the acute care nurse in relation to the provision of bereavement care. The 'doing' which encompassed findings that represented how the nurses attempted to meet the needs of dying patients and their families, with communication guiding their care. In addition, the 'doing' involved providing person-centred care that suited both the patient and family, inclusive of cultural and religious support to meet the needs of patients and their families, keeping dying patients comfortable, using end-of-life care pathways to support the delivery of both bereavement and end-of-life care, and providing after-death care for families. The 'coping' encompassed findings that represented how the nurses coped with the delivery of end-of-life and bereavement care in rural hospitals and related to how the nurses reflected and used coping mechanisms to sustain care delivery. Both the 'doing' and the 'coping' work was influenced by personal and professional experiences of death and dying and the impact the acute care rural setting had on the delivery of end-of-life and bereavement care.

The findings provided clarity of the roles that the rural nurses undertook as bereavement care, including factors influencing the competence and confidence of the nurses which mainly involved having had personal experience of death/dying and the professional experience of caring for dying patients. In addition, the needs and clinical barriers that impacted on the provision of bereavement care in rural

hospitals were also established. This included the 'reality of space', the acute care environment and 'place' the non-metropolitan location of the hospitals. The study nurses described that having time to be with patient/family was essential to the delivery of quality end-of-life care and the impact of end-of-life often took its toll emotionally for the nurses who had to cope to sustain the provisions of bereavement care.

A detailed interpretation of the study findings, along with the application of the findings to research and the literature about the provision of bereavement care, including practice guidelines about quality palliative care and end-of-life care pathways in acute care setting, was also completed. The findings of this study were applied to a 'trekking' metaphor, to help describe the bereavement care roles of nurses as 'trekking leaders' through their engagement with patients and their families during the delivery of end-of-life care.

A link was identified between some of the bereavement care provided by the nurses and the potential 'grief work' required by the families in relation to published grief and bereavement models. It was however, interpreted that the bereavement care provided by the nurses was quite superficial in comparison to the depth and complexity of the 'grief work' required for each bereaved individual, based on the different theories. In addition, there was also no end to the bereavement process, with the bereaved individual needing to adapt to their death related losses, over time, as part of growing around grief. It was therefore anticipated that the bulk of the bereavement work would be occurring for families after the acute hospital phase and when families leave the care of the hospital, following a patient's death. Despite this, nurses were unaware of bereavement care resources to support families in the community and rarely made referrals.

It was also obvious that the bereavement care provided to patients concerning their grief experience was different to that of family members and although more time was spent supporting families, patients were also recipients of care. Interpretation of the study findings also reinforced the individual nature of grief experience and how based on the uniqueness of people, bereavement care needed to change to suit the needs of the patient and individual family members. Communication was again a key role of nurses in the provision of bereavement care, which they performed using techniques such as 'active

listening' and 'silence' that 'opened up' conversations about death and dying and grief for patients, but mostly with families to help identify their needs.

The study nurses therefore utilised an individualised approach to care, that was both patient and family centred which was believed to have the potential of creating positive memories and the creation of a 'good death' as perceived by the study nurses. The end-of-life journey was an arduous one as confirmed by the emotional care provided by the study nurses to patients/families and this sometimes took its toll on the study nurses and precipitated the need for the nurses to employ self-care measures to be able to sustain the provisions of bereavement care, during end-of-life. The interpretation of the findings has supported the study's conclusions, recommendations, strengths, and limitations of the research, and will be further outlined to conclude this thesis.

Conclusions

Nursing roles in bereavement care

The acute care nurses in rural hospitals helped facilitate the end-of-life journey for patients and their families using their own personal and professional experiences of death to help guide care.

Bereavement care occurred in a dual delivery fashion, alongside end-of-life care for patients and their families, and the nurses although providing care to both patient and family as one unit of care, the necessary bereavement care was different for the patient and each individual family member. A multidisciplinary approach was described to provide bereavement care through more senior nurse engagement and with the support of the wider multidisciplinary team, to enhance the delivery of bereavement care to both patients and their families.

End-of-life care pathways were a common resource, used by the acute care nurses in rural hospitals, and signalled the time that end-of-life and bereavement care commenced. In areas with highest acuity care, such as Emergency and Critical Care, the nurses used this resource less frequently. However, the end-of-life care pathways did not always reflect the person-centred care that was described as required for and delivered to patients and their families, due to the standardised nature of the tool. The complexity of the care required was also not believed to be reflected in the tool, given the different approaches

employed to ensure effective communication and strategies undertaken to provide positive experiences concerning death and dying. It was also apparent that each of the individual narratives reflected different care measures to address the individualised grief experience of patients and families which occurred as part of the end-of-life, and this care was also not well represented on the end-of-life pathways.

Bereavement care was provided as person-centred care to address the different needs of patients and their families during the end-of-life process. Bereavement care ceased shortly after patient death for families, with no further contact made by the nurses with families. Bereavement care was occurring for patients during short time periods until death, while patients were still conscious and engaged with end-of-life care provisions with the bulk of bereavement care being directed to family members.

The nurses in this study also needed to maintain levels of self-care to be able to sustain the delivery of end-of-life care and they utilised informal support mechanisms to do so. Despite describing the emotional burden of end-of-life care and bereavement care was heavy, the nurses preferred informal supports through debriefing with their peers and family, rather than formal employee assistance programs.

Communication was identified as a pivotal skill that acute care nurses used to assess the needs of dying patients and their families, and was also used to deliver bereavement care, particularly during periods of emotional crisis for families. Acute care nurses prioritised time to have open conversations about death/dying with both patients and their families, to identify their needs and this was seen as highly significant to the provision of bereavement care during end-of-life care. Communication in the form of 'active listening' and 'silence' were strategies used by the study nurses and have been described as significant to 'grief work' and opening conversations concerning spirituality/religion that are important components of the bereavement process.

Competence and confidence in the delivery of end-of-life and bereavement care

Bereavement care required both professional and personal experience to ensure rural nurses felt comfortable with the delivery of care to dying patients. Competence and confidence were not formally

measured in this study, rather the perceptions of the nurses regarding their ability to deliver care to dying patients and their families were identified through their narratives. The delivery of end-of-life care and subsequent bereavement care was described by the nurses in this study as more challenging during the earlier periods of their careers. The incorrect use of language by the nurse participants for patients at end of life, with reference to patients as 'palliative' or recipients of 'palliative care', during the care of patients in the final stages of life, indicated a potential knowledge gap in relation to palliative care, potentially impacting on referral to these services. The need to utilise multidisciplinary support in the delivery of care at end-of-life also indicated that a team approach was necessary to ensure adequate provisions of care. It was also unclear if the study nurses knew exactly how significant their care provisions could be, to a patient and family's bereavement, given they often didn't use bereavement or grief care as a term to describe their work.

Needs and barriers in the provisions of bereavement care

The acute care setting, although considered not the ideal environment to deliver bereavement care, was manipulated by the nurses to create what they believed was a positive end-of-life experience for patients and their families. Within areas of highest acuity, such as emergency and critical care, the nurse participants were less accepting of patients receiving end-of-life care in these settings, preferring patients to be moved to medical units where it was perceived that their needs could be better met. Attitudes concerning acute care being an environment to restore health and not fitting to deliver care at end-of-life were also identified throughout the study's findings.

The busyness of the acute care environment, with the need for patient flow and bed availability, was also a perceived barrier, impacting on their available time for nurses to spend with patients and their families. This was complicated by caring for multiple patients, with some patients requiring active treatment to facilitate recovery, as well as patients who were at end-of-life, which was both physically and emotionally taxing for the nurses. These factors sometimes caused the nurses in this study to question the quality of care that they provided for patients and their families at end of life, which impacted negatively on them as care providers.

A significant finding, and a potential barrier to bereavement care delivery, were the descriptions of the impact that caring for dying patients and families had on nurses in rural hospitals. The nurses needed time to reflect and cope with their clinical experiences and the care they provided to patients and their families during end of life. If the rural nurses were not able to cope with the delivery of end-of-life care, they were inclined to disengage from the patient and their family and the end-of-life process, which jeopardised the delivery of bereavement care. In many cases, the care of dying patients also triggered memories about their own personal experiences of loss associated with death, which identified some links to bereavement models that conceptualise individuals learning to live with loss over time. Therefore, the possibility existed that the nurses themselves may have been undertaking their own bereavement process, during the delivery of end-of-life care to patients and families. As a result, the use of coping and self-care mechanisms for acute care nurses is necessary to support the delivery of end-of-life care by acute care nurses.

Study strengths and limitations

This research has contributed to a significant knowledge gap regarding the roles nurses undertake in end-of-life care that constitute bereavement care, for patients and their families in non-metropolitan hospitals. Semi-structured interviews were a successful approach to help accomplish the aim of the study, with enough participants recruited to establish data saturation. The findings of this study support the notion that nurses in rural hospitals play a key role in the delivery of bereavement care to patients and their families, which is of significance to the bereavement process for families, both during and after the death of patients, within rural communities. The study also highlighted the individualised nature of grief and how bereavement care needed to be individualised to suit the needs of both patients and individual family members involved in the end-of-life process. This research was successful in defining the roles of acute care nurses in the provision of bereavement care in non-metropolitan hospitals and raise awareness of the journey that the nurses undertake with the wider multi-disciplinary team along with the patient/family during end-of-life care to patient death. This study has also identified some of the needs as perceived by study nurses in the provision of quality care at end-of-life that includes appropriate workload allocation so that adequate time can be provided with patients and families to

develop therapeutic relationships and ensure effective communication is occurring. In addition, expertise which was attributed to personal and professional experience in death/dying, was also a key contributor to competence and confidence as described by the acute rural nurses.

The limitations of the study include an inability to generalise the findings as specific rural issues, with only one rural region included in the study; although given the nature of a qualitative study generalisation was not the purpose. Transferability of the study findings would also be most specific to nurses in rural hospitals who have no formal palliative care speciality training and have similar levels of personal and professional experience in death and dying as the nurses in this study. There was also difficulty comparing rural bereavement care practices to metropolitan practices, with the finding's representative of the nurses in this study, who had predominantly only been employed in non-metropolitan hospitals. Making comparisons with other research studies was also compounded by a lack of published research concerning bereavement care provided by nurses in rural or metropolitan hospitals.

The perspectives of multidisciplinary services and the creation of positive end-of-life experiences for patients and their families regarding the provision of quality end-of-life care were also perceived through the role of the nurses providing end-of-life care, with nurses being the only participant voice in this study. Further research including patient and families as recipients of bereavement care and other key multidisciplinary bereavement care providers, such as doctors and social workers, would contribute to understanding bereavement care in non-metropolitan hospital settings. Additionally, although elements of competence and confidence relating to care of the dying patient were described by the nurse participants, these were perceived through self-assessment only, without using a formal assessment tool or measurement scale.

Recommendations

The implications and recommendations arising from this study are described in three areas: nursing practice, research, and education.

Nursing practice

Consideration of nurse patient allocations and nursing ratios is necessary to ensure that workloads are manageable, and time can be spent with patients and their families to understand their needs and to assess how bereavement care provisions are being received by them, during end-of-life care.

Communication was jeopardised when there was limited time to spend with patients and their families, and this was always reflective of the workload of rural nurses and the combination of caring both for patients receiving end-of-life care and those receiving active treatment. It was also evident that less experienced nursing staff often found communication with patient/family during end-of-life more challenging and often required additional help from the wider health care team. Levels of communication also impacted on the identification and provisions of person-centred care to patient/families.

Therefore, ensuring that an adequate skill mix is available on each shift to support less experienced nursing staff is necessary to ensure quality bereavement care is provided in acute rural hospitals, with a mix of both junior and senior staff being the most beneficial to support the overall care of dying patients and their families. Pairing or mentoring opportunities for junior staff with more experienced nurses may also be beneficial to support the delivery of end-of-life care to patients and their families. Graduate nurse programs could also enhance opportunities for education and clinical skill development, through role plays and scenarios relating to communication along with the identification of person-centred care during end-of-life, in clinical scenarios. This will help support higher level communication techniques such as 'active listening' and the use of 'silence' as effective strategies employed by nurses to help facilitate quality bereavement care during care at end-of-life.

Clinical support should focus on the development of the necessary skills to create positive memories in support of end-of-life care for patients and families given these skills were acquired over time, through both professional and personal experiences of death and dying. Ongoing clinical support should be based on understanding of grief and bereavement models to assist the provision of care for families in a way that aligns with the 'grief work' that is required for individuals as part of the bereavement process. A greater understanding of grief and the bereavement process may also be beneficial to nurses own

self-care. In addition, a more in-depth understanding of 'grief' will also provide a better understanding of potential behaviours and the different emotions that relate to how grief may be expressed by the bereaved person. This not only includes a better understanding of the emotional turmoil but includes the significance of spirituality and religion as part of the bereavement process for patients and their families. In addition, the need to generate better awareness of how bereavement care exists and is delivered as part of nursing care during the delivery of end-of-life care for patients and their families, in non-metropolitan hospitals is paramount.

