

Registered Nurses' ***recognition of*** and  
***responsiveness to*** the dying patient in the  
acute hospital (non-palliative care) ward

Submitted by

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*Death is not the worst evil,  
but rather when we wish to die and cannot*

Sophocles (ca. 496 B.C. – 406 B.C.)

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## *LIST OF ABBREVIATIONS*

EOL	End of life
FATCOD	Frommelt's attitude toward care of the dying
FATCOD-DOC	Frommelt's attitude toward care of the dying – Doctor version
LCP	Liverpool Care Pathway
PICF	Participant Information and Consent Form
ED	Emergency Department
NIC	Nurse In Charge

# ***ABSTRACT***

## **Introduction**

Changes in society, an ageing population and improvements in healthcare have changed how and where people die, with more people dying in acute hospitals than ever before. Where palliative care clinicians are considered specialists on dying, non-palliative care clinicians, such as nurses working in acute care are now required to care for an increasing number of dying patients.

## **Aims**

The aims of this study were to explore registered nurses' *recognition of* and *responsiveness to* dying patients in acute hospital (non-palliative care) wards in Australian acute hospital settings, and to understand nurses' influence, if any, on the provision of end of life care.

## **Method**

The research aims were examined using a sequential exploratory mixed methods design, which included two phases of research - a large qualitative study and a smaller quantitative study. Phase One used non-participant observation to gather data on how registered nurses recognised when a patient was dying, and how they subsequently responded to the dying patient. Following the observation (20 episodes), focus groups (2) and individual interviews (2) were used to further explore and clarify the observation data. Phase Two utilised a survey to measure attitudes of registered nurses and final year (pre-service) medical students toward care of the dying patient.

## **Results**

Results were analysed and then considered in light of 'death anxiety' theory. Phase One findings indicated that nurses found recognising dying difficult and took a passive role in this

respect. Responding to the needs of a dying patient in the context of an acute hospital ward was difficult, impacted by ward culture and design, patient acuity and nurse workload, allocation practices, and the emotional and educational preparation of nurses. These findings suggest that death anxiety, while not measured directly, could be a significant contributor to nurse behaviour, and may have contributed to the perception that nurses had a negative attitude towards caring for a dying patient. Phase Two findings, however, indicated that nurses and final year (pre-service) medical students demonstrated highly positive attitudes towards care of the dying; nevertheless issues similar to those highlighted in Phase One were also identified in the survey analysis.

## **Conclusion**

The study suggests that recognising dying is difficult for nurses. When dying is recognised, nurses' passivity often results in a delay in their change of care focus from curative to end-of-life care. This study also suggests that many nurses are not adequately prepared to care for and support the dying patient. There is also a noticeable lack of emotional and educational support for nurses in this study, particularly those who may be inexperienced in end of life care. Other variables such as ward culture, design, nurse allocation, patient acuity and nurse workload impacts negatively on a nurse's responsiveness to the dying patient. While death anxiety was not the primary focus of this study, nor was it measured, this study suggests that death anxiety may have impacted significantly on the care provided to the dying patient in the acute hospital setting.

## ***PART A: GENERAL DECLARATION***

### **Monash University - Declaration for thesis based or partially based on conjointly published or unpublished work**

In accordance with Monash University Doctorate Regulation 17 Doctor of Philosophy and Research Master's regulations the following declarations are made:

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 5 original papers published in peer reviewed journals. The core theme of the thesis is 'Registered Nurses' recognition of and responsiveness to the dying patient in the acute hospital (non-palliative care) ward'. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the candidate, working within the School of Nursing and Midwifery under the supervision of Professor Wendy Cross.

The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research. In the case of Chapters 2 to 4 my contribution to the work involved the following:

Thesis chapter	Publication title	Publication status	Nature and extent of candidate's contribution
2	End-of-life (EOL) care in acute Hospitals – An integrative literature review	Published	80% - Concept development and writing
2	Problems associated with end of life care in acute hospitals	Published	80% - Concept development and writing
3	Qualitative Observation in a Clinical Setting: Challenges at End of Life	Published	80% - Concept development and writing
3	How the observed create ethical dilemmas for the observer: Experiences from studies conducted in clinical settings in the UK and Australia	Published	80% - Concept development and writing
4	The 'dis-ease' of dying: Challenges in nursing care of the dying in the acute hospital setting	Published	80% Concept development and writing

I have have / have not (circle that which applies) renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.

Signed:



Date: .....12/08/2013.....

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## ACKNOWLEDGMENTS

This thesis deals with an issue that has always been important to me. As a nurse, I have witnessed all too often how death, an inevitable ending, was seen as a failure, and too often poorly managed. This thesis represents one small step on my journey towards changing the culture around death in hospital, with many life lessons and personal hurdles along the way.

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*Thanks for putting up with my never-ending study. You are both so incredible, so loving, so giving and tolerant. You inspire me every day. Let this show you that you can do whatever you put your mind to.*

Dad

*'Death leaves a heartache no one can heal, Love leaves memories no one can steal'  
Forever in my heart, and often in my thoughts. You have taught me so much about myself and life.*

God

*You know me better than I know myself. So often I question what You have planned for me. I have learnt not to question, rather to just 'know' that you have everything in hand.*

I also wish to acknowledge Dr. Brendan Moloney PhD (Melb) for proof reading the final draft of my thesis.

## ***CHAPTER ONE - INTRODUCTION***

### **1.1 Introduction to the study**

Caring for a dying patient is a privileged and unique role. For this reason, care provided at end of life and after death should be considered as important as the care provided to any other patient at any point. 'End of life' (EOL) is described as the stage where people are living with, or who are impaired by, a life limiting illness, not limited by prognosis or diagnosis (2010). EOL care is the care provided to people in this stage and includes support and services delivered by all health care professionals (Aleksandric & Hanson, 2010).

Changes in society, technology, and patterns of health care delivery have resulted in changes to physical, psychosocial and spiritual care. These changes have also greatly impacted the attitudes of health care professionals towards caring for the dying patient (Thompson, McClement & Daeninck, 2006). As a result of several factors, including advances in medical treatment and health care delivery (World Health Organization, 2004), the population of developed countries is ageing, chronic illness is now the leading cause of death worldwide (Thompson, et al., 2006) and many people are living with multiple comorbidities (O'Grady, 2005). Australians are living longer and dying from different causes than Australians who died 50 years ago (Aleksandric & Hanson, 2010). From an epidemiological standpoint, not only is the size of the population requiring EOL care increasing - both as a proportion of the population and in absolute terms - but the duration of life lived by patients requiring complex care or with high care needs is also increasing (Palliative Care Australia, 2008a).

Recent Australian statistics report that approximately 140,000 people die per year (Australian Bureau of Statistics, 2009) and whilst most people say they want to die at home (Foreman, Hunt, Luke & Roder, 2006), hospital remains the most likely place of death for the majority of

Australians (Palliative Care Australia, 2008a). It is also estimated that almost three quarters of deaths each year could have been anticipated or expected (Palliative Care Australia, 2008b).

In a submission to the National Health and Hospitals Reform Commission, Palliative Care Australia (Palliative Care Australia, 2008a) reported that the current experience of end of life care in Australia is inconsistent and disparate, with access to services, models of care, and care standards differing across health services. While some people will experience quality care at EOL based on their individual needs, others will receive fragmented care that fails to acknowledge their individual social, emotional and physical needs (Tilden & Thompson, 2009). Certainly, it must also be realised that not every patient who is dying will need specialist palliative care services. While not every nurse who cares for a dying patient will need expert palliative care skills in order to provide a 'good' death, that is one in which pain and other symptoms are holistically managed (De Jong & Clarke, 2009), further education for clinicians working outside specialist palliative care settings was one of the key recommendations made in a recent report to The Senate on palliative care in Australia (Holland et al., 2012).

Whilst palliative care services attract the most attention when referring to death and dying, and palliative care service provision has traditionally been for people with a malignant disease, many more people with non-malignant diagnoses have also benefitted from access to this type of specialist care (Aleksandric & Hanson, 2010). However, less than 8% of the world's population who need palliative care are able to access it (Prall & Pahl, 2007). The care delivered to the dying patient being cared for outside of a specialist palliative care environment is less defined, often not integrated into the acute hospital structures and systems, and is regarded as less than ideal for this reason (Cooper et al., 2009). Given that so many patients die in acute hospital wards rather than palliative care wards, there is a need to explore how patients are identified as dying, what care to deliver, and how the dying process is managed by nurses.



### **1.1.1 Focus of the study**

The focus of this study was to explore how registered nurses working in acute hospital wards, other than palliative care and critical care areas, 'recognised' when a patient was dying and how they 'responded' to the dying patient.

### **1.1.2 Study Setting**

The setting for this study was the acute hospital environment, excluding palliative care and critical care areas. The exclusion was because it was considered that the approach to dying in critical care areas, and wards known to have a stronger connection to palliative care such as palliative care units and oncology wards, which could give a different view of dying and EOL care than in the remaining acute hospital settings. Consequently, two acute wards that were identified as having the highest rates of death within the chosen health service were used as the sites for this study.

## **1.2 The challenges of recognising dying**

Predicting the timeline for dying for any given patient is problematic. Many clinicians resist suggesting a prognosis or timeline, or identifying a patient entering the 'end of their life', as for most people there is not an obvious period of time that can be identified as the 'dying' phase (Palliative Care Australia, 2008a). Dying manifests in each patient differently (Twycross & Ludmerer, 1982). Acknowledging different patient reactions to death, attempts have been made to assist prognostication and recognition of dying. Pugh et al. (2010) attempted to define dying in terms of a set of criteria. They suggested that a patient can be considered to be dying when they meet two of the following four criteria: - (i) bed bound, (ii) semi-comatose, (iii) only able to take sips of fluids and (iv) no longer able to take tablets. However, even when these criteria are applied, not all dying patients will meet all of them. Some dying patients for

example, will meet at least two of these criteria, many will not. Conversely, some patients may meet two or more, but not be imminently dying, such as those with progressive long term neurological conditions.

The Gold Standards Framework (GSF)(2012) prognostic indicator, which utilises eleven diagnostic criteria to identify patients who may benefit from palliative care input was also used to identify dying patients (Gardiner et al., 2012). However, this indicator is more specifically a measure of palliative care need, not imminent death. Therefore, even though such tools/measures criteria may be helpful if dying is not recognised, others may still miss the opportunity to receive quality care at the EOL (Pugh et al. 2010).

### **1.3 A palliative care approach**

The World Health Organisation describes palliative care as an

*“...approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention of suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual”* (World Health Organization, 2012).

Palliative care aims to provide relief from pain and other distressing symptoms, to integrate spiritual and psychological care into the care plan, to offer a support system to help the family cope during the patient’s illness and after and to work to enhance quality of life (Palliative Care Australia, 2005).

Palliative care aims to achieve the best quality of life for dying patients (O'Connor, Davis & Abernathy, 2010) utilising a deliberate and coordinated inter-professional approach to the care of the dying, with service delivery models having been developed to meet the needs of cancer patients (Palliative Care Australia, 2008a). Unfortunately, as a result, not all patients

who will die in acute hospitals, who could benefit from palliative care services or a palliative care approach to their care, will access or utilise palliative care services.

### ***1.3.1 The acute hospital environment***

A significant issue impeding quality care for the dying population in the acute hospital environment stems from the dominant medical paradigm which creates discord between the goal of medicine 'to cure' by using all possible treatments to save or lengthen life (Palliative Care Australia, 2008a) and the acceptance that death is the most likely and sometimes the best outcome (Tilden & Thompson, 2009). The Australian health system is designed to treat and cure disease, where health professionals have a duty of care to cure the curable (Palliative Care Australia, 2008a) through short-term episodic care (Tilden & Thompson, 2009). The focus is on avoiding death (Aleksandric & Hanson, 2010), but for those patients who are reaching the end of a life-limiting illness, the goals of care delivery in the acute hospital environment may not only be unrealistic, but may also result in inappropriate or inadequate care (Aleksandric & Hanson, 2010) and a missed opportunity for clinicians to deliver timely and appropriate EOL care (Murphy, Bolger & Agar, 2007).

The opportunity to deliver quality EOL care in acute hospital settings principally relies on clinicians acknowledging that care of the dying, or EOL care, should be "the core business of hospitals" (Palliative Care Australia, 2008a, p.7), rather than just palliative care environments. Until this change occurs, the discord between EOL care delivered in a palliative care setting and an acute hospital setting will continue.

### ***1.3.2 The Nurse's role***

The primary role of nurses is to care, and this role extends to those who are dying. It has already been suggested that nurses and other health professionals, working outside the

palliative care environment, where there is a curative culture, are ill-equipped to provide quality EOL care (Aleksandric & Hanson, 2010). Aleksandric and Hanson (2010) describe as a fundamental barrier to achieving quality EOL care, the inability or unwillingness of many health professionals to recognise those who are dying and treat them appropriately. This lack of recognition may be attributed to the culture of our health care system to focus heavily on survival and cure (Economist Intelligence Unit, 2010), difficulties health professionals may have in the actual 'recognition' of dying (Aleksandric & Hanson, 2010), or the challenge of changing the goals of care from 'active' to 'end of life' once dying has begun (Le & Watt, 2010).

## **1.4 Aim of the study**

The aim of this study was to explore the registered nurses' recognition of and responsiveness to dying patients in acute hospital (non-palliative care) wards in the Australian acute hospital setting and to understand the nurses' influence, if any, on the provision of EOL care in these settings.

### ***1.4.1 Research questions***

1. How do nurses recognise the onset of dying?
2. How do nurses respond to the dying patient?
3. How do nurses influence the care a dying person receives?
4. What systems and processes influence care of the dying person?

### ***1.4.2 Significance of the study***

Much of the previous research which has focused on the dying patient and the care provided to them comes from a palliative care perspective. This research has explored issues related to accessing palliative care, palliative care service delivery, and the integration and implementation of the palliative care approach in other settings such as residential aged care

and other non-palliative care settings (detailed in Chapter Two). Whilst this work is important, it fails to address the needs or examine the care provided to the majority of patients who die outside of specialist palliative care settings or where a planned and coordinated approach to the death is not possible. Given that the majority of people who die have not accessed palliative care and the number of people dying in acute hospital settings is increasing, it is essential that the care delivered to patients who die in the acute hospital setting is also explored. More specifically, given that nurses are primary carers, research that examines how nurses recognise when a patient is dying, and the subsequent care that they provide is essential if we are to improve EOL care.

To date, no research has been undertaken that specifically seeks to understand nurses' influence on the provision of EOL care in acute hospital settings. The significance of this study lies in its potential to identify processes through which nurses exert influence on the provision of EOL care to dying patients in acute care settings. Knowing more about these processes will enable researchers and clinicians to make changes to the care provided to the dying patient. Moreover, this research will enable nurses, who are the primary care-givers, to influence and facilitate change from a 'cure-all' perspective to an 'EOL care' perspective.

### ***1.4.3 Research processes***

This study utilised a mixed methods approach. When both qualitative and quantitative research elements are combined, the strengths of both approaches have been found to provide more in depth understanding than using a single method (Creswell, 2009).

Within the mixed-methods approach, a 'Sequential Exploratory Strategy' as described by Creswell (2009) was used. This strategy involves an initial phase of qualitative data collection and analysis, followed by a phase of quantitative data collection and analysis that *builds* on the findings of the initial qualitative phase (Creswell, 2009). Given the lack of research literature

exploring this issue, there was a need initially to explore through the direct observation of nursing care how nurses recognise and respond to the dying patient in the acute hospital setting. Following the observation, interviews and focus groups were used to assist in clarifying and understanding of what was observed. This qualitative data collection phase was essential to the development of theory and understanding (Morse, 1991). Subsequently, quantitative data generated in the second phase were used to further explain and assist in the interpretation of the qualitative findings produced from the first phase of the study, where the primary focus of the model was to explore the situation in question (Creswell, 2009).

### **1.5 Structure of the thesis**

This thesis consists of seven chapters. Chapter One provides an introduction to the study, Chapter Two details the theoretical dimensions of the research and reviews existing literature. Chapter Three describes the methods, research processes and ethics. Chapter Four details the results of Phase One, Chapter Five details the results of Phase Two, and Chapter 6 is the discussion. Chapter Seven concludes the thesis, providing a summary of the findings, the implications, limitations of the study and recommendations for further research.

This PhD thesis is inclusive of the candidate's publications and in chapters two, three and four and the traditional content and/or structure of these chapters has been altered to accommodate relevant publications.

## CHAPTER TWO - LITERATURE

### PART B: Suggested Declaration for Thesis Chapter

Monash University

#### Declaration for Thesis Chapter Two

##### Declaration by candidate

In the case of Chapter Two, the nature and extent of my contribution to the work was the following:

Nature of contribution	Extent of contribution (%)
Concept development, key ideas, development, writing up and critical revisions	80%

The following co-authors contributed to the work. If co-authors are students at Monash University, the extent of their contribution in percentage terms must be stated:

Name	Nature of contribution	Extent of contribution (%) for student co-authors only
Professor Wendy Cross	Critical Revision	
Assoc. Professor Cheryle Moss	Critical Revision	

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the candidate's and co-authors' contributions to this work\*.

Candidate's Signature		Date 12/08/2013
-----------------------	---	--------------------

Main Supervisor's Signature		Date
-----------------------------	--	------

\*Note: Where the responsible author is not the candidate's main supervisor, the main supervisor should consult with the responsible author to agree on the respective contributions of the authors.

## 2.1 Introduction

This chapter examines literature on nursing and dying, which builds on the research problem identified in Chapter One, demonstrating the connection between the background to the study with a more comprehensive body of literature. The purpose of this literature review was to identify what contributions have already been made towards understanding the research topic and to identify what remained to be researched.

There are four distinct parts to this chapter. First, a publication entitled 'End-of-life Care in Acute Hospitals: An Integrative Literature Review' is presented and serves as the substantive literature review to inform methodological decisions. An integrative approach to the literature review was necessary because of the lack of evidence-based research. Much of the existing work in this field included poor quality studies and anecdotal evidence on what worked, rather than scientific evidence (O'Connor, et al., 2010). Thus, it was necessary to incorporate all sources and evidence on how they may impact upon the research problem.

Second, a publication entitled: 'Problems Associated with Care at the End of Life in Acute Hospitals' is presented, prompted by a 2010 white paper suggesting that the United Kingdom (UK) and Australia ranked first and second respectively from an analysis of 40 nations on 'quality of death' in the provision of EOL care (Economist Intelligence Unit, 2010). In this report, 40 nations were scored against more than 20 indicators and while this report may have suggested that EOL care in the UK and Australia lead the world, other literature (research and non-research) suggests that there is still some room for improvement. Therefore, the purpose of this integrative literature review was to explore and to compare EOL care in the acute hospital setting in the UK and Australia, identifying the issues that currently impact on EOL care delivery in the acute hospital setting.



Third, since the publication of these two integrative literature reviews in 2011, which together informed the research aim and design of this study, further literature has emerged that warrants attention and inclusion because of its relevance to the topic. However, as it was published subsequent to the two literature reviews, it was not possible to consider this literature when planning this study. This more recent literature is presented at Section 2.2.

The publications included in this chapter focused on specific aspects of the literature that relate to EOL care, recognition of dying and the nursing response to dying in the acute hospital setting. However, in order to assist with data analysis, further literature that encompasses a broader sociological and psychological understanding of the phenomena was necessary.

# Publication – End-of-life care in acute hospitals: an integrative literature review



REVIEW

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## End-of-life care in acute hospitals: an integrative literature review

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### End-of-life care in acute hospitals: an integrative literature review

**Aim.** To explore and define the current status of published literature related to end-of-life care in the acute hospital setting.

**Background.** Chronic illness is now the leading cause of death in developed countries because the population is and the advances in health care delivery. In Australia, two-third of people with chronic illness who die is inpatient in an acute hospital. Whilst most of the attention regarding end of life care and dying has focused on palliative care settings, there is a need to consider those dying outside of specialist palliative care settings.

**Design.** Integrative literature review.

**Methods.** Using an integrative approach, electronic searches of selected databases were undertaken, using comprehensive search terms. Secondary sources were also identified through the reference lists of retrieved literature.

**Results.** The literature review identified a lack of high-quality scientific evidence to direct end-of-life care as delivered in the acute (non-palliative care) sector. From the literature available, five core themes/issues were generated to reflect the literature.

**Conclusions.** There is a need for research to investigate end of life care in the acute hospital setting. Care pathways are in use to varying degrees without validation, but implementation alone does not ensure quality end of life care. Cultural factors can impact practice and the ability of clinicians to recognise 'active dying' has been shown to be problematic, delaying the transition to end-of-life care.

**Relevance to clinical practice.** Given that the majority of deaths in Australia occur in acute hospital settings, clinicians should be delivering expert life-sustaining acute care and also quality end-of-life care.

**Key words:** chronic illness, end-of-life, hospital, literature review

## Introduction

Care of the person at end-of-life (EOL) has changed dramatically over the last century (Thompson *et al.* 2006). In Australia, there was over 140 000 deaths in 2008 (Australian Bureau of Statistics 2009) and the 2006 figures tell us that around two-third of deaths occur in hospital (Australian Institute of Health and Welfare 2010). More over, it is estimated that almost three quarters of these deaths could have been anticipated (Palliative Care Australia 2008).

With the population of developed countries ageing, longer life expectancy also comes as a result of advances in medical treatment and health care delivery (World Health Organization 2004). These advances are increasing longevity, the pattern of disease worldwide is changing (World Health Organization 2004) and chronic illness is now the leading cause of death (Thompson *et al.* 2006), where chronic illness is defined as illness that persists over time with the person's health status fluctuating between maximal functioning and serious, even life-threatening health relapses (Crisp & Taylor 2009). Treatment advances mean that many people are living longer with a chronic illness and in some cases they are living with multiple chronic illnesses (O'Grady 2005). Whilst most of the attention regarding EOL care and dying has focused on people with cancer, many others, such as those with chronic illness and chronic organ failure are similarly in need of EOL care (Department of Health 2009).