The end-of-life care pathway commonly used to support bereavement care by the acute rural nurses in this study was the Pathway for Improving Care of the Dying (PICD). The PICD was described by the study nurses as a rough guide because the pathway was not representative of the person-centred care required by patients and their families at end of life. Review of the PICD, therefore, is necessary to provide more comprehensive details of what bereavement care may be for patient/family as part of end-of-life care. More detailed information concerning grief and the benefits of spiritual/religious connections for patients and families should be outlined. The use of specialist palliative care nurses, chaplains or religious ministers, social workers may be also presented as valuable resources to ensure that appropriate conversations are occurring, and patients/families are given the opportunity to start to 'make sense' of death occurrence and their anticipated losses. Role clarity for nurses in the delivery of bereavement care should also be detailed in end-of-life care policies and protocols to strengthen understanding and support practice compliance through a clinical governance framework. This information would provide added depth regarding grief and bereavement both from an inpatient and external community sense to support the work required by the multidisciplinary team and as per the PICD.

The PICD can also be a tool to help clarify the roles that nurses undertake in bereavement care, to enhance quality end-of-life care. Developing the PICD as a more comprehensive resource will also help to build the knowledge of novice nurses and guide them throughout their provision of care to dying patients. It is also anticipated that, if the PICD better reflects the required bereavement care for both patients and their families during end-of-life care, then its uptake will be enhanced in areas such as

emergency or critical care, regardless of the timeframe to death for patients. This information would also accentuate the difference between bereavement care and end-of-life care for the acute care nurses in non-metropolitan hospitals, highlighting a need for attention and/or delivery of specific care in support of both components as part of the care of dying patients and their families.

Bereavement care ceased abruptly once patients died and no further care or support was provided to families by the study nurses. This shortfall in care may be attributed to the nurses in this study not fully understanding bereavement as a process and the risks associated with families leaving hospitals without referral to, or knowledge of, external bereavement supports or services, which may be necessary as they continue to live with the loss of a significant person. Or, perhaps, the study nurses had limited knowledge outside of the context of the hospital regarding available bereavement supports or services for families in rural communities, which impacted their ability to put this knowledge into practice and strengthen their capacity for caring. Greater awareness and promotion of the services of the region and in rural areas is therefore necessary to encourage uptake by families through nursing referrals which would again be supportive of quality end-of-life care. Therefore, early interventions through appropriate referral to community services in support of the necessary ongoing bereavement care that may be required for families would be recommended.

Ongoing awareness of the potential for burnout and disengagement with clinical practice, including methods to monitor levels of well-being, is necessary for nurses to be able to deliver care to patients and their families at end of life, as part of their nursing role. Strategies such as the use of mental health continuum models to perform self-assessments could be employed by acute care nurses to help keep track of their resilience and coping. Self-assessment check ins could also be supported by wider acute care teams and managers, to help monitor and provide additional resource allocation to nurses. A team or unit approach acknowledges the importance of self-care raising awareness of the risk of stress and burnout during end-of-life care which could also potentially strengthen peer support between nursing staff.

Information within this study suggests that nurses, themselves, are subject to clinical situations that trigger memories of significant others who have previously died, and this puts them at added risk of

emotional burden as they revisit their own loss and the bereavement process. Providing opportunities for debriefing with nursing peers to support the work of coping was described as an extremely important coping mechanism to sustain the delivery of end-of-life care. Benefits of this practice in minimising the impact of burn out and stress should be reinforced to acute care nurses and relevant to sustaining the work they do. Therefore, debriefing with nursing peers should become routine in practice and occur frequently, with sessions scheduled before the end of each shift for nurses who have directly cared for dying patients. It is also recommended that peer debrief occur soon after the death of patients, with options for sessions to continue if nursing staff still feel impacted emotionally. Given the most practical and accessible time for debriefing to occur with nursing staff may be during a shift, and this would need to be factored into workloads, with staff allocation to debriefing sessions initiated by unit managers. Informal debrief huddles with the wider multidisciplinary team members providing end-of-life care for patients and their families may also help support nurses providing end-of-life care to patients and their families. The option for ongoing clinical supervision or mentoring should also be offered to acute care nurses to support their coping and help them to manage the emotional stress experienced when caring for patients and their families at the end of life.

Education needs for acute care nurses relating to bereavement care

Nurses are in the unique position of providing bereavement care to patients and their families during end-of-life care. The nature and circumstance of deaths in acute care are also associated with an enhanced risk for complicated grief for bereaved family members. It is therefore crucial that the highest quality of bereavement care is provided and at the earliest time possible for patients given the short time frames to death for patients and that families are provided with initial or foundational bereavement care to support the ongoing bereavement process which continues after the death of patients. Therefore, knowledge acquisition concerning grief and bereavement as a process, is crucial to the delivery of quality care, including a clear understanding of the significance of spirituality and religion in support of grief care. Education regarding internal and external bereavement supports that can be used during inpatient admissions or accessed after families are discharged through outpatient referral

should involve clarity regarding hospital and community palliative care services and other after-death-related non-metropolitan services that are available for families once they leave the hospital.

It is also necessary to ensure that nurses caring for patients during end of life are aware of their own emotions, undertaking self-care strategies and understanding bereavement as a process to maintain their own mental health and well-being. Education that is targeted at wellbeing strategies to help manage stress, resilience and coping would be also useful for acute care nurses along with the importance of adopting some of these measures as part of their clinical work.

Continued undergraduate or postgraduate study in palliative care would be beneficial for acute care nurses who care for dying patients in hospitals. Palliative care education may promote the need for earlier bereavement care by nurses to patients, rather than relying on end-of-life care pathways to signal the need, which is essentially at a very late stage for patients. Providing palliative care and bereavement care earlier in patient's disease trajectory allows for longer time frames to better address patient's needs, beliefs and aims allowing greater ownership and patient engagement in the dying process. Further education concerning the benefits of early identification of patients for referral to palliative care services in support of quality of life for patients with advanced disease is again essential to support quality care.

Further education concerning how bereavement can impact the behaviours of families is a necessary focus to support relationship building and raise awareness that grief may impact the ability for family members to understand, and fully process information that is being received, including the potential for anger and aggression to be displayed as a response. This education for acute care nurses, based on the findings of this study, has the potential to better support quality care given that the nurses may feel better prepared to address these behaviours that patient/family members display at the patient bedside and understand the origins in relation to grief. Short courses that support de-escalation and aggression training management, may also be useful education to help manage some of the behaviours displayed by family members during end-of-life care.

Further research concerning bereavement care in hospitals

A better understanding of the involvement of multidisciplinary staff in both the delivery of bereavement and end-of-life care for patients and their families would be worthy of further research. Although the nurses in this study described their collaborative approach and how they utilised the skills of the wider disciplinary team, the true level of engagement and the specific roles undertaken by other health professionals was unclear. Having a greater depth of understanding of multidisciplinary contributions and how the wider acute care healthcare team functions to provide bereavement care, would enhance role clarity and provide a better insight into how bereavement care is provided to patient/families in hospitals. Greater role awareness of the wider multidisciplinary team can also support the identification of potential resources for nurses and strengthen pathways in support of end-of-life care. Deficits associated with provisions of multidisciplinary services can also be better understood, to benefit the provision of quality care both during and after death, for patients and their families.

The nurses in this study also described provisions of person-centred care to meet the needs of patients and their families during end-of-life care, which were delivered with the intent to create positive experiences during the period of end-of-life care. However, the implementation of these nursing care measures was based only on the nurses' personal and professional experiences regarding the care of dying patients and not the perceptions of the patients and their families. Encouraging a family presence at the bedside and involving family in some aspects of care for the dying patient, with attempts to personalise the space with patient belongings, were examples of bereavement care measures believed to create a more positive experience for families. Further research is necessary to better establish the impact of such bereavement care interventions as perceived by families and the impact such interventions have on the end-of-life experience in rural hospitals.

This study was indicative of the negative effects end-of-life care can have on acute care nurses and the need to undertake self-care measures to be able to cope with the delivery of end-of-life care. Further research is required to measure the resilience, stress and coping of acute care nurses, to better understand the emotional burden associated with caring for dying patients and their families, specifically in rural hospitals. In addition, the impact of nursing experience on the level of stress for

acute care nurses should be better identified so appropriate supports can be introduced. Overall specific strategies and interventions used to address levels of coping for acute care should be further investigated so the most effective method to support nurses in rural hospitals, caring for patients at end-of-life can be implemented.

Further research into the belief held by nurse participants' that dying patients could not be cared for appropriately in high acuity area, such as emergency and critical care settings, given the incidence of death occurrence in this location, is also necessary. The clinical underpinnings for acute care nurses that support this belief, particularly in an emergency department, require further research enquiry to better understand the motivations behind this idea. As it is inevitable that some patients will die in these high acuity areas, further evaluation of the resources and the environment within the emergency and critical care setting in comparison to medical units needs to assess the appropriateness and requirements of these settings for end-of-life care.

Research into the PICD tool should also be undertaken to identify the extent of compliance by acute care nurses and the contribution to bereavement care for patients/families during end-of-life care. This could help to identify more accurately deficit areas to the tool and promote the development of a less standardised tool that better supports the individualised nature of bereavement and end-of-life care.

Summary

Acute care nurses in non-metropolitan provided bereavement care to both patients and their families during end-of-life care. The bereavement care required was different for each individual as a consequence to their grief, and was displayed differently for each patient and each family member during the end-of-life process. It was evident that bereavement care was provided directly to patients for short time frames before death and provided directly to families throughout the end-of-life process and for short periods after the death of patients by acute care nurses. It was evident that some of the bereavement care provided by the acute care nurses to family members was in alignment with the 'grief work' required in some of the published bereavement models.

It was acknowledged that acute care nurses, had limited understanding of the bereavement process and the risks associated with families leaving hospitals without referral to, or knowledge of, external bereavement supports or services which was common practice. It was also thought that a greater understanding of palliative care nursing would help to precipitate the need for earlier patient engagement in bereavement care, rather than end-of-life pathways being the signal which were at late stages of a patient's disease trajectory, or acute illness.

Acute care nurses need to have appropriate workloads to provide the required time with patients and families, to utilise techniques of effective communication, to identify individualised needs in support of bereavement care. Strong hospital policy and protocols that identify and guide bereavement and end-of-life care need to be developed. The review of end-of-life care pathways that incorporate a less standardised tool to reflect the person-centred care needs of patient/family may promote better uptake by acute care nurses. Strategies in support of self-care are crucial for acute care nurses, in rural hospitals, to be able to sustain the delivery of bereavement care.

Research which investigates bereavement care for patients/families on behalf of the wider multidisciplinary team will also contribute to a better understanding of how bereavement care occurs in acute care non-metropolitan settings. Further research into the impact of caring for dying patients and their families on acute care nurses, is also warranted to identify measures to best support nurses and also ensure quality bereavement care during end-of-life is being delivered.

References

- Allard, E., Genest, C., & Legault, A. (2020). Theoretical and philosophical assumptions behind the concept of anticipatory grief. *International Journal of Palliative Nursing*, 26(2), 56-63. doi: <https://doi.org/10.12968/ijpn.2020.26.2.56>
- Anderson, D., & DesSouza, J. (2021). The importance and meaning of prayer rituals at the end of life. *British Journal of Nursing*, 30(1), 34-39. doi: <https://doi.org/10.12968/bjon.2021.30.1.34>
- Anderson, R., Bloch, S., Armstrong, M., Stone, P., & Low, J. (2019). Communication between healthcare professionals and relatives of patients approaching end-of-life: a systematic review of qualitative evidence. *Palliative Medicine*, 33(8), 926-941. doi: <https://doi.org/10.1177/0269216319852007>
- Andersson, E., Salickiene, Z., & Rosengren, K. (2016). To be involved - a qualitative study of nurses' experiences of caring for dying patients. *Nurse Education Today*, 38, 144-149. doi: <https://doi.org/10.1016/j.nedt.2015.11.026>
- Aoun, S., Rumbold, B., Howting, D., Bolleter, A., & Breen, L. (2017). Bereavement support for family caregivers: the gap between guidelines and practice in palliative care. *PLoS ONE*, 12(10). doi:<https://doi.org/10.1371/journal.pone.0184750>
- Arbour, R., & Wiegand, D. (2014). Self-described nursing roles experienced during care of dying patients and their families: A phenomenological study. *Intensive & Critical Care Nursing*, 30(4), 211-218. doi:[10.1016/j.iccn.2013.12.002](https://doi.org/10.1016/j.iccn.2013.12.002)
- Asawalikar, P. (2019). *5 qualities of an outdoor leader*. Retrieved from <https://www.getbeyondlimits.com/blog/view/Pratusha-Asawalikar/5-QUALITIES-OF-AN-OUTDOOR-LEADER>
- Aspers, P., & Corte, U. (2019). What is qualitative in qualitative research. *Qualitative Sociology*, 42, 139-160. doi:<https://doi.org/10.1007/s11133-019-9413-7>
- Attia, A., Abd-Elaziz, W., & Kandeel, N. (2012). Critical Care Nurses' Perception of Barriers and Supportive Behaviors in End-of-Life Care. *American Journal of Hospice and Palliative Medicine*, 30(3), 297-304. doi: <https://doi.org/10.1177/1049909112450067>

Australian Bureau of Statistics. (2020). Data by region. Retrieved from

<http://stat.abs.gov.au/itt/r.jsp?databyregion>

Australian Commission on Safety and Quality in Health Care. (2018). *The NSQHS Standards*. Sydney,

NSW: Australian Commission on Safety and Quality in Health Care. Retrieved from

<https://www.safetyandquality.gov.au/>

Australian Institute of Health and Welfare. (2016). *Australia's health 2016*. Canberra, Australia:

Australian Institute of Health and Welfare. Retrieved from

<https://www.aihw.gov.au/reports/australias-health/australias-health-2016/contents/summary>

Australian Institute of Health and Welfare. (2019). *Rural and remote health*. Canberra, Australia:

Australian Institute of Health and Welfare. Retrieved from

<https://www.aihw.gov.au/reports/rural-remote-australians/rural-remote-health/contents/summary>

Australian Medical Association. (2021). *Rural workforce initiatives 2017*. ACT, Australia: Retrieved from

https://ama.com.au/sites/default/files/documents/Rural_Workforce_Initiatives_2017_0.pdf

Bach, S., & Grant, A. (2015). *Communication & interpersonal skills in nursing* (3rd ed.). California: SAGE

Bach, V., Ploeg, J., & Black, M. (2009). Nursing roles in end-of-life decision making in critical care settings

Western Journal of Nursing Research, 31(4), 496-512. doi:

<https://doi.org/10.1177/0193945908331178>

Baier, M., & Buechsel, R. (2012). A model to help bereaved individuals understand the grief process.

Mental Health Practice, 16(1), 28-32.

Bailey, C., Murphy, R., & Porock, D. (2011). Trajectories of end-of-life care in the emergency department.

Annals of Emergency Medicine, 57(4), 362-369. doi:

<https://doi.org/10.1016/j.annemergmed.2010.10.010>

- Bassett, L., Bingley, A., & Brearley, S. (2018). Silence as an element of care: a meta-ethnographic review of professional caregivers' experience in clinical and pastoral settings. *Palliative Medicine*, 32(1), 185-194. doi: <https://doi.org/10.1177/0269216317722444>
- Baughcum, A., Fortney, C., Winning, A., Schultz, E., Keim, M., Humphrey, L., . . . Gerhardt, C. (2017). Perspectives from bereaved parents on improving end of life care in the NICU. *Clinical Practice in Pediatric Psychology*, 5(4), 392-403. doi: <https://psycnet.apa.org/doi/10.1037/cpp0000221>
- Beck, C. (2011). Secondary traumatic stress in nurses: a systematic review. *Archives of Psychiatric Nursing*, 25, 1-10. doi: <https://doi.org/10.1016/j.apnu.2010.05.005>
- Becker, C., Wright, G., & Schmit, K. (2017). Perceptions of dying well and distressing death by acute care nurses. *Applied Nursing Research*, 33, 149-154.
doi:<http://dx.doi.org/10.1016/j.apnr.2016.11.006>
- Beckstrand, R., Collette, J., Callister, L., & Luthy, K. (2012). Oncology nurses' obstacles and supportive Behaviors in end-of-life care: providing vital family care. *Oncology Nursing Forum*, 39, E398-406.
doi: <https://doi.org/10.1188/12.onf.e398-e406>
- Beckstrand, R., & Kirchhoff, K. (2005). Providing end-of-life care to patients: critical care nurses' perceived obstacles and supportive behaviors. *American Journal of Critical Care*, 14(5), 395-403.
doi: <http://dx.doi.org/10.4037/ajcc2005.14.5.395>
- Beckstrand, R., Smith, K., Luthy, K., & Macintosh, J. (2017). Rural emergency nurses' suggestions for improving end-of-life care *Journal Emergency Nursing*, 43(3), 214-220.
doi:<https://doi.org/10.1016/j.jen.2017.03.012>
- Bikat Adventures. (2021). Chadar trek packing list. Retrieved from
www.bikatadventures.com/Home/Blog/chadar-trek-checklist
- Blazeviciene, A., Laurs, L., & Newland, J. (2020). Attitudes of registered nurses about the end-of-life care in multi-profile hospitals: a cross sectional survey. *BMC Palliative Care*, 19(131), 1-8.
doi:<https://doi.org/10.1186/s12904-020-00637-7>

- Bloomer, M., Endacott, R., Copnell, B., & O'Connor, M. (2015). 'Something normal in a very, very abnormal environment' - Nursing work to honour the life of dying infants and children in neonatal and paediatric intensive care in Australia. *Intensive & Critical Care Nursing*, 33, 5-11. doi: <https://doi.org/10.1016/j.iccn.2015.09.001>
- Bloomer, M., Endacott, R., O'Connor, M., & Cross, W. (2013). The 'dis-ease' of dying: challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study. *Palliative Medicine*, 27(8), 757-764. doi: <https://doi.org/10.1177%2F0269216313477176>
- Bloomer, M., & O'Connor, M. (2012). Providing end-of-life care in the intensive care unit: issues that impact on nurse professionalism. *Singapore Nursing Journal*, 39(3), 25-30.
- Bloomfield, J., O'Neill, B., & Gillett, K. (2015). Enhancing student communication during end-of-life care: a pilot study. *Palliative & Supportive Care*, 1-11. doi: <https://doi.org/10.1017/s147895151500022x>
- Boerner, K., Stroebe, M., Schut, H., & Wortman, C. (2016). Grief and Bereavment: Theoretical Perspectives. *Encyclopedia of Geropsychology*, 979-986.
- Boyd, D., Merkh, K., Rutledge, D., & Randall, V. (2011). Nurses' perceptions and experiences with end-of-life communication and care. *Oncology Nursing Forum*, 38(3), 229-239. doi: <https://doi.org/10.1188/11.onf.e229-e239>
- Boyle, D. (2019). Nursing care at the end of life: optimising care of the family in the clinical setting. *Clinical Journal of Oncology Nursing*, 23(1), 13-17. doi: <https://doi.org/10.1188/19.cjon.13-17>
- Braun, V., Clarke, V., & Hayfield, N. (2019). A starting point for your journey, not a map: Nikki Hayfield in conversation with Virginia Braun and Victoria Clarke about thematic analysis. *Qualitative Research in Psychology*, 1-22. doi: <https://doi.org/10.1080/14780887.2019.1670765>
- Breen, L. J., & O'Connor, M. (2013). Rural health professionals' perspectives on providing grief and loss support in cancer care. *European Journal of Cancer Care*, 22(6), 765-772. doi: <https://psycnet.apa.org/doi/10.1111/ecc.12091>

- Brighton, L., & Bristowe, K. (2016). Communication in palliative care: talking about the end of life, before the end of life. *Postgraduate Medical Journal*, *92*, 466-470. doi:
<https://doi.org/10.1136/postgradmedj-2015-133368>
- Brooks, L., Manias, E., & Nicholson, P. (2017). Communication and decision-making about end-of-life care in the intensive care unit. *American Journal of Critical Care*, *26*(4), 336-341. doi:
<https://doi.org/10.4037/ajcc2017774>
- Buckley, T., Spinaze, M., Bartrop, R., McKinley, S., Whitfield, V., Havyatt, J., . . . Tofler, G. (2015). The nature of death, coping response and intensity of bereavement following death in the critical care environment. *Australian Critical Care*, *28*, 64-70.
doi:<http://dx.doi.org/10.1016/j.aucc.2015.02.003>
- Burdine, J., Thorne, S., & Sandhu, G. (2021). Interpretive description: a flexible qualitative methodology for medical education research. *Medical Education*, *55*, 336-343. doi:
<https://doi.org/10.1111/medu.14380>
- Calvin, A. O., Kite-Powell, D. M., & Hickey, J. V. (2007). The neuroscience ICU nurse's perceptions about end-of-life care. *Journal of Neuroscience Nursing*, *39*(3), 143-150. doi:
<https://doi.org/10.1097/01376517-200706000-00004>
- Carvajal, A., Haraldsdottir, E., Kroll, T., McCormack, B., Errasti-Ibarrondo, B., & Larkin, P. (2019). Barriers and facilitators perceived by registered nurses to providing person-centred care at end-of-life: a scoping review. *International Practice Development Journal*, *9*(2), 1-22. doi:
<https://10.19043/ipdj.92.008>
- Caswell, G., Pollock, K., Harwood, R., & Porock, D. (2015). Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study. *BMC Palliative Care*, *14*(35), 1-14. doi: <https://10.1186/s12904-015-0032-0>
- Chan, H., Lee, L., & Chan, C. (2012). The perceptions and experiences of nurses and bereaved families toward bereavement care in an oncology unit. *Supportive Care in Cancer*, *21*, 1551-1556. doi:
<https://doi.org/10.1007/s00520-012-1692-4>

- Chan, H., Lee, L., & Chan, C. (2013). The perceptions and experiences of nurses and bereaved families towards bereavement care in an oncology unit. *Supportive Care in Cancer*, 21(6), 1551-1556. doi: <https://10.1007/s00520-012-1692-4>
- Colley, S. (2016). Senior nursing students' perceptions of caring for patients at the end of life. *Journal of Nursing Education*, 55(5), 279-283. doi:<https://doi.org/10.2190/il.22.4.c>
- Coombs, M. (2015). A scoping review of family experience and need during end-of-life care in intensive care. *Nursing Open*, 24-34. doi: <https://10.1002/nop2.14>
- Coombs, M., Mitchell, M., James, S., & Wetzig, K. (2016). Intensive care bereavement practices across New Zealand and Australian intensive care units: a qualitative content analysis. *Journal of Clinical Nursing*, 26, 2944-2952. doi: <https://10.1111/jocn.13624>
- Cooper, J., Stock, R., & Wilson, J. (2019). Emergency department grief support: A multidisciplinary intervention to provide bereavement support after death in the emergency department. *The Journal of Emergency Medicine*, 58(1), 141-147
doi:<https://doi.org/10.1016/j.jemermed.2019.09.034>
- Corners, B. (2015). *Four things you learn by transcribing interviews*. Retrieved from <https://www.transcribe.com/transcribing-interviews>
- Creswell, J., & Clarke, V. (2017). *Designing & Conducting Mixed Methods Research* (3rd ed.). Thousand Oaks, United States: Sage Publications Inc.
- Cronin, J., Arnstein, P., & Flanagan, J. (2015). Family members perceptions of most helpful interventions during end-of-life care. *Journal of Hospice & Palliative Nursing*, 17(3). doi: <https://10.1097/NJH.0000000000000151>
- Croxon, L., Deravin, L., & Anderson, J. (2018). Dealing with end of life - new graduated nurse experiences. *Journal of Clinical Nursing*, 27, 337-344. doi: <https://10.1111/jocn.13907>
- Crump, S., Schaffer, M., & Schulte, E. (2010). Critical care nurses' perceptions of obstacles, supports, and knowledge needed in providing quality end-of-life care. *Dimensions of Critical Care Nursing*, 29(6), 297-306. doi: <https://10.1097/DCC.0b013e3181f0c43c>

- Damianakis, T., & Marziali, E. (2012). Older adults' response to the loss of a spouse: the function of spirituality in understanding the grieving process. *Aging & Mental Health, 16*(1), 57-66. doi: <https://doi.org/10.1080/13607863.2011.609531>
- Decker, K., Lee, S., & Morphet, J. (2015). The experiences of emergency nurses in providing end-of-life care to patients in the emergency department. *American Emergency Nursing Journal, 18*, 68-74. doi: <https://doi.org/10.1016/j.aenj.2014.11.001>
- Doka, K. (2011). Religion and spirituality: assessment and intervention. *Journal of Social Work in End-of-Life & Palliative Care, 7*(1), 99-109. doi: <https://doi.org/10.1080/15524256.2011.548049>
- Doka, K., & Martin, T. (2010). *Grieving beyond gender: understanding the ways men and women mourn*. New York: Routledge.
- Doka, K., & Martin, T. (2011). Grieving styles: gender and grief. *Grief Matters, 14*(2), 42-45. doi: <https://doi.org/10.1080/08952841.2011.589290>
- Doka, K., & Martin, T. (2021). *The influence of gender and socialisation on grieving styles* (1st ed.). New York: Routledge.
- Dong, F., Zheng, R., Chen, X., Wang, Y., Zhou, H., & Sun, R. (2016). Caring for dying cancer patients in the Chinese cultural context: a qualitative study from the perspectives of physicians and nurses. *European Journal of Oncology Nursing, 21*, 189-196. doi: <https://doi.org/10.1016/j.ejon.2015.10.003>
- Donnelly, S., & Dickson, M. (2012). Relatives' matched with staff's experience of the moment of death in a tertiary referral hospital. *Internal Medicine Journal, 106*(8), 731-736. doi: <https://doi.org/10.1093/qjmed/hct095>
- Donovan, L., Wakefield, C., Russell, V., & Cohn, R. (2015). Hospital-based bereavement services following the death of a child: a mixed study review. *Palliative Medicine, 29*(3), 193-210. doi: <https://doi.org/10.1177/0269216314556851>
- Dube, S. (2019). Therapeutic silence in spiritual care: lessons from Eli and Job's friends. *Asia-Africa Journal of Mission & Ministry, 19*, 42-46. doi: <https://doi.org/10.21806/aamm.2019.19.3>
- Dunne, K. (2004). Grief and its manifestations. *Nursing Standard, 18*(45), 45-51. doi: <https://doi.org/10.7748/ns2004.07.18.45.45.c3652>