In Australia, acute care hospitals still remain as the most common place of death (Heyland *et al.* 2005) with figures showing that 50–60% of those who die in Australia, actually die in a hospital setting (Jennings 2005, Foreman *et al.* 2006, Tabor *et al.* 2007, Department of Health, 2009). This is despite findings from a study by Murphy *et al.* (2007), which reported that when asked the majority of people stated that their preference was to die at home, rather than in hospital. Society's expectations of care at EOL impacts significantly on how healthcare is viewed and the current reality of service delivery may not meet the wishes of society.

## Aim

The aim of this integrative literature review is to explore and define the current status of research and other non-research literature related to EOL care in the acute hospital setting.

## Method

### Integrative review

Given the diverse origins of data related to EOL care and the lack of higher level evidence in this area, an integrative literature review was considered to be the most appropriate method to enquire, explore and create new meaning from the available literature which comes from a variety of sources, including scientific, political, humanitarian and anecdotal sources. An integrative literature review is used to determine the current state of knowledge and identify any knowledge gaps through the investigation of literature (Whittemore 2005) generated previously from diverse methodologies, where both experimental and non experimental research and theoretical papers are included (Whittemore & Knafl 2005, Schneider *et al.* 2007). By re-interpreting and re-analysing text data (Pope *et al.* 2007), this integration has the potential to build nursing science, inform future research, care delivery and policy (Whittemore & Knafl 2005).

### Sample

Well defined literature searches are critical in enhancing the rigour of the integrative review (Whittemore & Knafl 2005), because incomplete and biased searches can result in an inadequate search and inaccurate findings (Conn *et al.* 2005). A search was carried out using CINAHL, Medline, Google Scholar and Google, for literature published in English between 2005–2010, however, if other publications were deemed particularly relevant and important or were regularly cited in other retrieved publications, but published before 2005, they may have been included also. The rationale for a Google search was to ensure that non-research publications, such as government/policy reports/guidelines/position statements etc. were identified, as these may make direct recommendations for EOL care and not be identified via an academic database search.

The search terms were limited to end-of-life/end-of-life/EOL/death/dying/terminal care combined with hospital and articles retrieved from these searches were selected based on their relevance to care provided in acute care hospital environments. Any literature that more specifically related to specialist palliative care or palliative care or hospice environments was excluded. Further, associated searches were undertaken for literature on 'chronic illness' and statistics related to 'place of dying' to assist to understand the magnitude of this situation under review. A total of 73

publications were included in this integrative review, of which 41 were research publications and 32 were non-research publications.

After these initial retrievals were undertaken and from reading the literature retrieved, it became clear it was impossible to explore EOL care in acute hospitals without giving consideration to the Liverpool care pathway (LCP). The LCP was developed in the UK from a collaboration between a hospital-based palliative care team and the Marie Curie Hospice Liverpool to assist in transfer of the best practice model of care of the dying patient from the hospice setting to the acute setting (Murphy *et al.* 2007). Fourteen publications relating to LCP use were included.

Assessing the quality of sources in an integrative review is complex and challenging due to the diversity of studies and publications that can be included in this type of review (Whitmore & Knaff 2005). However, each publication source included was evaluated on its own merit, with consideration given to study design or conclusions drawn, or the public integrity of the organisation who produced the publication. Any publications that were deemed to be questionable or lacking credibility were also excluded.

## Findings

This integrative literature review identified five core themes/issues that are reported to impact directly on the care of the dying in the acute hospital environment.

### The terminology used to refer to care of the dying

Common and clearly defined terminology related to EOL care is a crucial foundation for ensuring consistent quality care (Goodridge 2010). The terminology applied to care of people dying in the clinical setting creates confusion and ambiguity, which may contribute to inequity in care delivery. Most notable is the relationship between the dying and 'palliative care'. Many scholarly articles refer to 'end-of-life' and 'palliative care' interchangeably, as well as other terms such as 'terminal care', 'hospice care' and 'care of the dying' (Lorenz *et al.* 2005, Thompson *et al.* 2006, Murphy *et al.* 2007). There is a need for differentiation between palliative care and EOL care to ensure clinicians are clear about the intent (Goodridge 2010). EOL care in the acute setting may take place over a very short time frame, where death is recognisably imminent (Lorenz *et al.* 2005, Pugh *et al.* 2010, Norton *et al.* in press), for example where the patient is dying from an unexpected event, or illness (Hardy *et al.* 2007) or where little time passes between diagnosis and death (Norton *et al.* in press). In this way, a planned palliative care approach

to dying is not possible, thus highlighting the clear difference between palliative care and EOL care delivery. The ambiguity surrounding this terminology hinders development and delivery of EOL care (O'Grady 2003).

Although the World Health Organization (WHO) (World Health Organization, 2009) defines palliative care, there is no WHO definition available for EOL care. Lunnay *et al.* (2003) define EOL care in a way that differentiates it from palliative care. EOL care is that which focuses on the last days and hours-of-life and is not preceded by a planned coordinated team approach to symptom control and disease progression (Lunnay *et al.* 2003). This definition more appropriately describes care for dying, where previous plans about the dying process had not been made, or where the person is dying from an unexpected sudden event. In respect of the definition, what is explicit is the need for the dying person to have access to the right care at the right time.

### How fear of death and dying influences actions

In 2009, a policy brief was published (Tilden & Thompson 2009) which reports that individuals are not only afraid of death, but they are also concerned about how they will die and the possibility of 'suffering', more than the death itself. Further, a significant issue impeding quality EOL care for the dying worldwide stems from the discordance between the goal of medicine 'to cure' and the acceptance that death is the most likely and sometimes the best option (Tilden & Thompson 2009). Whilst the United States leads the way in the medicalisation of death (Tilden & Thompson 2009), the Australian health system is similarly designed to treat and cure disease and to provide short-term episodic care for acute illness.

Similarly, although all people are mortal and will die, the beliefs and culture surrounding death needs to be acknowledged. An interesting finding from the literature is that there is a widespread reluctance to talk about death (Department of Health 2009), where death is considered a 'taboo' topic (Grady 2000, Wasserman 2008) and as a result talking about death and dying is not done enough (Ingelton *et al.* 2009).

Death of the aged and frail may be more acceptable than death of the young. Likewise, death as a result of a cancer diagnosis is perhaps more acknowledged or accepted as a possible outcome; however, the same acceptance has not been afforded to other chronic illnesses or disease states which are also likely to result in death. Nevertheless, the likely outcome for people with chronic illness is death either at home or in acute settings. Some may receive palliative care in specialist palliative care settings, but the majority will not and will subsequently die in acute settings. But when death is not



expected, recognising or acceptance that death is the likely outcome is a difficult process for individuals, fraught with uncertainty and emotions (Thompson *et al.* 2006), in particular, where a person is facing their own imminent death or that of a close loved one.

According to Murray *et al.* (2005), acknowledging and openly discussing illness trajectories with patients and their families enables them to understand how they may die and make appropriate plans. The implications for service planning and development means that different models of care will be required for different illness trajectories and that planning may assist to avoid hospitalisation. 'Now-a-days, we can cure some diseases and manage others effectively'. Where we cannot alter the course of events we must at least (when the patient so wishes) predict sensitively and together plan care for better or for worse' (Murray *et al.* 2005, p. 1011).

In tertiary care settings, the overall momentum in care delivery is towards life extension (Chen 2008). The focus is on resuscitation and assertive treatment to restore health, increase survival and avoid death (Aleksandric & Hanson 2010a). For those patients who are in the dying phase, aiming for cure is not only unrealistic, but may result in over-inflated expectations for patients and family, situations of conflict and inappropriate or inadequate care (Aleksandric & Hanson 2010a). This failure to recognise or acknowledge treatment futility (Chan & Webster 2010) results in a system, where clinicians miss the opportunity to deliver timely and appropriate EOL care (Murphy *et al.* 2007).

#### Transitioning to an EOL care focus

The essential first step in planning and providing EOL care is acceptance that death is the likely outcome by the patient, family and clinicians (Thompson *et al.* 2006). This acknowledgment in itself can be a difficult process for all the treating team, patients, their family and significant others (Duggleby & Wright 2004, Jackson *et al.* 2006, Thompson *et al.* 2006). Furthermore, the difficulty in accurate prognostication by physicians and 'waffling' mean that patients and families are often given a broad range of survival estimates that create more uncertainty than certainty (Thompson *et al.* 2006).

When symptoms are out of control (Buckley & Harb 2004), when the patient has pain (Appelin & Berenson 2004), when there is a fear of addiction to strong drugs (Tilden & Thompson 2009) and when patients and their families fear a hastening of death (Arnold 2004), acceptance of a change in care direction can be traumatic and frightening for patients and also their families.

Tilden and Thompson (2009) describe how families and often patients themselves resist the option of transfer to a

hospice setting, which implies acceptance of death and is tantamount to 'giving up'; a situation similarly described in other literature, where changing focus for curative treatment to EOL care results in patients and family losing 'hope' (Jackson *et al.* 2006, Kyrna *et al.* 2009). Thompson *et al.* (2006) also explains that the uncertainty and emotions experienced at this time make acceptance of death complicated and a clear cut transition from curative care to an EOL care is rare.

Notably, Thompson *et al.* (2006) found that clinicians also described losing hope once the active treatment was discontinued for their patient. The recognition by clinicians that treatment is futile is not easy (Chan & Webster 2010) and the decision to stop a life-sustaining treatment, or withhold a treatment in the first place can be very difficult and a source of moral distress (Yam *et al.* 2001). In Western societies, where death has become medicalised and curative procedures are often prioritised ahead of palliation (Economist Intelligence Unit 2010), many clinicians still report regarding patient death as their 'failure' or as a result of their inadequacy (Donoujan *et al.* 2008), rather than the inevitable outcome of disease (General Medical Council 2010).

Regardless of the difficulties and emotions experienced when transitioning from curative care to EOL care, what should be of primary concern is that 'Good care at the end of life and a dignified death should be regarded as basic human rights ...' (Clark 2007, p. 108), where the dying patient and their family are supported in the respectful completion of the life cycle (Wasserman 2008) and, where care is person-centred (Murphy *et al.* 2007) irrespective of the illness, timeline, diagnosis, age or any other variable.

Knox and Vereb (2005) suggest a change to the curative focus of medical care as a strategy that may improve acceptance and understanding of EOL care. Replacing the term 'Do not Resuscitate' with the term 'Allow Natural Death', which reflects that death is the likely outcome, may assist in enabling clinicians, their patients and families, to see EOL care as an empowered choice, rather than the end result of failed curative care.

For physicians, even when the decision is made to provide EOL care in some parts of the US health system, certification that the patient's life expectancy is less than six months is necessary and agreement by the patient, physician and family to forego any further curative care is essential before a patient is eligible (Weiner & Tilly 2003, Higginson 2005).

#### Guiding care

Multiple organisations, national and international, government and non-government have developed position statements, standards for care, care pathways, guidelines and

recommendations designed to inform the provision of EOL care. A 2010 review from the Cochrane Collaboration reported, however, that there was insufficient data at present to make recommendations regarding the development and evaluation of EOL care pathways, due to the lack of evidence from randomised control trials (RCTs), quasi randomised trials or high quality controlled before and after studies (Chan & Webster 2010). Studies of this type that deal with the dying are difficult and fraught with ethical and methodological issues (Powell *et al.* 2004). As a result, current guidelines, recommendations, standards and position statements are not supported by a strong evidence base (Goodridge 2010) and instead, are reliant on lower levels of evidence to inform practice and guide care.

These documents describe best available practice for care of people at EOL. They are used as a resource and contribute to the existing knowledge base for clinical competence. Moreover, they provide a framework that supports clinical decision-making (Taylor & Randall 2007) and promotes practice change (Ellershaw 2002, Curuss 2004). Importantly, they promote practice change in mainstream acute hospitals, where many dying patients and their families (Jack *et al.* 2003) would benefit from guided EOL care, not just in specialist palliative care facilities.

In the United States, the National Consensus Project for Quality Palliative Care released the second edition of Clinical Practice Guidelines for Quality Palliative Care (2004), which aims to promote quality and reduce the variation in new and existing programs and encourage continuity and consistency of care across all healthcare delivery settings. Whilst there is an obvious synergy between palliative care and EOL care, the differences between palliative and EOL care means that palliative care clinical practice guidelines are not entirely appropriate for the patient in the acute care setting who is imminently about to die, with no known/imminent illness trajectory leading to death, prohibiting a more planned response. Having said that Domain 7 of the Guidelines relates more specifically to 'Care of the Imminently Dying Patient' and suggests that the signs and symptoms of impending death are recognized and communicated, that post death care is delivered in a respectful manner and that a post death bereavement plan is activated (National Consensus Project for Quality Palliative 2004), all of which is relevant EOL care in the acute care setting.

Recognising the lack of high-quality evidence, The American College of Physicians has also released recommendations for care delivery at EOL (Huntzinger 2008). These recommendations focus on symptom management, for common symptoms, such as pain, dyspnoea and depression, ensuring regular assessment and treatment with therapies of proven

effectiveness. They also encourage clinicians to ensure advance care plans (ACP) are initiated for all patients as early as possible and re-assessed when significant clinical changes occur (Huntzinger 2008). Nevertheless, the unpredictability of acute illness means that some patients will be near dying and not have considered or used an ACP.

In Australia, the Respecting Patient Choices Program was launched to promote the use of ACPs and ensure that the patients have the ability to make their wishes known about future care in the event that they lose capacity to communicate (Seal 2007), however the program has not resulted in significant uptake, with fewer than 1% of acute hospital case notes in South Australia containing an advanced directive (AD) (Harrison Health Research 2004 as cited by Seal 2007). Other studies, which looked at the prevalence of ADs in Australia also found that the presence of an AD was the exception, rather than the rule (Berrina 2009) with very low levels of formal planning (Nair *et al.* 2000). This may be related to cultural issues (Johnstone & Kanitsaki 2009) that make planning for death unpopular or that many people die without luxury of advanced warning (Norton *et al.* *in press*). But also, for those patients not afforded advance warning of death, time is not available to consider AD as a part of planning for their death.

In the absence of an ACP or AD, or when decision making is complex, NSW (New South Wales) Health, Australia, released Guidelines for EOL care decision-making (NSW Health 2005), where the goal is to assist clinicians to reach consensus in decision-making, where the patient and family are included in the process. Given that family inclusion is promoted by some (American Association of Colleges of Nursing 2004, Cook *et al.* 2006, Truog *et al.* 2008), it must be acknowledged that family/significant others do not always wish to be included or involved in decision-making, where the negative impact of sharing in these processes is significant and results in symptoms of anxiety and depression (Pochard *et al.* 2005) and post-traumatic stress disorder (Azoulay *et al.* 2005). Although the guidelines are clear and supportive of collaborative decision-making they do not guide care.

Care/clinical pathways have also become a common source of guidance for clinicians, but the terms used to describe a clinical pathway number more than 80 (Kinsman *et al.* 2010), where the goal of such a pathway is to base the care of the patient on the best available evidence and establish an institutional commitment of care for a particular diagnosis (Verdu *et al.* 2009). In the United Kingdom, the Department of Health developed an EOL care pathway, which identifies five steps to care of those approaching EOL. The first step in this care pathway is to identify those who are approaching EOL, so that 'good care' can be made available to all persons

approaching EOL regardless of their diagnosis, rather than just those with cancer who are most commonly the recipients of palliative and EOL care (Department of Health 2009). Again, the luxury of forewarning or advance notice is not afforded to all dying patients and their families and the recognition of condition changes that may indicate *active dying* has been reported as a difficult step for clinicians (Jack *et al.* 2003, Alsop 2010).

Care pathways encourage forward planning, effective coordination of care and central monitoring (Taylor & Randall 2007, Department of Health, 2009) and whilst ideal, may have little to no relevance to those persons rapidly approaching death in the acute healthcare system. For those at their last days of life, the LCP is recommended for guiding care (Department of Health 2009), as it was designed to assist in transfer of the best practice model of care of the dying patient from the hospice setting to the acute setting (Murphy *et al.* 2007), thus ensuring that the patient and family are provided with the best possible care at this time (Ellershaw & Ward 2003, Jack *et al.* 2003). Ellershaw explains that previously, care of the dying was the goal and mainstay of hospice care, which resulted in feeling that the only place patients can die well is in a hospice and a de-skilling of other staff. This creates an affirmation of the sense of 'care failure' for clinicians working outside of the hospice sector (Ellershaw 2007), so the need for urgent integration of such a pathway into acute hospital environments becomes an even higher priority.

Many iterations, adaptations and modifications of the LCP have been developed and tailored for various hospital and healthcare settings worldwide with a variety of challenges and successes. What is common, however, is that the LCP focuses on the physical, psychological, spiritual, social and religious aspects of care of the dying, the information needs of the patient and their carers (Ellershaw 2007), as well as care of the family before and after patient death (Ellershaw & Ward 2003).

Although the focus of this integrative review is on EOL care in the acute hospital sector, it is interesting to note that in the residential aged care setting the introduction and implementation of the LCP to guide care delivery to the dying is reported as a positive step (Duffy & Woodland 2006). Given that the median length of stay in these facilities ranged from 1–2 years (Lebbington *et al.* 1998) and that the population was already aged and requiring nursing support, the acceptance of a pathway for the dying may not have been considered such a vast change from attitudes and care goals already in place in the facility. Improvement in cross-boundary communication was reported as another positive outcome, leading to improved care (Hockley *et al.* 2005,

Duffy & Woodland 2006), where staff reported that the LCP empowered them to speak more openly and proactively with relatives and promote EOL care, resulting in an overall reduction in the number of residents being transferred to acute facilities only to die in the Emergency Department (ED) (Duffy & Woodland 2006). The introduction of the LCP into residential aged care facilities also resulted in staff feeling empowered and prepared to enter into conversations residents, families and other clinicians about death and dying (Hockley *et al.* 2005).

Now to focus on the acute hospital sector, the results are similar. The LCP has been implemented and its use evaluated, where it was used to direct care for the acutely dying in the ED, such as those patients who were nearcardiac arrest. This study highlighted increased staff satisfaction when the LCP was used to guide care for the dying and more importantly, it showed that patient care improved (Paterson *et al.* 2009).

In Australia, an adaptation of the LCP was also implemented and evaluated in medical wards with the aim to facilitate 'good deaths' by acknowledging the inevitability of a patient's death and guiding care. The study showed marked improvements in care for the dying patients in terms of involvement of support service personnel, such as social work and pastoral care and the facilitation of communication (Jackson *et al.* 2009).

The LCP was also implemented and evaluated in a large Dutch cancer hospital (Verbeek *et al.* 2006). The findings were largely positive however Verbeek *et al.* study report that in 30% of cases some care goals/recommendations for the after death period were marked as 'not applicable' and a relatively high number of missing assessments were reported (Verbeek *et al.* 2006), suggesting that clinicians chose to disregard recommendations on the pathway for alternate/absent care. The authors suggest that ongoing education is a necessary requirement for the LCP to maintain its function as a tool that facilitates quality care of the dying (Verbeek *et al.* 2006).

Improvements in the quality and completeness of documentation were reported in another study following implementation and evaluation of the LCP into hospital, nursing home and home settings. Whilst this does not necessarily translate to an improvement in care delivery, improvements in care documentation is still a positive outcome from the LCP (Verbeek *et al.* 2008).

### Clinical judgment in dying

Whilst evaluations of the LCP are positive, what they also show is the continual need for clinical judgment. Active dying manifests in each and every patient differently and even



when clear criteria apply, not all dying patients will fit. How does a dying patient present or look differently than a chronically ill patient who is not dying? Pugh *et al.* (2010) suggest the commencement of the LCP when death is expected within one to two days, based upon the patient meeting at least two of the following four criteria: (1) bed bound, (2) semi-comatose, (3) only able to take sips of fluids and (4) is no longer able to take tablets. Some dying patients will meet at least two of these criteria, many will not. Conversely, some patients may also have met two or more of these criteria for a long time, but not be dying, such as progressive long-term neurological conditions. Therefore, even though the criteria may be helpful if dying is not recognised, others may still miss the opportunity to receive quality care at the EOL. Verbeek *et al.* (2006) report that clinicians have difficulty in diagnosing impending death and thus commencing EOL care. For some clinicians, acceptance that death is likely difficult to accept, so their focus remains on curative treatment (Thompson *et al.* 2006).

### Implications for clinical practice

This integrative literature review has highlighted several factors that are imperative if care for people who are dying in the acute sector of health care is to improve. First, there is a need for further research to investigate the care outcomes for those receiving current standard care vs. those whose care is guided by a care pathway. However this type of study may be fraught with ethical issues, given that current care delivery is determined by lower levels of evidence.

Second, care pathways such as the LCP, aim to assist clinicians to provide better care for the dying patient and aim to ensure dignified death is as important as saving lives. However, the implementation of care pathways/care guidelines alone is not enough to ensure ongoing success in austere acute hospital wards. This literature review showed the degree of fluidity in results evident in evaluations of the LCP across a variety of settings and that the nursing/medical and healthcare cultures and workplace systems/process can impede practice change in this area. As a result, persons dying from an unexpected illness, or where palliative care services were not already in place, will not receive EOL care comparable to that delivered in palliative care settings.

Third, despite the introduction of ACP and ADs, their prevalence in practice is negligible. Notwithstanding their promotion, individuals are not using them, resulting in little more patient self-determination than previously. Given that the population is ageing and chronic illness is the leading cause of death, the need for individuals to use ADs is now more urgent than ever. As previously stated, unless the

prognosis is acknowledged as terminal, both patients and clinicians are unlikely to consider death as inevitable.