- Efstathiou, N., & Clifford, C. (2011). The critical care nurse's role in end-of-life care: issues and challenges. *British Association of Critical Care Nurses*, 16(3), 116-122. doi: <https://10.1111/j.1478-55153.2010.00438.x>
- Efstathiou, N., & Walker, W. (2014). Intensive care nurses' experiences of providing end-of-life care after treatment withdrawal: a qualitative study. *Journal of Clinical Nursing*, 23, 3188-3196. doi: <https://10.1111/jocn.12565>
- Efstathiou, N., Walker, W., Metcalfe, A., & Vanderspank-Wright, B. (2018). The state of bereavement support in adult intensive care: a systematic review & narrative synthesis. *The Journal of Critical Care*, 50, 177-187. doi: <https://doi.org/10.1016/j.icrc.2018.11.026>
- Egerod, I., Kaldan, G., Albarraan, J., Coombs, M., Mitchell, M., & Latour, J. (2019). Elements of intensive care bereavement follow-up services: a European study. *British Association of Critical Care Nurses*, 24, 201-208. doi: <https://10.1111/nicc.12459>
- Egerod, I., Kaldan, G., Coombs, M., & Mitchell, M. (2018). Family-centred bereavement practices in Danish intensive care units: a cross-sectional national survey. *Intensive & Critical Care Nursing*, 45, 52-57. doi: <https://doi.org/10.1016/j.iccn.2017.10.003>
- Eisma, M., deLang, T., & Stroebe, M. (2021). Restoration-oriented stressors of bereavement. *Anxiety, Stress & Coping*, 1-15. doi: <https://10.1028/10615806.2021.1957849>
- Ek, K., Westin, L., Prah, C., Osterlind, J., Strang, S., Bergh, I., . . . Hammarlund, K. (2014). Death and caring for dying patients: exploring first-year nursing students' descriptive experiences. *International Journal of Palliative Nursing*, 20(10), 509-515. doi: <https://doi.org.ezproxy.lib.monash.edu.au/10.12968/ijpn.2014.20.10.509>
- Enoksen, E., & Lynch, P. (2018). Learning leadership: becoming an outdoor leader. *Journal of Adventure Education and Outdoor Learning*, 18(2), 176-188. doi: <https://10.1080/14729679.2017.1391105>
- Fauri, D. P., Ettner, B., & Kovacs, P. J. (2000). Bereavement services in acute care settings. *Death Studies*, 24(1), 51-64. doi: <https://10.1080/074811800200694>
- Frey, R., Robinson, J., Wong, C., & Gott, M. (2018). Burnout, compassion fatigue and psychological capital: findings from a survey of nurses delivering palliative care. *Applied Nursing Research*, 43, 1-9. doi: <https://10.1016/j.apnr.2018.06.003>

- Fridh, I., Forsberg, A., & Bergbom, I. (2009). Doing one's utmost: Nurses' descriptions of caring for dying patients in an intensive care environment. *Intensive & Critical Care Nursing*, 25, 233-241. doi: <https://10.1016/j.iccn.2009.06.007>
- Gamino, L., & Ritter, H. (2011). Death competence: an ethical imperative. *Death Studies*, 36(1), 23-40. doi: <https://10.1080/07481187.2011.553503>
- Gippsland Primary Health Network (2021). *Reports*. Retrieved from <https://gphn.org.au/wp-content/uploads/2021/10/DOC-21-7924-Gippsland-PHN-2021-Regional-Health-Workforce-Survey-Summary-Report.pdf>
- Gippsland Region Palliative Care Consortium (2017). *Who are the GRPCC?*. Retrieved from <http://www.grpcc.com.au/about-us/>
- Gippsland.com (2022). *Gippsland Regional Profile*. Retrieved from <http://gippsland.com/AboutUs/>
- Glover, T., Garvan, C., Nealis, R., Citty, S., & Derrico, D. (2017). Improving end-of-life care knowledge among senior baccalaureate nursing students. *American Academy of Hospice and Palliative Medicine*, 34(10), 938-945. doi: <https://10.1177/1049909117693214>
- Griffith, S. (2018). Prepared for end-of-life care: a concept analysis *International Journal of Palliative Nursing*, 24(8), 399-410. doi: <https://10.12968/ijpn.2018.24.8.399>
- Griffiths, I. (2019). What are the challenges for nurses when providing end-of-life care in intensive care units? *British Journal of Nursing*, 1047-1052(28), 16. doi: <https://103.039136.012>
- Guo, Q., & Zheng, R. (2019). Assessing oncology nurses' attitudes towards death and the prevalence of burnout: a cross sectional study *European Journal of Oncology Nursing*, 42, 69-75. doi: <https://10.1016/j.ejon.2019.08.002>
- Gwynn, M., & Laugesen, A. (Eds). (2020). *Oxford Dictionary* (5th ed.). Oxford University Press
- Hall, C. (2014). Bereavement theory: recent development in our understanding of grief & bereavement. *Bereavement Care*, 33(1), 7-12. doi:<https://doi.org/10.1080/02682621.2014.902610>
- Hall, C., Hudson, P., & Boughey, A. (2012). *Bereavement support standards for specialist palliative care services*. Melbourne: Department of Health, State Government of Victoria. Retrieved from [https://engonetcpc.blob.core.windows.net/assets/uploads/files/Assets/Bereavement%20support%20standards\(1\).pdf](https://engonetcpc.blob.core.windows.net/assets/uploads/files/Assets/Bereavement%20support%20standards(1).pdf)

- Hansen, L., Goodell, T. T., Dehaven, J., & Smith, M. (2009). Nurses' perceptions of end-of-life care after multiple interventions for improvement. *American Journal of Critical Care, 18*(3), 263-271. doi: <https://doi.org/10.4037/ajcc2009727>
- Harrad, R., Consentino, C., Keasley, R., & Sulla, F. (2019). Spiritual care in nursing: an overview of the measures used to assess spiritual care provisions and related factors amongst nurses. *ACTA Biomed for Health Professions, 90*(4), 44-55. doi: <https://10.23750/abm.v90i4-S.8300>
- Hendricks-Ferguson, V., Sawin, K., Montgomery, K., Phillips-Salimi, C., Carr, B., & Haase, J. (2014). Novice nurses' experiences with palliative end-of-life communication. *Journal of Paediatric Oncology Nursing, 1*(13), 1-13. doi: <https://10.1177/1043454214555196>
- Higgs, J., McAllister, L., & Sefton, A. (2012). *Communication in Health Sciences*. (3rd Edition ed.). Melbourne: Oxford University Press.
- Hinderer, A. (2012). Reactions to patient death: the lived experience of critical care nurses. *Dimensions of Critical Care Nursing, 31*, 252-259. doi: <https://10.1097/DCC.0b013e318256e0fl>
- Hogan, K., Bourbonnais, F., Brajtman, S., Phillips, S., & Wilson, K. (2016). When someone dies in the emergency department: perspectives of emergency nurses. *Journal Emergency Nursing, 42*(3), 2018-2212 doi: <https://doi.org/10.1016/j.jen.2015.09.003>
- Holdsworth, L. (2015). Bereaved carers' accounts of the end of life and the role of care providers in a 'good death': a qualitative study. *Palliative Medicine, 29*(9), 834-841. doi: <https://10.1177/0269216315584865>
- Hopkinson, J., Hallet, C., & Luker, K. (2003). Caring for dying people in hospital. *Journal of Advanced Nursing, 44*(5), 525-533. doi: <https://10.1046/j.0309-2402.2003.02836.x>
- Hudson, P., Collins, A., Boughey, M., & Philip, J. (2021). Reframing palliative care to improve the quality of life of people diagnosed with a serious illness. *Medical Journal of Australia, 215*(10), 443-446. doi: <https://10.5694/mja2.51307>
- Hulley, S., Cummings, S., Browner, W., Grady, D., & Newman, T. (2013). *Designing Clinical Research* (4th ed.). Philadelphia: Wolters Kluwer.

- Hussin, E., Wong, L., Chong, M., & Subramanian, P. (2018a). Factors associated with nurses' perceptions about quality of end-of-life care. *International Council of Nurses*, 65(2), 200-208. doi: <https://10.1111/inr.12428>
- Hussin, E., Wong, L., Chong, M., & Subramanian, P. (2018b). Nurses' perceptions of barriers and facilitators and their associations with the quality of end-of-life care. *Journal of Clinical Nursing*, 27, e688-e702. doi: <https://10.1111/jocn.14130>
- Latrobe Health Advocate. (2021). *Improving Palliative Care Services in Latrobe* (2019). Retrieved from <https://www.lhadvocate.vic.gov.au/improving-palliative-care-services-in-latrobe/>
- Iranmanesh, S., & Banazadeh, M. (2014). Nursing staff's perception of facilitators in providing end-of-life care to terminally ill pediatric patients in South East Iran. *Asian Journal of Nurse Education and Research*, 4(4), 394-402. doi: <https://doi.org/10.1177/1049909114556878>
- Ito, Y., Tsubaki, M., Fujimoto, M., & Sakaguchi, Y. (2020). Exploring the components of the quality of death in Japanese emergency departments: A qualitative study. *Applied Nursing Research*, 56, 1-7. doi:<https://10.1016/j.apnr.2020.151371>
- Jackson, K., Mooney, C., & Campbell, D. (2009). The development and implementation of the Pathway for Improving the Care of the Dying in general medical wards. *International Medicine Journal*, 39(10), 695-699. doi: <https://10.1111/j.1445-5994.2009.02002.x>
- Johansson, K., & Lindahl, B. (2010). Moving between rooms - moving between life and death: nurses experiences of caring for terminally ill patients in hospitals. *Journal of Clinical Nursing*, 21(13-14), 2034-2043. doi: <https://10.1111/j.1365-2702.2011.03952.x>.
- Josselson, R. (2013). *Interviewing for qualitative inquiry: a relational approach*. NewYork, USA: The Guilford Press.
- Kalocsai, C., Ordons, A., Sinuff, T., Koo, E., Smith, O., Cook, D., . . . Downar, J. (2020). Critical care providers' support of families in bereavement: a mixed methods study. *Canadian Anaesthesiologists Society*, 2020(67), 857-865. doi:<https://doi.org/10.1007/s12630-020-01645-0>
- Kiger, M., & Varpio, L. (2020). Thematic analysis of qualitative data: AMEE Guide No. 131. *Medical Teacher*, 42(8), 846-854. doi: <https://10.1080/0142159X.2020.1755030>

- King, P., & Thomas, S. (2013). Phenomenological study of ICU nurses experiences caring for dying patients. *Western Journal of Nursing Research*, 35(10), 1292-1308. doi: <https://10.1177/0193945913492571>
- Kisorio, L., & Langley, G. (2016). Intensive care nurses experience of end-of-life care. *Intensive & Critical Care Nursing*, 33, 30-38. doi:<https://doi.org/10.1016/j.iccn.2015.11.002>
- Klass, D. (2006). Continuing conversations about continuing bonds. *Death Studies*, 30(9), 843-858. doi: <https://10.1080/07481180600886959>
- Klass, D., Silverman, P., & Nickman, S. (1996). *Continuing Bonds: New Understandings of Grief* (1st ed.). New York: Taylor & Francis.
- Kobler, K. (2014). Leaning in and holding on: Team support with unexpected death. *Journal of Maternal/Child Nursing*, 39, 148-154. doi:<http://dx.doi:10.1097/NMC.0000000000000028>
- Kochen, E., Jenken, F., Boelen, P., Deben, L., Fahner, J., Hoogen, A., . . . Kars, M. (2020). When a child dies: a systematic review of well-defined parent focused bereavement interventions and their alignment with grief and loss theories. *BMC Palliative Care*, 19(28), 1-22. doi:<https://doi.org/10.1186/s12904-020-0529-z>
- Kongsuwan, W., Matchim, Y., Nilmanat, K., Locsin, R., Tanioka, T., & Yasuhara, Y. (2016). Lived experience of caring for dying patients in emergency room. *International Council of Nurses*, 63, 132-138. doi: <https://10.1111/inr.12234>
- Kostopoulou, S., Tsilika, E., Katsaragakis, S., Papazoglou, I., Zygianni, A., Glanos, A., & Mystakidiou, K. (2018). Advanced cancer patient's perceptions of dignity: the impact of psychologically depressive symptoms and preparatory grief. *Journal of Palliative Care*, 33(2), 88-94. doi: <https://10.1177/10825859718759882>
- Kovacs, M., Kovacs, E., & Hegedus, K. (2010). Is emotional dissonance more prevalent in oncology care? Emotion work, burnout and coping. *Psychooncology*, 19(8), 855-862. doi: <https://psycnet.apa.org/doi/10.1002/pon.1631>
- Kubler-Ross, E. (2014). *On Death & Dying*. New York: Scribner.

Kurian, M. J., Daniel, S., James, A., James, C., Joseph, L., Malecha, A. T., . . . Mick, J. M. (2014). Intensive care registered nurses' role in bereavement support. *Journal of Hospice & Palliative Nursing*, 16(1), 31-39. doi: <https://10.1097/njh.000000000000018>

Latrobe Regional Hospital Annual Report. (2020). *Latrobe Regional Hospital Annual Report*. Retrieved from https://www.parliament.vic.gov.au/file_uploads/Latrobe_Regional_Hospital_Annual_Report_2019-2020_g5v6zYmB.PDF

LeBrocq, P., Charles, A., Chan, T., & Buchanan, M. (2003). Establishing a bereavement program: caring for bereaved families and staff in the emergency department. *Accident and Emergency Nursing*, 11(2), 85-90. doi: [https://10.1016/s09652302\(02\)00210-2](https://10.1016/s09652302(02)00210-2)

Lee, J. (2021). 5 things I learned about leadership by trekking in Malaysian Borneo. *Travel Intelligence*. Retrieved from <https://www.vergemagazine.com/volunteer-abroad/articles/2104-5-things-i-learned-about-leadership-by-trekking-in-malaysian-borneo.html>

Liaschenko, J., O'Conner-Von, S., & Peden-McAlpine, C. (2009). The "Big Picture" communicating with families about end-of-life. *Dimensions of Critical Care Nursing*, 28(5), 224-230. doi: <https://10.1097/DCC.ob013e3181ac4c95>

Lippe, M., Volker, D., Jones, T., & Carter, P. (2017). Evaluating end-of-life care education within nursing programs. *Journal of Hospice & Palliative Nursing*, 19(3), 266-274. doi: <https://10.1097/NJH.0000000000000341>

Liu, Y., & Chiang, H. (2017). From vulnerability to passion in the end-of-life care: The lived experience of nurses. *European Journal of Oncology Nursing*, 31, 30-36. doi:<https://doi.org/10.1016/j.ejon.2017.09.002>

Lovgren, M., Sveen, J., Steineck, G., Wallin, A., Eilertsen, M., & Kreicbergs, U. (2017). Spirituality and religious coping are related to cancer-bereaved siblings' long-term grief. *Palliative & Supportive Care*, 17, 138-142. doi: <https://10.1017/S1478951517001146>

- Mak, Y., Chiang, V., & Chui, W. (2013). Experiences and perceptions of nurses caring for dying patients and families in the acute medical admission setting. *International Journal of Palliative Nursing*, 19(9). doi: <https://10.12968/ijpn.2013.19.9.423>
- Marck, C., Weil, J., Weiland, T., Philip, J., Boughey, M., & Jelinek, G. (2014). Care of the dying cancer patient in the emergency department: findings from a national survey of Australian emergency department clinicians. *Internal Medicine Journal*, 44(4), 362-368. doi: <https://10.1111/imj/imj.12379>
- Martin, T., & Doka, K. (2000). *Men don't cry, women do: transcending gender stereotypes of grief*. New York: Brunner/Mazel.
- Maxwell, J. (2016). *Qualitative research design: an interactive approach*. (3rd ed.). Thousand Oaks, United States: Sage Publications Inc.
- McAdam, J., & Erikson, A. (2016). Bereavement services offered in adult intensive care units in the United States. *American Journal of Critical Care*, 25(2), 110-117. doi:<http://dx.doi.org/10.4037/ajcc2016981>
- McCabe, C., & Timmins, F. (2013). *Communication skills for nursing practice* (2nd ed.). Great Britain: Palgrave Macmillan.
- McCallum, K., Jackson, D., Walthall, H., & Aveyard, H. (2018). Exploring the quality of the dying and death experience in the Emergency Department: An integrative literature review. *International Journal of Nursing Studies*, 85, 106-117. doi:<https://doi.org/10.1016/j.ijnurstu.2018.05.011>
- McConnell-Henry, T., Chapman, Y., & Francis, K. (2011). Rural nursing: Looking after people we know. *Australian Nursing Journal*, 17(8), 42.
- McCourt, R., Power, J., & Glackin, M. (2020). General nurses' experiences of end-of-life care in acute hospital setting: a literature review. *International Journal of Palliative Nursing*, 19(10), 510-516. doi: <https://doi.org/10.12968/ijpn.2013.19.10.510>
- McGrail, M., Humphreys, J., Joyce, C., Scott, A., & Kalb, G. (2011). Rural amenity and medical workforce shortage: Is there a relationship? *Geographical Research*, 49(2), 192-202. doi: <https://10.1111/j.1745-5871.2011.00690.x>

- Meichsner, F., O'Connor, M., Skritskaya, N., & Shear, K. (2020). Grief before and after bereavement in the elderly: an approach to care. *American Association of Geriatric Psychiatry*, 28(5), 560-569. doi: <https://10.1016/j.jagp.2019.12.010>
- Miller-Lewis, R., Lewis, W., Tieman, J., Rawlings, D., & Sanderson, R. (2021). Words describing feelings about death: A comparison of sentiment for self and others and changes over time. *PLoS ONE*, 16(1). doi: <https://10.1371/journal.pone.0242848>
- Minton, M., Isaacson, M., Varilek, B., Stadick, J., & O'Connell-Persaud, S. (2017). A willingness to go there: nurses and spiritual care. *Journal of Clinical Nursing*, 27, 173-181. doi: <https://doi.org/10.1111/jocn.13867>
- Naef, R., Peng-Keller, S., Rettke, H., Rufer, M., & Petry, H. (2020). Hospital-based bereavement care provision: a cross sectional survey with health professionals. *Palliative Medicine*, 34(4), 547-552. doi: <https://10.1177/02692163198910070>
- National Palliative Care Standards. (2018). *National Palliative Care Standards*. Palliative Care Australia. Retrieved from https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/11/PalliativeCare-National-Standards-2018_Nov-web.pdf
- National Statement on Ethical Conduct in Human Research (2007) - Updated 2018. (2018). *National Health and Medical Research Council of Australia*. Retrieved from <https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018>
- Nedjat-Haiem, F., Carrion, I., Gonzalez, K., Ell, K., Thompson, B., & Mishra, S. (2017). Exploring health care providers' views about initiating end-of-life care communication. *American Journal of Hospice and Palliative Medicine*, 34(4), 308-317. doi: <https://10.1177/1049909115627773>
- Neimeyer, R. (2012). *Techniques of grief therapy: assessment and intervention*. New York: Taylor & Francis.
- Neimeyer, R. (2013). *Techniques of grief therapies: creative practices for counselling*. New York: Taylor and Francis Group
- Neimeyer, R., & Burke, L. (2012). *Complicated grief and the end-of-life: risk factors and treatment considerations*. New York: Springer

- Neimeyer, R., Harris, D., Winokeur, H., & Thorton, G. (2012). Grief and bereavement in contemporary society : bridging research and practice. *Social Work in Health Care*, 51(5), 479-482. doi: <https://10.1080/00981389.2012.656045>
- Neimeyer, R., Herrero, O., & Botella, L. (2006). Chaos to coherence: psychotheapeutic intergration of traumatic loss. *Journal of Constructivist Psychology*, 19(2), 127-145. doi: <https://10.1080/10720530500508738>
- Neimeyer, R., Prigerson, H., & Davies, B. (2002). Mourning and meaning. *American Behavioral Scientist*, 46 (2), 235-251. doi: <https://doi.org/10.1177%2F000276402236676>
- Nelson-Becker, H. (2013). Spirituality in end-of-life and palliative care: what matters? *Journal of social work in end-of-life & palliative care*, 9(2-3), 112-116. doi: <https://10.1080/15524256.2013.794000>
- Noome, M., Dijkstra, B., Leeuwen, E., & Vloet, L. (2016). Exploring family experiences of nursing aspects of end-of-life care in the ICU: a qualitative study. *Intensive & Critical Care Nursing*, 33, 56-64. doi:<https://doi.org/10.1016/j.iccn.2015.12.004>
- Noonan, K., Horsfall, D., Leonard, R., & Rosenerg, J. (2016). Developing death literacy. *Progress in Palliative Care*, 24(1), 31-35. doi: <https://10.1080/09699260.20151103498>
- Nurse, S., & Price, J. (2017). 'No second chance' - Junior neonatal nurses experiences of caring for an infant at th end-of-life and their family. *Journal of Neonatal Nursing*, 23, 50-57. doi:<http://dx.doi.org/10.1016/j.jnn.2016.04.008>
- NVivo 11 Plus. (2020). Retrieved from https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home?_ga=2.251953292.444155466.1630386037-1877173498.1630386037
- O'Toole, G. (2016). *Communication: core interpersonal skills for health professionals* (3rd ed.). Chatswood, NSW: Elsevier Australia.
- Oginska-Bulik, N., & Michalska, P. (2020). Psychological resilience and secondary traumatic stress in nurses working with terminally ill patients - the mediating role of job burnout. *Psychological Services*. 18(3), 398-405. doi: <https://10.1037/ser0000421>

- Overton, B., & Cottone, R. (2016). Anticipatory grief: a family systems approach. *The Family Journal: Counselling and Therapy for Couples and Families*, 24(4), 430-432. doi:
<https://10.1177/1066480716663490>
- Australian Government Department of Health. (2018). *What is palliative care?* Retrieved from
<https://www.health.gov.au/health-topics/palliative-care/about-palliative-care/what-is-palliative-care>
- Palliative Care Social Work Australia. (2020). Retrieved from <https://pcswa.org.au/standards/>
- Phillips, C., & Volker, D. (2020). Riding the roller coaster. *Cancer Nursing*, 43(5). doi:
<https://10.1097/NCC.0000000000000734>
- Polit, D., & Beck, C. (2014). *Essentials of nursing research: appraising evidence for nursing practice*. Philadelphia, PA: Wolters Kluwer - Lippincott Williams & Wilkins.
- Polit, D., & Beck, C. (2017). *Nursing research: generating and assessing evidence for nursing practice*. (10th ed.). Philadelphia: Wolters Kluwer Health.
- Pringle, J., Bridget, J., & Buchanan, D. (2016). Dignity and patient-centred care for people with palliative care needs in acute hospital setting: A systematic review. *Palliative Medicine*, 29(8), 675-694. doi: <https://doi.org/10.1177%2F0269216315575681>
- Rando, T., Doka, K., Fleming, S., Franco, M., Lobb, E., Parkes, C., & Steele, R. (2012). A call to the field: complicated grief in the DSM-5. *OMEGA*, 65(4), 251-255. doi:
<https://doi.org/10.2190%2FOM.65.4.a>
- Raymond, A., Lee, S., & Bloomer, M. (2017). Understanding the bereavement care roles of nurses within acute care: a systematic review. *Journal of Clinical Nursing*, 26(13-14), 1787-1800. doi:
<https://10.1111/jocn.13503>
- Reyniers, T., Houttekier, D., Cohen, J., Pasman, H., & Deliens, L. (2014). The acute hospital setting as a place of death and final care: A qualitative study on perspectives of family physicians, nurses and family carers. *Health & Place*, 5(27), 77-83. doi:
<https://doi.org/10.1016/j.healthplace.2014.02.002>

- Riegel, M., Randall, S., & Buckley, T. (2021). Healthcare professionals' knowledge, skills, and role in offering and facilitating memory making during end-of-life care in the adult intensive care unit. *Australian Critical Care*, *36*(21), 00129-6. doi: <https://10.1016/j.aucc.2021.08.003>
- Rogalla, K. (2020). Anticipatory grief, proactive coping, social support and growth: exploring positive experiences of preparing for loss. *Journal of Death and Dying*, *81*(1), 107-129. doi: <https://10.1177/00302222818761461>
- Rozalski, V., Holland, J., & Neimeyer, R. (2017). Circumstances of death and complicated grief: indirect associations through meaning made of loss. *Journal of Loss and Trauma*, *22*(1), 11-23. doi: <https://10.1080/15325024.2016.1161426>
- Shannon, S., Long-Suthehall, T., & Coombs, M. (2011). Conversations in end-of-life care: communication tools for critical care practitioners. *Nursing in Critical Care*, *16*(3), 124-130. doi: <http://dx.doi.org/10.1111/j.1478-5153.2011.00456.x>
- Shariff, A., Olson, J., Salas, A., & Cranley, L. (2017). Nurses' experiences of providing care to bereaved families who experience unexpected death in intensive care units: a narrative overview. *The Canadian Journal of Critical Care Nursing*, *28*(1), 21-33.
- Shear, K. (2015). Complicated Grief. *The New England Journal of Medicine*, *372*(2), 153-160. doi: <https://10.1056/NEJMcp1315618>
- Shorter, M., & Stayt, C. (2010). Critical care nurses' experiences of grief in an adult intensive care unit. *Journal of Advanced Nursing*, *66*, 159-167. doi: <http://dx.doi:10.1111/j.1365-2648.2009.05191.x>
- Silloway, C., Glover, T., Coleman, B., & Kittleson, S. (2018). Filling the void: Hospital palliative care and community hospice: A collaborative approach to providing hospital bereavement support. *Journal of Social Work in End-of-Life & Palliative Care*, *14*(2-3), 153-161. doi: <https://10.1080/15524256.2018.1493627>
- Simon, N. (2013). Treating complicated grief. *Journal of American Medical Association*, *310*(4), 416-423. doi: <https://10.1001/jama.2013.8614>
- Sleeman, K., & Collis, E. (2013). Caring for the dying patient in hospital. *BMJ*, *346*, 1-9. doi: <https://10.1136/bmj.f2174>
- Stayt, L. (2010). Nurses experience bereavement too. *Nursing Standard*, *24*(50), 62-63.