Fourth, the ability of clinicians to recognise 'active dying' has also shown to be problematic, particularly if the clinical presentation of the chronically ill patient, sometimes with multiple diagnoses, may not be too different from the dying. This creates uncertainty for clinicians about when to transition from life saving treatment to dignified and quality care of the dying.

### Conclusion

The literature identifies the need for ongoing education as a mechanism to assist clinicians to appropriately assess patients, recognise active dying, accept that death is the likely outcome for some patients and thus improve care of the dying. Education of patients and their families, including the broader community would also assist in the improved transition between care states. Given that the majority of deaths in Australia occur in acute hospital beds, clinicians should be working towards an environment, where expert life-sustaining acute care is delivered, as well as quality EOL care.

### Contributions

Study design: MD, CM, WC; data analysis: MB, CM, WC and manuscript preparation: MB, CM, WC.

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## Publication – Problems associated with care at the end of life in acute hospitals

PROFESSIONAL ISSUES

End of life journal with St Christopher's

# PROBLEMS ASSOCIATED WITH CARE AT THE END OF LIFE IN ACUTE HOSPITALS

Melissa J Bloomer, Cheryle Moss, Wendy Cross

Many more people die in acute hospitals than ever before. An integrative literature review was undertaken to explore end-of-life care (EoLC) delivered in non-palliative care settings. It showed that providing EoLC in acute hospitals is difficult, given the emphasis on life extension and cure. EoLC pathways can assist with the planning and delivery of care. According to an international report, the UK and Australia lead the world in quality care at the end of life. However, even in these countries, acute hospital culture has the potential to have a negative effect on care of dying people. There is a false assumption that clinicians are educationally, culturally and emotionally prepared to recognise dying and respond appropriately. This article reviews the delivery of EoLC in acute hospitals. It identifies workplace cultural difficulties and care-delivery models that impact on providing quality EoLC. Programmes and initiatives that seek to address cultural, health service and educational issues are identified and discussed. The knowledge deficit of health professionals, in particular nurses, with regard to providing quality EoLC is also examined. *Conflicts of interest: none*

### Keywords

Acute hospitals  
Care pathways  
Culture  
Dying  
Education  
End-of-life care

Care of people at the end of life has changed dramatically over the last century (Thompson *et al*, 2006). Humans are healthier and live longer than ever before (Economist Intelligence

Unit, 2010), resulting in an increase in ageing populations in developed countries (Davies and Higginson, 2004). Advances in health care and treatment have been responsible for significant gains in life expectancy (Davies and Higginson, 2004; Economist Intelligence Unit, 2010). Chronic illness is now the leading cause of death worldwide (Davies and Higginson, 2004), with many older people living for longer with multiple chronic illnesses (Crady, 2005). An ageing population means that the demand for end-of-life care (EoLC) is rising rapidly (Economist Intelligence Unit, 2010). While 115 countries worldwide have some kind of hospital or palliative care service, it is estimated that less than 8% of the world's population who need this type of care at the end of life are able to access it (Prill and Fish, 2007).

In 2010, the Lien Foundation, a Singaporean philanthropic organisation, commissioned a White Paper to rank the quality of death around the world, according to provision of EoLC. A total of 40 nations were scored on 24 indicators that were divided into four categories: basic end-of-life health care environment; availability of EoLC; cost

of EoLC; and quality of EoLC. The indicators were quantitative (e.g. life expectancy and health care spending as a percentage of GDP, gross domestic product), qualitative assessments (e.g. level of public awareness of EoLC) and outcome related (e.g. whether a country has a government-led EoLC strategy or is in the process of setting one up) (Economist Intelligence Unit, 2010). Of the 40 countries the UK was ranked the highest for quality of death, with Australia second (Economist Intelligence Unit, 2010). However, while these countries may lead the world in providing quality EoLC, people dying in acute hospital beds in both countries do not always have access to the same quality of care as they would in hospices and palliative care units.

UK statistics show that 58% of people who died between 2005 and 2007 (an average of 277,056 people per year), died so whilst on life support in an acute hospital (National End of Life Care Intelligence Network, 2010). Australian statistics are similar. There were over 110,000 deaths in Australia in 2009 (Australian Bureau of Statistics, 2009), with between 66% and 70% of those deaths occurring in

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hospitals (Lowell et al, 2007; Australian Institute of Health and Welfare, 2008; Hillman, 2009). Seventy per cent of people who died in hospital in Australia were receiving active treatment right up until the moment of death, rather than EoLC (Hillman, 2009; Aleksandric and Hanson, 2010), and only 11% of patients who died were in a palliative care setting (Australian Institute of Health and Welfare, 2008). Worldwide statistics demonstrate that acute care hospitals still remain the most common place of death (Hay and et al, 2005), i.e. 80–60% of people who die are cared for in a hospital setting (Jennings, 2005; Department of Health, 2005). A recent UK report stated that only 5% of the dying population die in a palliative care or hospice setting (Ruth et al, 2013). Obviously, not every dying patient can or wants to die in a hospital. However these statistics show that only a minority of dying patients are able to access a palliative care or hospice setting when dying.

The aim of this integrative literature review was to explore EoLC as evidenced in the acute hospital setting. The particular focus of the discussion will be on the UK and Australia, the highest and second highest ranked countries in the quality of death index (Economist Intelligence Unit, 2013).

## Method

### Integrative review

Studies using terminally ill patients as participants can be challenging because of the methodological and ethical issues associated with conducting research using vulnerable populations, such as patients who are dying, or whose condition prevents them from being able to provide informed consent (Lowell et al, 2007). Also, the heterogeneous nature of the patient populations found in palliative care environments, created by a variety of illness and dying trajectories, can further complicate studies in this area (Addington-Hall, 2007). Consequently, research into death and dying is fraught with difficulty. The majority of evidence relating to EoLC is not derived from randomised controlled trials or other methodologically rigorous studies

(Abernethy et al, 2010). Indeed, a 2008 audit of research articles published between 2003 and 2005 relating to palliative care found that only 5% of studies were randomised controlled trials (Geltman and Morrison, 2008). Given the lack of higher-level evidence an integrative review was considered the most appropriate method to inquire, explore and create new meaning from literature coming from a variety of sources, eg scientific, political, humanitarian and anecdotal. An integrative literature review, by investigating literature generated from diverse methodologies, including experimental and non-experimental research and theoretical papers, can help determine the current state of knowledge and identify knowledge gaps (Whittemore, 2005; Whittemore and Knafl, 2006; Sarason et al, 2007). By reinterpreting and analysing various sources of textual data (Pope et al, 2007), this integration of information has the potential to inform future research, care delivery and policy (Whittemore and Knafl, 2005).

### Sample

The Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE and the Cochrane Database of Systematic Reviews were searched for literature published in English since 2000, in order to retrieve the most up-to-date information. Keywords used in the data searches were 'end-of-life', 'end of life', 'EoL', 'death', 'dying', 'terminal care', 'preparedness' and 'education'. Articles retrieved from these searches were selected based on their relevance to the care provided to dying people in the acute hospital environment. Literature from the palliative care specialty was not specifically sought but if the content of a paper was deemed to add to the phenomena in question, then it was included. Further searches were undertaken for relevant international literature such as statistics related to death and dying in the UK, Australia and elsewhere and nurse and health education. Non-research publications and websites, such as those produced by government and nongovernment organisations that are integral in the development or

influence of policy documents, funding and care delivery models for EoLC were also included. As a secondary source of information, the reference lists of all included literature were scanned for further relevant articles that may not have been identified in the initial search. A total of 50 publications were included in this integrative review. Four main areas of dialogue will be explored in this article: fragmentation in care delivery, changing culture, interventions aimed at improving EoLC and clinician preparedness.

### Fragmentation in care delivery

There appears to be a misalignment between the focus of the acute health system and the needs of people approaching the end of life. Advances in medical treatment and the development of specialty areas mean that more can be done to treat illness within the acute care system. Acute care is now very much focused on providing treatment and cure, increasing survival and reducing mortality (Aleksandric and Hanson, 2010). This creates some challenges in terms of ensuring that dying patients and their families receive optimal care (Aleksandric and Hanson, 2010).

The fragmentation of the health system into multiple specialty areas and wards (such as respiratory renal and high-dependency etc), means that care delivery for the dying patient has become the responsibility of many different specialities. All provide fragments of care, but none are focused specifically on care of the dying (Ticer and Thompson, 2009; Abernethy et al, 2010). This fragmentation of health care, also known as the care/cure dilemma, creates an obvious mismatch between the dominant culture of recovery-focused medicine in acute hospitals and the needs of dying people (Benedit, 1977; Sullivan, 2002; Liden and Thompson, 2009; Abernethy et al, 2010). This results in a workforce that is not prepared adequately to provide EoLC (Grady, 2000). Such fragmentation creates a healthcare environment where good care at the end of life and a 'good death' cannot be assured (Clark, 2007). Another

nous of significance is the culture of society and the readiness to wonder (Department of Health, 2008, 2009).

### Changing culture

The UK's *End of Life Care Strategy: Promoting High Quality Care for all Adults at the End of Life* (Department of Health, 2008) identifies that there was widespread reluctance, among both the general public and clinicians, to discuss issues of death, dying and bereavement. In some countries, e.g. Japan and China, and specific cultural groups, strong taboos exist that inhibit people from talking about death. For example, in India, there is a reluctance to disclose a patient's diagnosis (National Intelligence Unit, 2010). Yet in countries where death is discussed more openly, such as the US, patients, their families and even clinicians can still be reluctant to talk about the dying process and death (Wasserman, 2008; Economist Intelligence Unit, 2010). For example, euphemisms such as 'passed away' are often used by clinicians as a way of avoiding the word 'died', and to mask the discomfort or panic that may be felt in the face of death (Nyanga, 2010). Furthermore, the stress and discomfort felt by clinicians regarding dying and death often results in clinicians deciding to postpone such conversations for another time (Schachter, 2005).

In the UK, in order to address this issue, the National Council for Palliative Care was established as a medium for raising awareness of death, dying and bereavement among the general public and care providers (Department of Health, 2009). However, the orientation of the acute health system towards curative treatment, and the attitudes of clinicians who work within that model, may be the greatest impediments to discussing death and dying (Alexandrie and Hanson, 2010). Palliative Care Australia (an Australian national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life), as well as the UK's *End of Life Care Strategy*, have both acknowledged that taboos exist with regard to talking about death and dying, creating barriers in communication (Alexandrie and

Hanson, 2010; Department of Health, 2010). It is therefore imperative that clinicians involved in caring for dying people acknowledge the barriers to such care and participation, and encourage open communication about dying and death with the patient and family/friends. Although that will involve a big cultural shift, it is essential to improving care (Department of Health, 2009; Alexandrie and Hanson, 2010). While such conversations are not easy to initiate and have with patients/families/friends, most patients expect clinicians to initiate such discussions and may welcome the opportunity to talk about the dying process (Burgess et al., 2004; Gull et al., 2005).