- Stilos, K., Ford, B., & Chakraborty, A. (2020). Quality improvement of the end of life care experience through bereavement calls made by spiritual care. *Journal of Health Care Chaplaincy*, 26(3),1-8. doi: <https://10.1080/08854726.2020.1722260>
- Streubert, H., & Carpenter, D. (2011). *Qualitative research in nursing: advancing the humanistic imperative*. Philadelphia: Wolters Kluwer Health & Lippincott Williams & Wilkins.
- Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: rationale and description. *Death Studies*, 23(3), 197-224. doi: <https://psycnet.apa.org/doi/10.1080/074811899201046>
- Stroebe, M., Schut, H., & Boerner, K. (2010). Continuing bonds in adaptation to bereavement: toward theoretical integration. *Clinical Psychology Review*, 30, 259-268. doi: <https://10.1016/j.cpr.2009.11.007>
- Sullivan, S., Silva, C., & Meeker, M. (2015). Family meetings at end of life: a systematic review. *Journal of Hospice & Palliative Nursing*, 17(3), 196-204. doi: <https://doi.org/10.1097/NJH.0000000000000147>
- Tasmania Expeditions. (2021). *How to pack a trekking bag*. Retrieved from <https://www.tasmanianexpeditions.com.au/Blog/pack-trekking-bag>
- Thacker, K. (2008). Nurses' advocacy behaviours in end-of-life nursing care. *Nursing Ethics*, 15(2). doi: <https://10.1177/0969733007086015>
- Thompson, G., McClement, S., & Daeninck, P. (2006). Nurses' perceptions of quality end-of-life care on an acute medical ward. *Journal of Advanced Nursing*, 53(2), 169-177. doi: <https://doi.org/10.1111/j.1365-2648.2006.03712.x>
- Thorne, S. (2008). *Interpretive description*. Walnut Creek, CA: Left Coast Press Inc.
- Thorne, S. (2013). *Routledge international handbook of qualitative nursing research* (1st ed.). London: Routledge.
- Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice* (2nd ed.). New York: Taylor & Francis Group.
- Thorne, S., Stephens, J., & Truant, T. (2016). Building qualitative study design using nursing's disciplinary epistemology. *Journal of Advanced Nursing*, 72(2), 451-460. doi: <https://10.1111/jan.12822>

- Tracy, S. (2013). *Qualitative research methods*. Sussex, UK: Wiley-Blackwell.
- Vaismoradi, M., & Turunen, H. (2013). Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. *Nursing and Health Sciences, 15*, 398-405. doi: <https://doi.org/10.1111/nhs.12048>
- Vergo, M., Whyman, J., Li, Z., Kestel, J., James, S., Rector, C., & Salsman, J. (2017). Assessing preparatory grief in advanced cancer patients as a predictor of distress in American population. *Journal of Palliative Medicine, 20*(1), 48-52. doi: <https://10.1089/jpm.2016.0136>
- Wakanako, O. (2016). Development of grief care education program for visiting nurses in Japan. *Journal of Hospice and Palliative Nursing, 18*(3), 233-241. doi: <https://10.1097/NJH.000000000000023>
- Walker, W., & Deacon, K. (2016). Nurses' experience of caring for the suddenly bereaved in adult acute and critical care settings, and provisions of person-centred care: A qualitative study. *Intensive & Critical Care Nursing, 33*, 39-47. doi:<https://doi-org.ezproxy.lib.monash.edu.au/10.1016/j.iccn.2015.12.005>
- Weinhold, I., & Gurtner, S. (2018). Rural - urban differences in determinants of patient satisfaction with primary care. *Social Science & Medicine, 212*, 76-85. doi: <https://10.1016/j.socscimed.2018.06.019>
- Wenzel, J., Shaha, M., Klimmek, R., & Krumm, S. (2011). Working through grief and loss: Oncology nurses' perspectives on professional bereavement. *Oncology Nursing Forum, 38*(4), E272-E282.
- West Gippsland Healthcare Group. (2020). *West Gippsland Healthcare Group*. Retrieved from <https://wghg.com.au/wp-content/uploads/2021/01/WGHG-Annual-Report-2019-20.pdf>
- Whittaker, B., Gillum, D., & Kelly, J. (2018). Burnout, moral distress and job turnover in critical care nurses. *International Journal of Studies in Nursing, 3*(3), 108-121. doi: <https://10.20849/ijsn.v3i3.516>
- Williams, R., Harris, S., Randall, L., Nichols, R., & Brown, S. (2003). A bereavement after-care service for intensive care relatives and staff: the story so far. *Nursing in Critical Care, 8*(3), 109-115. doi: <http://dx.doi.org/10.1046/j.1478-5153.2003.00017.x>

- Wilson, D., Dhanji, N., Playfair, R., Nayak, S., Pupilampu, G., & Macleod, R. (2017). A scoping review of bereavement service outcomes *Palliative & Supportive Care*, *15*, 242-259. doi: <http://dx.doi.org/10.1017/S147895151600047X>
- Wolf, L., Delao, A., Perhats, C., Clark, P., Moon, M., Baker, K., . . . Plaines, D. (2015). Exploring the management of death: emergency nurses' perceptions of challenges and facilitators in the provision of end-of-life care in the emergency department. *Journal Emergency Nursing*, *41*, 23-33. doi: <https://doi.org/10.1016/j.jen.2015.05.018>
- Worden, W. (2009). *Grief counselling and grief therapy: a handbook for the mental health practitioner*. New York: Springer Publishing Company.
- Worden, W. (2018). *Grief counseling and grief therapy: a handbook for the mental health practitioner*. New York: Springer Publishing Company.
- World Health Organization. (2015). *Health systems and services: the role of acute care*. Retrieved from <http://www.who.int/bulletin/volumes/91/5/12-112664/en/>
- Yoshiyasa, I., Michihiro, T., Fujimoto, M., & Sakaguchi, Y. (2020). Exploring the components of the quality of death in Japanese emergency departments: A qualitative study. *Applied Nursing Research*, *56*, 1-7. doi:<https://doi.org/10.1016/j.apnr.2020.151371>
- Zheng, R., Lee, S., & Bloomer, M. (2018). How nurses cope with patient death: A systematic review and qualitative meta-synthesis. *Journal of Clinical Nursing*, *27*, 39-49. doi: <https://10.1111/jocn.13975>

Appendices

Appendix 1- ACGB Conference

Australian Centre for Grief and Bereavement Conference 2014

Name: Anita Raymond

Organisation: Monash University

Abstract Title: Daughter, Nurse, Academic: Personal & Professional Imperatives for Improving Bereavement in Gippsland.

Full Abstract:

(i) Introduction. During my personal and professional life, I have experienced grief and bereavement from the perspective of a daughter and that of a Registered Nurse within the Gippsland region. I have a sense that the bereavement experience could be managed better. I would like to extend on this experience as an Academic and as early career researcher in the area of bereavement management in Gippsland. **(ii) Objectives.** To trace multiple perspectives of grief and bereavement in Gippsland. **(iii) Approach.** I will reflect on both my personal and professional experiences of bereavement and provide a background to pursuing a mixed method research approach for continued research as a PhD project. **(iv) Practice Implications:** Individual experiences of grief and bereavement in Gippsland can be used to develop strategies or practice implications to assist others in similar circumstances. Literature, services, and support networks will be shared to develop a background for topic enquiry.

(v) Conclusions: Given the complexity of grief and bereavement and the impact that living in a rural area can pose, there is great value in exploring needs and resources through the lens of lived experiences.

Time	Parkside 4	Parkside 5	Parkside 2	Parkside 3	Parkside 1	Dame Nellie Melba	Lord Melbourne	
8.00 am–8.00 pm	Registration and Exhibition							
9.00–10.30 am	<p>Keynote Speaker 3</p> <p>Dr Phyllis Koza-minsky How new insights about the brain are helping us understand attachment and loss</p>							
10.30–11.00 am	Morning Tea							
11.00–12.30 pm	<p>Symposium B</p> <p><i>Bridging the gap between practice and research – Responding to the needs of families following the death of a child in Australia</i> DONOVAN, L., RUSSELL, V., & GUNDRY, A.</p>	<p>Individual Papers D</p> <p><i>It's so much more real now": A study of the experiences, issues and needs of the long-term suicide bereaved</i> RYAN, M., FLYNN, L., & WARREN, S.</p> <p><i>Suicide grief: personal stories of suicide loss</i> SCARR, H.</p> <p><i>An evaluation of the Thank you for listening project (a writing/video project for those bereaved by suicide)</i> RYAN, M., LISTER, R., & FLYNN, L.</p> <p><i>"It's different for men"</i> CHARLES, C., & MCDONALD, G.</p>	<p>Individual Papers E</p> <p><i>Saying goodbye: An audit of bereavement services</i> DUFFIELD, J., FLEMING, S., & KOTBY, J.</p> <p><i>Preparing practitioners for grief and bereavement in the Multifaith Academy way</i> SMITH, G. & WILLIAMS, H.</p> <p><i>Daughter, nurse, academic: Personal and professional imperatives for improving bereavement in Gippsland</i> RAYMOND, A.</p> <p><i>Music and mourning: The psychological functions of music in coping with bereavement</i> GARRIDO, S., & DAVIDSON, J.</p>	<p>Individual Papers F</p> <p><i>The concept of finding balance in bereavement: Applying theory and research to practice</i> HOLTSLANDER, L., & BALLY, J.</p> <p><i>From knowledge to "know-how": Supporting responsiveness and resilience in bereavement practice</i> CLARK, R.</p> <p><i>On the front line with Words: A practitioner's observations</i> PENWICK, S.</p> <p><i>Transitions in grief – Meeting in the liminal space</i> COX, M.</p>	<p>How-To Session B</p> <p><i>The relationship between addiction and grief processes: Using bereavement and addiction models to assist bereaved persons in understanding the relationship between their grief processes and addiction experiences</i> FIELD, J.</p> <p><i>Lessons from bipolar disorder: How to understand grief in psychiatry and clinical psychology</i> BURKE, L. M., WILLIAMS, L., BERK, M., & PASCO, J.</p> <p><i>Meaning through art for bereaved children: A group art therapy approach</i> ONG, S.</p> <p><i>How to use autobiographical to process the experiences of loss, trauma and grief</i> ROBERTS, J.</p>	<p>Practice Forum B</p> <p><i>The impact grief has on parents' relationships after the death of their child</i> DEN HARTOG, P.</p>		
12.30–1.30 pm	Lunch							
1.30–3.00 pm	<p>Keynote Speaker 4</p> <p>Dr M. Katherine Shear Using research in treatment: Developing, testing and using Complicated Grief Treatment</p>							
3.00–3.30 pm	Afternoon Tea							



Participant Information Sheet/Consent Form

Non-Interventional Study - Adult providing own consent

Hospital Nurses

Title	Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.
Principal Investigator	Dr Susan Lee (Monash University)
Associate Investigator(s)	Anita Raymond (Monash University) Dr Melissa Bloomer (Deakin University)
Location	Latrobe Regional Hospital West Gippsland Healthcare Group

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project titled 'Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.

You have been invited to participate in this research project as you are a registered nurse working within an acute non-metropolitan hospital who has had experience in providing end-of-life care to patients and their families. Your experience of end-of-life care is highly valued in this research as it is during this period, that nurses are also providing early bereavement care to families.

This Participant Information Sheet and Consent Form tells you about the research project. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read

- Consent to take part in the research project.
- Consent to the use of the personal information as provided by you.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

Bereavement is defined as the entire experience including the anticipation, death, and subsequent adjustment following the death of a loved one. Nurses' providing end-of-life care for patients in hospitals, are also providing early bereavement care to families encountering grief and bereavement. The quality of bereavement care provided to families within hospitals can have a significant influence on grief and the subsequent bereavement process.

Acute care refers to treatment within a hospital setting, where a patient receives active but short-term treatment for acute injury or episodes of illness with intent to restore health. Death within acute care can therefore be an unexpected event with the resultant grief and bereavement for families of dying patients more pronounced. Limited research currently exists in Australia and specifically in non-metropolitan hospitals, surrounding nursing bereavement care for families.

The aim of this study is to better understand the roles of registered nurses in the provision of bereavement support during end-of-life care in acute non-metropolitan hospitals. This research will help identify what bereavement care measures are put into place for grieving families. The findings of this research will also help better inform clinical practice, generate role awareness of nursing bereavement care and positively impact on the grief and bereavement experienced by families, following the death of a loved one within a hospital.