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In the UK, advance care planning (ACP) is a process through which patients can express, discuss and document their preferences and priorities for care, e.g. where they want to be looked after and where they want to die (Department of Health, 2008). An example of an ACP tool is the *Preferred Priorities for Care* document (National Preferred Priorities for Care (PPC) Review Team, 2007). Similarly, in Australia, the *Respecting Patient Choices* Programme was launched in 2003 as a way of educating health professionals and the public, and encouraging discussion about and recording of, an individual's preferences for EoLC, supported by the necessary documentation. This programme has been promoted extensively to the public as well as health professionals, with varying degrees of success (Respecting Patient Choices, 2011). An evaluation study of this programme found a 13% increase in nurses' perception of their ability to support patients' requests of self-determination, such as contributing to

care planning, and informed decision making. There was also a 13% increase in job satisfaction for nursing staff because they felt they could deliver more appropriate EoLC (Neal, 2007). While raising the public profile of death and dying is important, so too is the need to ensure all health professionals are supported adequately and are educationally equipped to deliver quality care to dying people.

### Interventions to improve EoLC

The UK's *End of Life Care Strategy* provided a framework for improving care at the end of life (Ingelton et al., 2009). As a result, a number of interventions and changes have been implemented and promoted. A key example that was designed to address the needs of dying patients in acute hospital settings is the *Live and Care Pathway for the Dying Patient* (LCP) ([www.liv.ac.uk/mcpdli/verpool-care-pathway](http://www.liv.ac.uk/mcpdli/verpool-care-pathway)). The LCP was developed for the purpose of transferring the best practice hospice model of care for the dying patient to the acute hospital setting (Murphy et al., 2007). The LCP is a standardised care pathway designed to support and educate clinicians working outside of palliative care or hospice environments. It directs care practices taking into account the physical, psychosocial and spiritual needs of the dying person (Veenendaal et al., 2008). The LCP can be used as an aide-memoire for staff in providing consistent care (Ellershaw, 2007).

Evaluations of EoLC pathways have been conducted. For example, Jack et al. (2003) looked at the implementation of the LCP in an acute hospital setting. The care pathway was received positively by clinicians, with nurses reporting increased confidence and knowledge regarding caring for dying patients. Similarly when implemented in nursing homes, Duffy and Woodford (2006) reported that staff understood the need to change focus when residents began to die from rehabilitative care to EoLC. They also felt more able to speak openly with relatives about their dying loved one. An evaluation of LCP use in Scottish nursing homes found that communication between medical and



nursing staff and families had improved as a result (Hockley et al, 2005). Another reported benefit is improved documentation (Veerbeek et al, 2008). One Australian study, which evaluated the implementation of a modified LCP to reflect local conditions, practices and medications, known as the PRIDE (Pathway for Improving Care of the Dying), also reported improvements in communication, documentation and staff confidence in looking after dying patients and their families/friends. However, this was a pilot project with only 20 participants, so was too small for any meaningful statistical analysis (Jackson et al, 2009).

Despite such positive findings, the literature also suggests that the implementation of care pathways for dying people in acute care is not without its challenges. The decision of when to commence a pathway is made difficult by the need for an accurate estimation of death (Weiner and Lily, 2003). It has been found that the LCP is generally initiated when the patient is expected to die within 1–2 days (Pugh et al, 2010). To commence the pathway it must be recognised and agreed upon by the multidisciplinary team that the patient's deterioration is due to the natural process of dying (Jackson et al, 2009; Alsop, 2010). Jackson et al (2008) stated that initially the recognition of dying was based on the presence of two of the following criteria: the patient was bed bound, only able to take sips of fluid or none at all and was semi-comatose. However, these parameters do not describe adequately all dying patients and could apply to many patients even those who are not imminently dying. For people who are on a slow gradual decline, identifying the time when they are actively dying is not clear cut (Duffy and Woodland, 2006). In fact, several studies have reported that knowing when to commence the dying care pathway is one of the greatest difficulties faced by clinicians (Duffy and Woodland, 2006; Pugh et al, 2010). Also staff feel unsure whether it is acceptable to take the patient off the care pathway if their condition improves (Duffy and Woodland, 2006).

Whilst care guidelines are designed to help clinicians in the delivery of EoLC, they fail when clinicians lack the skills to recognise dying (Lloyd and Russell, 2010). An inability, or sometimes unwillingness, on the part of clinicians to recognise dying and initiate appropriate care is a fundamental barrier to achieving quality care at the end of life (Alexandrie and Hanson, 2010). Alexandrie and Hanson (2010) explained that in the context of increasingly complex medical conditions and treatments, a lack of clarity regarding when EoLC should begin is a significant issue. Improving progress relating to care of dying people in acute settings, where the overwhelming focus is on cure, treatment and short hospital stays (Veerbeek et al, 2008).

A recent study undertaken in an NHS hospital in the north of England showed that of those who had died in hospital, 58% had qualified for LCP use, but only 39% were actually placed on the care pathway. Likewise a Chinese study of the introduction of an EoLC pathway over two time periods reported that as few as 10% of patients who died were placed on the pathway during the first time period. At the second time period, 12 months later following ongoing support and education, only 40% of patients who died had been on the EoLC pathway (Lo et al, 2009). It needs to be understood why patients who should be placed on a dying care pathway are not (Pugh et al, 2010).

Implementation of a care pathway (or a protocol or guideline) is not sufficient to change clinical practice in caring for dying people. In addition, clinicians should not rely on a dying care pathway to provide knowledge and skills. Consequently increasing the culture and knowledge beliefs of health professionals is essential.

#### Educational preparedness

What becomes apparent from the literature presented above is that there is currently a lack of education on caring for dying patients. Given that 58% of the UK population and nearly two-thirds of the Australian population

die in acute hospitals (Australian Institute of Health and Welfare, 2008; Department of Health, 2005), the reality is that nurses working in the acute hospital setting are responsible for the care of the greatest proportion of dying patients (Australian Institute of Health and Welfare, 2008). However, the goal of such environments is cure and therefore active treatment is prioritised (H. Liner, 2009; Alexandrie and Hanson, 2010). The need for more education and training was a key finding in the previously cited quality of death thinking document (Economical Intelligence Unit, 2010). However, despite being ranked first and second respectively, the UK and Australia also require improvement in this area.

The need for more education and training was highlighted by a UK study that looked at the challenges of delivering EoLC in acute hospitals (Willard and Luter, 2006). It found that one of the most significant challenges of providing appropriate EoLC was that health professionals in this environment were preoccupied with active treatment. Accordingly EoLC was not considered to be as high status as active care. Care delivery was influenced by the normal values and practices of the ward, such as continuing with active cancer treatment, reflecting the lack of understanding of EoLC and competing priorities. This was detrimental to patient care (Willard and Luter, 2006). An Australian study showed that the transition of patients from acute to palliative care was seen as a difficult phase for clinicians who found it hard to 'let go' (Lo and Watt, 2010).

Elserslaw (2007) recommended that EoLC education should be at both undergraduate and graduate levels in order to ensure health professionals have the skills and confidence to care for dying patients. Similarly, Gendrey (2010) reported that generalist care providers need to possess sufficient knowledge, skill and comfort with end-of-life management to ensure high-quality care for those patients who die outside of a specialist palliative care unit. In the UK, a framework of national, occupational standards has

been developed to support workforce development, training and education for healthcare professionals involved in care of dying people, and to improve communication skills for clinicians (National End of Life Care Programme et al. 2010). The Gold Standards Frameworks training programmes are likewise aimed at improving the quality of care provided by generalists to patients with any end-stage illness in any setting (e.g. care homes, primary care and acute hospitals) ([www.goldstandardsframework.co.uk/](http://www.goldstandardsframework.co.uk/)).

In Australia, the situation is similar and the need is the same. The Australian National End of Life Guidance Framework has specified that all healthcare professionals whose role interfaces with EoLC have to acquire knowledge and skills to provide care to people who are approaching the end of life, underpinned by continuing professional education and a nationally consistent set of core competencies (Aleksandric and Hanson, 2010). Palliative Care Curriculum for Undergraduates (PCCMU) is an Australian programme aimed at improving undergraduate level education in this area. There has been some impact, for 76% of undergraduate and entry to practice health courses in Australia are currently implementing the PCCMU educational resources (Palliative Care Curriculum for Undergraduates (PCCMU), 2010). However, there is still concern that undergraduate education may not adequately prepare the health workforce for EoLC or sufficiently differentiate the type of care necessary for those who die in an acute hospital environment, rather than a specialist palliative care unit (Aleksandric and Hanson, 2010). This sentiment is reflected in the wider associated international literature.

In the US, there is concern that not enough attention is being given to the topics of palliative care and EoLC in the undergraduate nursing curriculum leaving nurses poorly prepared to meet the needs of patients approaching the end of life (Parker et al., 2006). Consequently, the American

Association of Colleges of Nursing (2004) has developed competencies for all undergraduate nursing students as well as curricular guidelines. The End-of-Life Nursing Education Consortium (ELNEC), an American education initiative, has built on this work to improve palliative care delivery through the education of undergraduate and practising nurses in the areas of nursing care at the end of life, symptom and symptom management, ethical/legal issues, cultural considerations in EoLC, communication, loss, grief/bereavement and preparation to end care at the time of death (End-of-Life Nursing Education Consortium 2010).

Unfortunately, while programmes such as these have improved competence and disseminated information to health professionals, courses on caring for dying people, and the integration of content into undergraduate and postgraduate curricula, are still the exception rather than the rule (Milden and Thompson, 2009; Palliative Care Curriculum for Undergraduates (PCCMU), 2010). The result is that the health professional workforce is poorly prepared to understand what the dying process entails and their role in that journey in Australia, just like the UK, a targeted programme is required to provide education for nurses. But focuses on how to care for dying people, the deceased and the bereaved family. Workplace cultures and attitudes towards caring for dying patients are likely to have developed as a consequence of nursing staff feeling unprepared and undereducated for the work (Ingletor et al., 2009; Jackson et al., 2009; Aleksandric and Hanson, 2010). Education delivery should not just be targeted at undergraduate level. It must be part of ongoing informal, in-service education and postgraduate studies. For this to be effective, the characteristics of nurses as adult learners need to be understood.

Nurses, like all adult learners, tend to learn when they have a sense of purpose and are frequently more motivated and self-directed when they determine that they have a learning

need (Davis and Chestnut, 2003). Life experiences, both at work and in their personal lives, can impact upon their learning experience (Davis and Chestnut, 2003). Therefore, previous experiences of caring for dying people, both good and bad as well as their own self-reflection on their professional performance, is likely to impact on a person's willingness and motivation to learn. Nurses also learn from each other: their experiences of caring for dying patients and their families/friends can be shared with others and contribute to an informal learning experience (Carper, 1978; Williams, 2010). While this informal learning is important, it is not sufficient alone. Therefore, formal learning is also necessary (Evenson et al., 2007). Formal learning programmes and opportunities enable healthcare organisations to assist their nursing employees in maintaining regulatory requirements, whilst addressing identified needs.

Both the UK's Nursing and Midwifery Council (2000) and the Australian Nursing and Midwifery Council (2006) specify that nurses must participate in ongoing professional development activities and keep their knowledge and skills up to date, so that best care is delivered. Interestingly, the Economist Intelligence Unit nursing document showed that countries that ranked poorly in terms of quality EoLC also ranked poorly when it came to education and training in EoLC (e.g. China and India) (Economist Intelligence Unit, 2010). The Economist Intelligence Unit (2010) warned that training in developed countries is still insufficiently established, with the vast majority of healthcare professionals lacking the necessary skills to provide quality care for dying people.

### Recommendations

- More research is necessary to examine further the impact of culture (e.g. both societal and within the acute hospital setting) on EoLC. Furthermore, current ways of working and models of care delivery in acute hospitals that may in addition EoLC require investigation.



- Work must also be aimed at raising public awareness and knowledge about death (Seymour et al. 2010) and ensuring that the language of death and dying is put back in everyday conversations (Alexandre and Linxon, 2010).
- There is an urgent need for nurses and other health professionals working in the acute setting to be properly, both educationally and professionally, to provide the type of care that will enable a quality death. A greater emphasis on training/education in care of the dying after death care and tools for care delivery such as care pathways, is necessary (Ellershaw et al. 2010).

### Conclusion

This integrative literature review has demonstrated that changing demographics and patterns of death and dying mean that nurses working in the acute sector are likely to care for an increasing number of dying patients. The majority of people who die do so in acute hospitals rather than at home or in palliative care settings such as hospices. However providing EoLC in acute hospitals is challenging because of the fragmentation of care specialists and workplace culture. Care-delivery models that focus on the extension, care and active treatment impact negatively on the delivery of quality care to the dying patient. End-of-life care pathways can assist with the planning and delivery of EoLC. However practitioners also need to be educated and supported to develop their skills with regard to caring for dying people and their families. **Impact**

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## Key Points

- ▶ The majority of deaths occur in an acute hospital setting, with many dying people receiving active treatment right up until the moment of death, rather than approaching end of life care (EOLC).
- ▶ Acute care settings are very much focused on providing treatment and cure, increasing survival, and reducing mortality.
- ▶ The acute sector has been divided into multiple specialty areas. Consequently care delivery for dying patients has become the responsibility of many different specialist practitioners. All provide fragments of care, but none are fully involved in care of dying people.
- ▶ Care pathways for dying patients can increase confidence and knowledge regarding caring for dying patients. However, the decision of when to commence patients onto a dying care pathway is made difficult by the need for an accurate estimation of death.
- ▶ There is an urgent need for nurses and other health professionals working in the acute setting to be prepared, academically and professionally so that they can provide the type of care that will enable a quality death.

## 2.2 Recognising dying

One of the challenges in the recognition of dying is the associated ambiguity and uncertainty associated with dying. The specific challenge for clinicians is in determining the right plan for care for each patient. A further challenge is the lack of universally accepted and validated criteria with which dying can be predicted (Phillips, Halcomb & Davidson, 2011). Indeed, the very nature of dying suggests that any measure designed to predict dying would not be universally accurate. Other factors that contribute to the difficulty in recognising dying can be divided into four main (and linked) categories: clinical experience; education and training; organisational and professional cultures (Watts, 2012). In terms of clinical experience, not all clinicians will have an appropriate level of confidence or expertise to accurately recognise dying or decide when death is imminent (Boyd & Murray, 2012), nor the education to underpin this skill. In addition, dominant organisational and professional cultures, currently embedded in biomedicine, clinical practices such as referral practices and the use of a dying care pathway can impact upon who recognises dying and how it is done (Watts, 2012).

Key to recognising dying and essential for a change in focus from curative care to dying care is the timing of the prognosis. In the acute hospital setting, recognition of dying most typically occurs close to death for the reasons discussed above. Where the focus of acute medicine is to cure, however, consideration for the possibility that the patient may die, often comes late in the illness trajectory (Gott, Ingleton, Bennett & Gardiner, 2011), sometimes as a result of the time needed for communication between clinicians and family about the possibility of dying (Coombs, Addington-Hall & Long-Sutehall, 2012). Others suggest that delays in the recognition of dying could come from a lack of understanding or agreement regarding whose responsibility it was to address a patient's palliative care needs. Many view this as a service to be delivered by specialists and not in the remit of those providing acute care (Gardiner, Cobb, Gott & Ingleton, 2011).

## 2.3 Dying in acute care

While not every person who is dying needs or receives specialist palliative care input, the literature suggests that the number of dying patients who could benefit from specialist palliative care is significantly greater than those who actually receive it. A UK study conducted in an acute care setting utilised the 'Gold Standards Framework' prognostic indicator (Gold Standards Framework (GSF), 2012). This framework utilises eleven diagnostic criteria to provide clinicians with an indication of patients who might benefit from palliative care input. The study found that as many as 36% of inpatients were identified as having palliative care needs but, respectively, only 15.5% were identified by doctors and 17.4% nurses (Gardiner, et al., 2012). This, however, was a measure of palliative care need, not imminent death.

Similarly, the acute care environment and culture has been shown to impact upon how dying is managed. As an example, a study into the early identification of disease trajectories in the Emergency Department (ED) found that within the resuscitative culture of the ED, if a doctor encounters a patient in acute distress or if information is unclear, they will default to life-prolonging treatment (Lamba, Nagurka, Murano, Zalenski & Comptom, 2012).

Other studies have identified that factors associated with clinical care in the acute care setting, such as patient acuity, workload and competing demands for time can impact upon care for the dying. A study investigating the needs of older people at the EOL found that prioritising the needs of the dying within a clinician's workload and time constraints was difficult and often resulted in a tension between what the clinician considers to be best practice and the reality of care they can deliver (Casey et al., 2011). O'Hara (2011) similarly conferred that dying in an acute care environment was not ideal because staff were under-resourced in terms of preparation, education and time to provide appropriate care.

A recent Spanish study (Arantzamendi, Addington-Hall, Saracibar & Richardson, 2012), published after the substantive literature reviews contained in this chapter were published, aimed to describe nurses' preparedness to care for the hospitalised terminally ill patient. This study found that while acute hospital nurses felt competent to provide the physical care required by the dying patient, they were less comfortable or confident in providing emotional care. These nurses reported a lack of support for them and a desire for further education (Arantzamendi, et al., 2012).

## **2.4 Care pathways**

A number of studies reviewed explored the use of care pathways (Costantini et al., 2011; Phillips, et al., 2011; Watts, 2012; Watts, 2013). The use of care pathways raises many issues. Firstly, initiating an EOL care pathway is contingent on professionals agreeing that a person is dying (Watts, 2012), their willingness to accept that a person is dying, and change the focus of care away from cure (Watts, 2013). Care pathways are described as social constructions and are only as effective as the clinicians who use them (O'Dowd, 2012). Watts (2013) suggests that while the improvements made to EOL care are often acknowledged, the challenges associated with care pathways and the potential impact this has on the patient are not known.

Despite their increasing use and a growing body of literature associated with care of the dying pathways, few studies have provided critical consideration or evaluation of these pathways (Watts, 2013). One study has evaluated the use of the Liverpool Care Pathway (LCP) in an acute care setting, drawing the conclusion that that the LCP positively influenced EOL care. The study found that the LCP was a critical factor in changing the processes associated with EOL care including identifying dying, changing the direction of care, and improving documentation, knowledge teamwork, communication and clinician confidence (Clark, Sheward, Marshall & Allan, 2012).

## **2.5 A sociological perspective**

One significant viewpoint omitted from the published papers is a sociological perspective of EOL care in acute hospitals. Given publishing guidelines including word limits and specific interests of the journal used for publication, it was not possible to include this important perspective in the two publications that form the substantive literature review.

Though all living things will die, the path to this eventuality is not the same for all; and humans/people do not die in the same way (Kellehear, 2007). From the moment a person is born, they are moving closer to death. For some, dying is seen as an inevitable outcome determined by God or fate (Howarth, 2011) and for others death is connected with luck and chance or an event that could strike anyone at any time (Lupton, 2012). Our contemporary understanding of dying is a culmination of features inherited from past traditions as well as from the current public health, political, and economic pressures of society (Kellehear, 2007).

### ***2.5.1 Medicalisation of death***

Where death was once a social and communal affair (Bishop, 2011; Kubler-Ross, 1969), typified by a bedside vigil occurring in the family home and officiated by a religious person for whom death was their domain (Howarth, 2007; Lupton, 2012), society has now changed and death is less likely to occur in the home. More deaths are occurring in healthcare environments (Palliative Care Australia, 2008a). Advances in medicine and technology have resulted in the assumption that medicine can control mortality and reverse dying (Bishop, 2011; Kellehear, 2000) with some people now believing that life can be sustained indefinitely (Bishop, 2011). Nowadays, someone is not considered dying unless it can be first said that medicine has given up on them (Bishop, 2011).

Even though death and dying are no longer the taboo subjects they once were, death has been regarded as a failure of care (Addicott & Ashton, 2009). Likewise the trend for dying to occur in

institutions has contributed to the medicalisation of death (Glaser & Strauss, 1965; Sudnow, 1982). Medicalisation is a sociological term for the increasing practice of attaching medical labels to behaviour considered socially and morally undesirable (Green, 1987). The implication of this definition is that by categorising or labelling something as a disease (including natural processes such as menopause or ageing) the condition is susceptible to being perceived as capable of cure or delay (Aronson, 2002). Several decades ago Ivan Illich (1976) argued that the medicalisation of dying meant there was a loss of capacity to accept death and dying and the role of clinicians in death care had devalued the traditional rituals surrounding death and dying. Professionals deny the imminence of death and instead focus on sickness and healing (Kellehear, 1984). Even with medicalisation, however, there is still no cure for death (Boyle & Carter, 1998). This has resulted in physicians endeavouring to balance technical intervention to prevent dying with a humanistic orientation to the dying patient (Clark, 2002).

### ***2.5.2 Sequestration of death***

In contemporary Western societies, death has been sequestered. Death has been removed from the community gaze and hidden from view (Howarth, 2007) and 'public access to death is controlled (Lupton, 2012). In the interests of preserving social boundaries associated with intimate bodily care (Exley & Allen, 2007) and the lack of family carers to provide care to the dying (Howarth, 2007), the majority of people now die in institutions such as hospitals and residential care, away from the public gaze (Howarth, 2007). Dying and mourning have been privatised and confined to the immediate family (O'Connor, et al., 2010). As a result, death is no longer a familiar occurrence in everyday life, nor do people have experiences of death (such as a death in their home of an elderly loved one) upon which to draw. Rather, members of society have come to rely on information from an expert to be informed about an impending death (Kellehear, 2007). As a result of sequestration, "The recognition of dying

hence became a social riddle... derived from a professional source of awareness such as a physician” (Kellehear, 2007, p. 252).

Sequestration of death is not just demonstrated by the relocation of dying from the community into institutions, but the impact can also be seen within institutions, where single rooms, considered the dying rooms of the ward are prioritised for people at the EOL (Howarth, 2007). Death and dying is often further hidden by the use of screens and curtains, ensuring the occurrence of death is neither seen nor known (Howarth, 2007; Kubler-Ross, 1969). This practice of hiding dying, may not be in the best interest of the dying person: “Never before have people died as noiselessly and hygienically as today in these societies and never in social conditions so much fostering solitude” (Elias, 1985, p. 85).