The results of this research will be used by the researcher Anita Raymond to obtain a Doctor of Philosophy qualification through Monash University and publish in peer reviewed journals. This research is not being funded.

3 What does participation in this research involve?

Participation in this research involves taking part in a semi-structured interview with the researcher. The researcher would like to discuss your experience of nursing dying patients in hospitals and will seek to clarify exactly what the nursing roles and responsibilities are during end-of-life care, particularly relating to families and bereavement care. The interview will take approximately 1 hour and the session will be audio-recorded. Although it is anticipated that only one interview is necessary, if the researcher requires further clarification of any issues discussed you may be contacted at a later date and invited to participate in a second interview. The interview will be conducted at a time and a location agreed on by you and the researcher.

4 What do I have to do?

Read this Participant Information and Consent form in its entirety. If you are interested, please make contact with the researcher – Anita Raymond and a mutually convenient date and time for an interview will be determined.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Your decision whether to take part or not, or to take part and to withdraw will not affect your relationship with your employer.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will personally receive any benefits from this research. Participation in this study does however give you the opportunity to share your experiences and contribute to the outcomes of this study, with the goal of improving bereavement care in non-metropolitan acute hospital settings.

7 What are the possible risks and disadvantages of taking part?

No risks to health are anticipated for participants who agree to take part in this project. However, given the topic of this study, there is a chance that you could become emotional or distressed during the interview. If you do feel distressed or become upset, the interview will be paused or terminated as determined by you. You can also choose not to answer any question you feel uncomfortable discussing. It should also be advised that if you become upset or distressed the researcher may call on the support of the Employee Assistance Program (EAP) for further counselling.

8 What if I withdraw from this research project?

You can withdraw at any time by notifying the researcher, who will provide you with a withdrawal of participation form to sign.

9 What happens when the research project ends?

On completion of this research project all data will be analysed to generate finding themes. It is anticipated that following data analysis, end-of-life care and specifically bereavement care will be well defined from a nursing perspective and in the context of a non-metropolitan acute hospital setting. All data findings will be in de-identified form and summary findings and clinical recommendations will be communicated back to participating hospitals.

Other reports generated from the study will be used for journal publication, conference presentation and as chapters within a thesis to meet the requirements of PhD.

Part 2 How is the research project being conducted?

10 What will happen to information about me?

By signing the consent form you consent to the relevant research staff collecting and using your information for this research project.

No information obtained in connection with this research project will allow for your identification. Your identity will remain anonymous and any information you provide will be confidential.

Consent forms and all audio recordings will be stored securely in a locked filing cabinet within the locked office of the researcher, Anita Raymond and will be accessible only to the research team named in this application. The electronic database containing research findings will be saved on a password protected computer and will only be accessible to the research team.

At completion of the project all the data will be transferred to disks and stored in a locked filing cabinet in a locked office of the School of Nursing Midwifery at Monash University and will be accessible only to the research team named in this application. In accordance with research and ethics policy, all information will be destroyed after a period of seven years.

Your information will only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. You will remain entirely anonymous and de-identified when reference is made to any relevant data from this research investigation.

11 Who has reviewed the research project?

The ethical aspects of this research project have been approved by the Human Research Ethics committee of Latrobe Regional Hospital, West Gippsland Healthcare Group and Monash University. The project will be carried out according to the National Statement on Ethical Conduct in Human research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

12 Further information and who to contact

If you would like any further information about any aspect of this study, please contact:

Name	Dr Susan Lee
Position	Principal Investigator
Telephone	+61 3 9904 4204
Email	susan.lee@monash.edu

If you would like to participate in this study, please contact the researcher below:

Name	Anita Raymond
Position	Associate Investigator
Telephone	03 51 22 6977
Email	agmic1@student.monash.edu

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Reviewing HREC name	Catherine Wilks
HREC Executive Officer	HREC Secretariat – Latrobe Regional Hospital
Telephone	03 5173 8554
Email	cwilks@lrh.com.au

Reviewing HREC name	Elizabeth Fenwick
HREC Executive Officer	HREC Secretariat – West Gippsland Healthcare Group
Telephone	03 56 230609
Email	Elizabeth.fenwick@wghg.com.au



Consent Form - *Adult providing own consent*

Title Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.

Principal Investigator Dr Susan Lee (Monash University)

Associate Investigator(s) Anita Raymond (Monash University)
Dr Melissa Bloomer (Deakin University)

Location Latrobe Regional Hospital

Declaration by Participant

I have read the Participant Information Sheet.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print)	_____	
Telephone contact	_____	Email contact
Signature	_____	Date
	_____	_____



Form for Withdrawal of Participation - *Adult providing own consent*

Title Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.

Principal Investigator Dr Susan Lee (Monash University)

Associate Investigator(s) Anita Raymond (Monash University)
Dr Melissa Bloomer (Deakin University)

Location Latrobe Regional Hospital

Declaration by Participant

I wish to withdraw from participation in the above research project

Name of Participant (please print) _____
Signature _____ Date _____

Researcher will need to provide a description of the circumstances below.

--



Participant Information Sheet/Consent Form

Non-Interventional Study - *Adult providing own consent*

Gippsland Acute Care Symposium nurse participants

Title	Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.
Principal Investigator	Dr Susan Lee (Monash University)
Associate Investigator(s)	Anita Raymond (Monash University) Dr Melissa Bloomer (Deakin University)
Location	Gippsland Acute Care Symposium nurse participants

Part 1 What does my participation involve?

2 Introduction

You are invited to take part in this research project titled 'Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.

You have been invited to participate in this research project as you are a registered nurse working within an acute non-metropolitan hospital who has had experience in providing end-of-life care to patients and their families. Your experience of end-of-life care is highly valued in this research as it is during this period, that nurses are also providing early bereavement care to families.

This Participant Information Sheet and Consent Form tells you about the research project. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project.
- Consent to the use of the personal information as provided by you.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

Bereavement is defined as the entire experience including the anticipation, death, and subsequent adjustment following the death of a loved one. Nurses' providing end-of-life care for patients in hospitals, are also providing early bereavement care to families encountering grief and bereavement. The quality of bereavement care provided to families within hospitals can have a significant influence on grief and the subsequent bereavement process.

Acute care refers to treatment within a hospital setting, where a patient receives active but short-term treatment for acute injury or episodes of illness with intent to restore health. Death within acute care can therefore be an unexpected event with the resultant grief and bereavement for families of dying patients more pronounced. Limited research currently exists in Australia and specifically in non-metropolitan hospitals, surrounding nursing bereavement care for families.

The aim of this study is to better understand the roles of registered nurses in the provision of bereavement support during end-of-life care in acute non-metropolitan hospitals. This research will help identify what bereavement care measures are put into place for grieving families. The findings of this research will also help better inform clinical practice, generate role awareness of nursing bereavement care and positively impact on the grief and bereavement experienced by families, following the death of a loved one within a hospital.

The results of this research will be used by the researcher Anita Raymond to obtain a Doctor of Philosophy qualification through Monash University and publish in peer reviewed journals. This research is not being funded.

3 What does participation in this research involve?

Participation in this research involves taking part in a semi-structured interview with the researcher. The researcher would like to discuss your experience of nursing dying patients in hospitals and will seek to clarify exactly what the nursing roles and responsibilities are during end-of-life care, particularly relating to families and bereavement care. The interview will take approximately 1 hour and the session will be audio-recorded. Although it is anticipated that only one interview is necessary, if the researcher requires further clarification of any issues discussed you may be contacted at a later date and invited to participate in a second interview. The interview will be conducted at a time and a location agreed on by you and the researcher.

4 What do I have to do?

Read this Participant Information and Consent form in its entirety. If you are interested, please make contact with the researcher – Anita Raymond and a mutually convenient date and time for an interview will be determined.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Your decision whether to take part or not, or to take part and to withdraw will not affect your relationship with your employer.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will personally receive any benefits from this research. Participation in this study does however give you the opportunity to share your experiences and contribute to the outcomes of this study, with the goal of improving bereavement care in non-metropolitan acute hospital settings.

7 What are the possible risks and disadvantages of taking part?

No risks to health are anticipated for participants who agree to take part in this project. However, given the topic of this study, there is a chance that you could become emotional or distressed during the interview. If you do feel distressed or become upset, the interview will be paused or terminated as determined by you. You can also choose not to answer any question you feel uncomfortable discussing. It should also be advised that if you become upset or distressed the researcher may call on the support of the Employee Assistance Program (EAP) for further counselling.

8 What if I withdraw from this research project?

You can withdraw at any time by notifying the researcher, who will provide you with a withdrawal of participation form to sign.

9 What happens when the research project ends?

On completion of this research project all data will be analysed to generate finding themes. It is anticipated that following data analysis, end-of-life care and specifically bereavement care will be well defined from a nursing perspective and in the context of a non-metropolitan acute hospital setting. All data findings will be in de-identified form and summary findings and clinical recommendations will be communicated back to participating hospitals.

Other reports generated from the study will be used for journal publication, conference presentation and as chapters within a thesis to meet the requirements of PhD.

Part 2 How is the research project being conducted?

10 What will happen to information about me?

By signing the consent form you consent to the relevant research staff collecting and using your information for this research project.

No information obtained in connection with this research project will allow for your identification. Your identity will remain anonymous and any information you provide will be confidential.

Consent forms and all audio recordings will be stored securely in a locked filing cabinet within the locked office of the researcher, Anita Raymond and will be accessible only to the research team named in this application. The electronic database containing research findings will be saved on a password protected computer and will only be accessible to the research team.

At completion of the project all the data will be transferred to disks and stored in a locked filing cabinet in a locked office of the School of Nursing Midwifery at Monash University and will be accessible only to the research team named in this application. In accordance with research and ethics policy, all information will be destroyed after a period of seven years.

Your information will only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. You will remain entirely anonymous and de-identified when reference is made to any relevant data from this research investigation.

11 Who has reviewed the research project?

The ethical aspects of this research project have been approved by the Human Research Ethics committee of Latrobe Regional Hospital, West Gippsland Healthcare Group and Monash University. The project will be carried out according to the National Statement on Ethical Conduct in Human research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

12 Further information and who to contact

If you would like any further information about any aspect of this study, please contact:

Name	Dr Susan Lee
Position	Principal Investigator
Telephone	+61 3 9904 4204
Email	susan.lee@monash.edu

If you would like to participate in this study, please contact the researcher below:

Name	Anita Raymond
Position	Associate Investigator
Telephone	03 51 22 6977
Email	agmic1@student.monash.edu

For complaints relating to this research project please contact the Monash University - Human Ethics Office below:

Name	Dr Souheir Houssami
Position	Executive Officer - Advice and/or complaints about projects
Telephone	+61 3 990 52052
Email	souheir.houssami@monash.edu



Consent Form - *Adult providing own consent*

Title	Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.
Principal Investigator	Dr Susan Lee (Monash University)
Associate Investigator(s)	Anita Raymond (Monash University) Dr Melissa Bloomer (Deakin University)
Location	Gippsland Acute Care Symposium nurse participants

Declaration by Participant

I have read the Participant Information Sheet.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____	
Telephone contact _____	Email contact _____
Signature _____	Date _____



Form for Withdrawal of Participation - *Adult providing own consent*

Title Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.

Principal Investigator Dr Susan Lee (Monash University)

Associate Investigator(s) Anita Raymond (Monash University)
Dr Melissa Bloomer (Deakin University)

Location Gippsland Acute Care Symposium nurse participants

Declaration by Participant

I wish to withdraw from participation in the above research project

Name of Participant (please print) _____
Signature _____ Date _____

Researcher will need to provide a description of the circumstances below.



Participant Information Sheet/Consent Form

Non-Interventional Study - *Adult providing own consent*

Gippsland Health Alliance (GHA) participants

Title	Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.
Principal Investigator	Dr Susan Lee (Monash University)
Associate Investigator(s)	Anita Raymond (Monash University) Dr Melissa Bloomer (Deakin University)
Location	Gippsland Health Alliance (GHA) website.

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project titled 'Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.

You have been invited to participate in this research project as you are a registered nurse working within an acute non-metropolitan hospital who has had experience in providing end-of-life care to patients and their families. Your experience of end-of-life care is highly valued in this research as it is during this period, that nurses are also providing early bereavement care to families.

This Participant Information Sheet and Consent Form tells you about the research project. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project.
- Consent to the use of the personal information as provided by you.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

Bereavement is defined as the entire experience including the anticipation, death, and subsequent adjustment following the death of a loved one. Nurses' providing end-of-life care for patients in hospitals, are also providing early bereavement care to families encountering grief and bereavement. The quality of bereavement care provided to families within hospitals can have a significant influence on grief and the subsequent bereavement process.

Acute care refers to treatment within a hospital setting, where a patient receives active but short-term treatment for acute injury or episodes of illness with intent to restore health. Death within acute care can therefore be an unexpected event with the resultant grief and bereavement for families of dying patients more pronounced. Limited research currently exists in Australia and specifically in non-metropolitan hospitals, surrounding nursing bereavement care for families.

The aim of this study is to better understand the roles of registered nurses in the provision of bereavement support during end-of-life care in acute non-metropolitan hospitals. This research will help identify what bereavement care measures are put into place for grieving families. The findings of this research will also help better inform clinical practice, generate role awareness of nursing bereavement care and positively impact on the grief and bereavement experienced by families, following the death of a loved one within a hospital.

The results of this research will be used by the researcher Anita Raymond to obtain a Doctor of Philosophy qualification through Monash University and publish in peer reviewed journals. This research is not being funded.

6 What does participation in this research involve?

Participation in this research involves taking part in a semi-structured interview with the researcher. The researcher would like to discuss your experience of nursing dying patients in hospitals and will seek to clarify exactly what the nursing roles and responsibilities are during end-of-life care, particularly relating to families and bereavement care. The interview will take approximately 1 hour, and the session will be audio-recorded. Although it is anticipated that only one interview is necessary, if the researcher requires further clarification of any issues discussed you may be contacted at a later date and invited to participate in a second interview. The interview will be conducted at a time and a location agreed on by you and the researcher.

7 What do I have to do?

Read this Participant Information and Consent form in its entirety. If you are interested, please make contact with the researcher – Anita Raymond and a mutually convenient date and time for an interview will be determined.

8 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Your decision whether to take part or not, or to take part and to withdraw will not affect your relationship with your employer.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will personally receive any benefits from this research. Participation in this study does however give you the opportunity to share your experiences and contribute to the outcomes of this study, with the goal of improving bereavement care in non-metropolitan acute hospital settings.

7 What are the possible risks and disadvantages of taking part?

No risks to health are anticipated for participants who agree to take part in this project. However, given the topic of this study, there is a chance that you could become emotional or distressed during the interview. If you do feel distressed or become upset, the interview will be paused or terminated as determined by you. You can also choose not to answer any question you feel uncomfortable discussing. It should also be advised that if you become upset or distressed the researcher may call on the support of the Employee Assistance Program (EAP) for further counselling.

8 What if I withdraw from this research project?

You can withdraw at any time by notifying the researcher, who will provide you with a withdrawal of participation form to sign.

9 What happens when the research project ends?

On completion of this research project all data will be analysed to generate finding themes. It is anticipated that following data analysis, end-of-life care and specifically bereavement care will be well defined from a nursing perspective and in the context of a non-metropolitan acute hospital setting. All data findings will be in de-identified form and summary findings and clinical recommendations will be communicated back to participating hospitals.

Other reports generated from the study will be used for journal publication, conference presentation and as chapters within a thesis to meet the requirements of PhD.

Part 2 How is the research project being conducted?

10 What will happen to information about me?

By signing the consent form you consent to the relevant research staff collecting and using your information for this research project.

No information obtained in connection with this research project will allow for your identification. Your identity will remain anonymous and any information you provide will be confidential.

Consent forms and all audio recordings will be stored securely in a locked filing cabinet within the locked office of the researcher, Anita Raymond and will be accessible only to the research team named in this application. The electronic database containing research findings will be saved on a password protected computer and will only be accessible to the research team.

At completion of the project all the data will be transferred to disks and stored in a locked filing cabinet in a locked office of the School of Nursing Midwifery at Monash University and will be accessible only to the research team named in this application. In accordance with research and ethics policy, all information will be destroyed after a period of five years.

Your information will only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. You will remain entirely anonymous and de-identified when reference is made to any relevant data from this research investigation.

11 Who has reviewed the research project?

The ethical aspects of this research project have been approved by the Human Research Ethics committee of Latrobe Regional Hospital, West Gippsland Healthcare Group and Monash University. The project will be carried out according to the National Statement on Ethical Conduct in Human research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

12 Further information and who to contact

If you would like any further information about any aspect of this study, please contact:

Name	Dr Susan Lee
Position	Principal Investigator
Telephone	+61 3 9904 4204
Email	susan.lee@monash.edu

If you would like to participate in this study, please contact the researcher below:

Name	Anita Raymond
Position	Associate Investigator
Telephone	03 51 22 6977
Email	agmic1@student.monash.edu

For complaints relating to this research project please contact the Monash University - Human Ethics Office below:

Name	Dr Souheir Houssami
Position	Executive Officer - Advice and/or complaints about projects
Telephone	+61 3 990 52052
Email	souheir.houssami@monash.edu



Consent Form - *Adult providing own consent*

Title	Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.
Principal Investigator	Dr Susan Lee (Monash University)
Associate Investigator(s)	Anita Raymond (Monash University) Dr Melissa Bloomer (Deakin University)
Location	Gippsland Health Alliance (GHA) website.

Declaration by Participant

I have read the Participant Information Sheet.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print)	_____	
Telephone contact	_____	Email contact
_____	_____	_____
Signature	_____	Date
_____	_____	_____



Form for Withdrawal of Participation - *Adult providing own consent*

Title Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.

Principal Investigator Dr Susan Lee (Monash University)

Associate Investigator(s) Anita Raymond (Monash University)
Dr Melissa Bloomer (Deakin University)

Location Gippsland Health Alliance (GHA) website.

Declaration by Participant

I wish to withdraw from participation in the above research project

Name of Participant (please print) _____
Signature _____ Date _____

Researcher will need to provide a description of the circumstances below.



MONASH University

Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.

Nurses' providing end-of-life care for patients in hospitals, are also providing early bereavement care to families encountering grief and bereavement. This project seeks clarity on the roles nurses have in providing early bereavement care to families.

If you are ***registered nurse*** and have worked in an ***acute care*** hospital and have had experience, in ***caring for dying patients***. The researchers encourage you to please participate in this study.

Participation gives you the opportunity to share your nursing experience and essentially provide clarity on the bereavement care nurses provide to families during end-of-life care. It is anticipated that the outcomes of this project will have a positive impact on bereavement care for families in non-metropolitan acute hospitals.

If you would like further information about the project or participation.

Please contact the researcher below:

Anita Raymond

agmic1@student.monash.edu

Telephone: 03 51 226977





MONASH University

Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals.

Nurses' providing end-of-life care for patients in hospitals, are also providing early bereavement care to families encountering grief and bereavement.

This project seeks clarity on the roles nurses have in providing early bereavement care to families in acute ward settings.

Participation in this study gives you the opportunity to share your experience and contribute to the outcomes of this study, with the goal of improving bereavement care for families in non-metropolitan hospitals.

1. Are you...
A registered nurse?



2. Do you...
Work in a non-
metropolitan hospital?

3. Have you...
Cared for a dying patient?

Yes ???

Please consider participation in this research project and contact the researcher below for further information.

Anita Raymond

agmic1@student.monash.edu

Interview Schedule

Qualitative Data Collection

Introduction:

- My name is Anita Raymond
- I am a student at Monash University – Peninsula Campus undertaking a research project for the requirements of Doctor of Philosophy (PhD)
- This research project is being conducted under the supervision of Associate Professor Susan Lee and Dr Kaori Shiminoba at Monash University.
- Interview sessions are the method of data collection for this Qualitative Interpretive Descriptive research project.

Purpose:

The aim of this study is:

To investigate the roles of registered nurses, in the provision of bereavement supports within acute, non-metropolitan hospital settings.

The participants are registered nurses who work within non-metropolitan acute care hospitals and have provided end-of-life care to patients.

This research will help identify what bereavement care measures are put into place for patients and families during end-of-life care.

The findings of this research will also help better inform clinical practice, generate role awareness of nursing bereavement care, and positively impact on bereavement care for patients and families in non-metropolitan hospitals.

Tape recording, participation, and confidentiality:

The researcher will ask the individual participants for permission to record the interview. If participants do not permit recording, copious note taking during the interview and post the session will be instituted.

The participants will be informed of their rights to withdraw from the study at any time or the freedom to refuse to answer any question they deem unsuitable. Participants will be de-identified using their interviewee number during the transcribing of the verbatim.

The recording device will be tested together. The date time and interview number will be stated.

Interview Questions:

- 1) Can you tell me about your background and nursing career to date?
- 2) Can you please share with me an experience of caring for a dying patient?
- 3) Can you recall an example when you acted as a patient advocate for a patient that was dying?
- 4) When you are spending time with patient and families what do you do? What do you talk about?
- 5) If you had more time to spend with patients and families, what would you be doing?
- 6) Can you describe end-of-life care that was individualised to suit a patient or family's needs? How did you do this?
- 7) What expectations do you think the family has for you as the nurse caring for their significant other who is dying?
- 8) Could you please think about the roles you have had in the provision of bereavement care during end-of-life care for patients and families and describe them to me?

- 9) What would you consider to be the most important aspects of bereavement care during the care of a dying patient and their family? Why?

- 10) How would you describe your experience of providing bereavement care for patients and families?

- 11) Do you feel confident when you are caring for dying patients and their families? Please explain?

- 12) Could you provide examples and describe some of the main resources and supports that you have used to facilitate bereavement supports for patients and families? Have they helped the process?

- 13) Overall, when you reflect to the care you have provided for patients and families during the dying process how would you describe the standard of care you provided? Do you have any thoughts on how bereavement care could be improved at your hospital?

Appendix 5 – HREC Approval Certificate

Hospital 1



Human Research Ethics Committee Certificate of Approval

PO Box 434
Traralgon, Latrobe City
Victoria 3845 Australia
Telephone +613 5173 8000
Facsimile +613 5173 8444
Also trading as Gippsland Health
ABN 18 120 843 652

This is to certify that

Project No: 2015-25

Project Title: Nursing bereavement care in acute non-metropolitan hospitals

Principal Researchers: Susan Lee, Anita Raymond

has been given approval by the Human Research Ethics Committee from:

Approval date: 27 July 2016

Expiry date: 2 January 2018

It is the Principal Researcher's responsibility to ensure that all researchers associated with this project are aware of the conditions of approval. A copy of the approved ethics application and supporting documents must be kept on your files for audit purposes.

The Principal Researcher is required to notify the Human Research Ethics Committee in relation to the following.

- Any significant changes to the project and the reason for that change, including an indication of ethical implications (Amendment Form on LRH Research website)
- Adverse Event Reports regarding participants;
- Any other unforeseen events or unexpected developments that merit notification;
- The inability of the Principal Researcher to continue in that role, or any other change in research personnel involved in the project;
- Commencement date of the project (form on LRH Research website); and
- Termination or closure of the project.

Additionally, the Principal Researcher is required to submit

- A Progress Report every 12 months for the duration of the project (form are available on the LRH Research website);
- A Request for Extension of the project prior to the expiry date, if applicable; and,
- A detailed Final Report at the conclusion of the project (form are available on the LRH Research website).

The Human Research Ethics Committee may conduct an audit at any time.

All research subject to the Latrobe Regional Hospital Human Research Ethics Committee review must be conducted in accordance with the *National Statement on Ethical Conduct in Human Research (2007)*.

The Latrobe Regional Hospital Human Research Ethics Committee is constituted in accordance with the *National Statement on Ethical Conduct in Human Research (2007)*.

SPECIAL CONDITIONS

Nil

A. Cameron
Chief Executive

Please quote Project No and Title in all correspondence

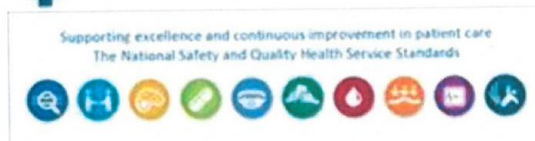
Anita Raymond

From: Diane More <Diane.More@wghg.com.au>
Sent: Friday, 24 June 2016 4:55 PM
To: Anita Raymond
Cc: Joanne Campbell (joannemc@dcsi.net.au); Alyson Mills
Subject: RE Nurses role in bereavement project proposal

Follow Up Flag: Follow up
Flag Status: Flagged

Hi Anita,
Your research proposal about nurses' role in bereavement support was tabled and accepted by the WGHG HREC last Tuesday 21st June 2016.
Please contact the Chief Executive Officer Assistant Alyson Mills (56230631), when you are at the stage of requiring office space to conduct interviews.
Kind regards,
Di More

Diane More | Performance Improvement Unit Manager | P: 03 562 30615 | E: diane.more@wghg.com.au
West Gippsland Healthcare Group | 41 Landsborough Street | Warragul Vic 3820 | www.wghg.com.au



Please consider the environment before printing this email

DISCLAIMER: If you are not the intended recipient, any disclosure, copying, or distribution of this message, or any action or omission taken by you in reliance on it, is prohibited and may be unlawful. Please immediately contact the sender if you have received this message in error. Thank you.



Monash University Human Research Ethics Committee Confirmation of Registration

Project Number: 0540

Project Title: Nursing bereavement care in acute non-metropolitan hospitals

Chief Investigator: Dr Susan Lee

Expiry Date: 10/08/2021

Terms:

1. Registration is valid whilst you hold a position at Monash University and approval at the primary HREC is current.
2. End of project: You should notify MUHREC at the conclusion of the project or if the project is discontinued before the expected date of completion.
3. Retention and storage of data: The Chief Investigator is responsible for the storage and retention of the original data pertaining to this project in accordance with the *Australian Code for the Responsible Conduct of Research*.

Thank you for your assistance. Professor Nip Thomson

Chair, MUHREC