### ***2.5.3 Nurse-doctor relationship and power***

In considering hospital care, attention to the relationship between the nurse and doctor is imperative, especially in its impact upon and on its influence on patient care. From its inception as an occupation in the nineteenth century, nursing was subordinate to medicine, similar to the sexual division of labour (Porter, 2006). Described as the ‘Doctor-Nurse Game’ (Stein, 1967) the relationship and interactions between doctors and nurses is influenced by numerous factors including gender, power, and training. Given that medical education was undertaken in university and nurse training occurred ‘on-the-job’ (until relatively recently), the divide in social class and status and the perception that nursing was sub-ordinate, continued (Lupton, 2012).

Traditionally, it was the doctor’s role to diagnose patients, decide on an appropriate course of treatment and the nurse’s function was to carry out the work (Porter, 2006). Nurses have often been regarded as little more than servants who simply carry out orders given by the doctor (Lupton, 2012). This unequal relationship between doctors and nurses has not just



been perpetuated by doctors. Nurses have also unknowingly and inadvertently perpetuated this unequal power relationship (Keddy, Jones, Burton & Rogers, 2006). Even when nurses are in a position of authority (for example, in charge of a ward and often are lead decision-makers on admissions and allocation) they continue to maintain an elaborate façade of sub-ordination, hiding the skills, knowledge and information they possess (Stein, 1967). A study in intensive care similarly found that nurses often may remain passive, reluctant to articulate their knowledge or contribute to patient management (Coombs & Ersser, 2004). Nevertheless, the work of Gamarnikow (1991) suggests that when nurses do share their knowledge, they often determine and make decisions on what is medically relevant. Assessing what they believe is happening with the patient, nurses influence the data available to the doctor and, hence, influence the doctor's decision-making or diagnosis (Gamarnikow, 1991).

The development of multi-disciplinary team meetings and ward rounds have helped to establish the equality of nurses and doctors, rather than nurses as subordinate (Svensson, 1996). Similarly, the change from task-focussed nursing to patient-centred care (Dempsey, French, Hillege & Wilson, 2009) is likely to have also further raised the profile and status of nurses. This is particularly notable because of the strong nurse-patient relationship that develops as a consequence, something at which doctors have not been so successful (Allen, 1997). Even so, a study of intensive care clinicians reported that while doctors placed significant importance on the nurse-patient relationship and the intimate knowledge that nurses can acquire as a result, doctors frequently ignore this source of information (Coombs, 2003).

Of equal importance to understanding the relationship between doctors and nurses, is the need to understand power as it pertains to nurses. Just as health professionals are socialised according to the norms and needs of a hospital, subject to demands and constraints which shape how they work, the nurse's ability to influence actions or assert power is also influenced



by the same socialisation process (Lupton, 2012). Nurses experience professional conflict over their responsibility for the patient, unequal power with medical personnel, sexism and paternalism. And while nurses are given primary responsibility for the care of patients, this responsibility is subject to institutional rules and the imposition of medical authority who wish to oversee the care, at times undermining a nurse's power and professional autonomy (May, 1992).

While the literature presented here is drawn from and presented using a sociological viewpoint, the amount of influence, if any, of these factors on this study and the study setting are highly interpretative and beyond the scope of this study. However, an understanding of history and the social construction of interactions between medicine and nursing contextualises the conclusion drawn about the interactions between clinicians and contemporary patient care and places them in the acute hospital environment.

## **2.6 A psychological perspective**

While all of the literature presented thus far provides an understanding of the context of this study, a psychological perspective, in particular the anxiety associated with death and dying is now examined.

### **2.6.1 Anxiety**

Anxiety is a primal emotion affecting an individual's whole being that occurs in response to a life event (Bourne, 2010), or the anticipation of a threatening but vague event (Rachman, 2004). It can be pervasive and persistent, lacking clear borders that define its onset and end. For many people anxiety is present in the background most of the time (Rachman, 2004). A state of heightened vigilance rather than an emergency reaction, in its purest form, anxiety is diffuse, unpleasant, and persistent (Rachman, 2004).

Many theoretical perspectives are proffered regarding anxiety. Sigmund Freud viewed anxiety as an inevitable part of living (Freud, 1969) and defined it as “an affective state...of most obviously unpleasurable character” (Freud, 1936, p.69, as cited by Spielberger, 1966), and “....as a signal indicating the presence of a danger-situation” (Freud, 1936, p. 119, as cited by Spielberger, 1966). Distinguishable from other unpleasant affective disorders, anxiety is characterised by a combination of phenomenological and physiological qualities, which together give to anxiety a special character of unpleasure (Spielberger, 1966).

Freud (1969) also claims that as well as physiological responses to anxiety, individuals have a psychological response in the form of defence mechanisms, which attempt to ward off anxiety by preventing conscious awareness of threatening feelings. These defence mechanisms operate on an unconscious level and work to distort, deny or falsify reality so that it is less threatening (Freud, 1969). The behaviour motivated by anxiety is avoidant in nature and when successful, leads to a reduction in anxiety, which in turn, reinforces the avoidant behaviour (Rachman, 2004).

### **2.6.2 Death anxiety**

According to death anxiety theory, death is seen as the final failure of life (Deffner & Bell, 2005) and the prospect of death of self or others can generate concern and anxiety amongst most human beings (Richardson, Berman & Piwowarski, 1983). Also referred to in the literature as ‘death fear’ (Thorson & Powell, 1988) and ‘death denial’ (Becker, 1973), ‘death anxiety’ is the term used to describe an unpleasant emotion of existential origin provoked on contemplation of death of self or others (Nyatanga & de Vocht, 2006). Freud also captured the anxiety associated with death:

*It is not for us to confess that in our civilised attitude towards death we are once more living psychologically beyond our means, and mist reform and give truth its due? Would it not be better to give death the place in actuality and in our thoughts which properly belongs to it, and to yield a little more prominence to that*

*unconscious attitude towards death which we have hitherto so carefully suppressed?*  
(Freud, 1915, as cited by Becker, 1973).

Irrespective of the definition, death anxiety is a multidimensional construct related to fear of, and anxiety related to the awareness and anticipation of the reality of death and dying and includes cognitive, emotional, and motivational components (Lehto & Stein, 2009). From a cognitive perspective, components of death anxiety include the ability to anticipate or predict the future, an awareness of the salience of death (Lehto & Stein, 2009) and attitudes to death, which develop as a result of cumulative life experiences (Neimeyer, Wittkowski & Moser, 2004).

Often largely repressed and hidden in activity, death anxiety influences an individual's action and reaction to death and dying (Lehto & Stein, 2009; Yalom, 2009). When death or dying is confronted, an individual's primal survival responses are evoked and the individual responds to protect themselves from the unknown. This protection comes in the form of defence mechanisms. These defence mechanisms may involve both unconscious and conscious psychological manoeuvres that attempt to reduce anxiety by deceiving the individual about the intensity of threat or reality of the situation (Bailey & Clarke, 1989).

Defence mechanisms commonly employed to lessen death anxiety include denial, withdrawal, avoidance, and rationalisation (American Psychiatric Association, 2000; Beck, Emery & Greenberg, 2005). Denial has been recognised for some time as a short-term coping strategy in situations deemed threatening (Boyle & Carter, 1998; Cox, 1985). Withdrawal and avoidance are also used as a way of avoiding pain and unpleasant emotions (Brisley & Wood, 2004). Rationalisation, such as rationalising a death, similarly helps the individual to lessen the anxiety and avoid the pain of loss (Boyle & Carter, 1998).

### **2.6.3 Nurses and death anxiety**

The concept of death anxiety holds significant importance to nursing because of the potential impact that it may have on the efficacy of care provided to dying patients (Deffner & Bell, 2005; Lehto & Stein, 2009; Thorson & Powell, 1988). Nurses are confronted by death and dying more frequently than any other health professional (Boyle & Carter, 1998; Brisley & Wood, 2004). Even though caring for the dying is part of the nursing role and acknowledged by nurses as something that 'comes with the territory' (Boyle & Carter, 1998), not all nurses are innately prepared for this part of their role. This suggests that a nurse's self-efficacy in relation to caring for the dying - that is, the individual's perceived ability and self-confidence in their ability (Bandura, 1977) may influence the care they provide, which in turn may influence attitudes. Self-efficacy is commonly explored in education research (Stump, Husman & Brem, 2012; Taylor & Reyes, 2012); however links between the concept of self-efficacy and end of life care have not been studied empirically.

A nurse's attitude to death and death anxiety is likely to be constantly evolving in response to life experiences, both personal and professional (Wilson & Kirshbaum, 2011). Where palliative care nurses, by the nature of their chosen specialty, deal with death and dying on a daily basis (Halliday & Boughton, 2008), nurses in non-palliative care areas may be less exposed to death and dying and, thus, less prepared (Peters et al., 2013). A recent Spanish study conducted in a hospital setting found that while nurses were confident in providing physical care to terminally ill patients, they were less comfortable in providing emotional care for the patients. More than 50% of nurse participants in this study mentioned anxiety and depression, indicating the severity and impact of this role upon them (Arantzamendi, et al., 2012).

There is also evidence to demonstrate the link between age and gender and death anxiety. Fortner and Neimeyer (1999) demonstrated that death anxiety was higher among the middle-aged and more recent research has demonstrated that death anxiety is more prevalent

amongst middle-aged females (Tan, O'Connor, Howard, Workman & O'Connor, 2013). This figure is representative of the average age of Australian nurses reported in demographic studies (Australian Institute of Health and Welfare, 2011).

Aside from these known contributing factors, establishing the presence or impact of death anxiety is complex. For some it is overt and easily identified, and for others it is covert and subtle (Yalom, 2009). Anxiety is likely to be identified by the behaviours that manifest in nurses as a way of coping. These coping mechanisms can directly impact on the care nurses provide to their patients (Brisley & Wood, 2004).

Death anxiety can manifest as professional distance (Glaser & Strauss, 1965) and avoidance of intimacy and interaction (Thorson & Powell, 1988; Wakefield, 1999; Wakefield, 2000). It enables the nurse to remain detached, withdrawn emotionally, and avoid pain (Brisley & Wood, 2004). Nurses also rely on single rooms to isolate the dying from other patients as a way of managing the dying and hiding the source of their anxiety (Brisley & Wood, 2004; Porock, Pollock & Jurgens, 2009). After a death, nurses have been found to use rationalisation in order to evaluate a death and minimise their own anxiety (Glaser & Strauss, 1964).

### ***Professional Distance***

Many factors influence how much time a nurse may be able to spend with any one patient (Thompson, et al., 2006). When a nurse is confronted by a dying patient, however, this may influence how much time the nurse chooses to spend with the patient and how the time is spent. Glaser and Strauss (1965) detail how nurses use professional distancing to limit or avoid any contact with a dying patient not deemed necessary, as a way of coping with their death anxiety. Similarly Arantzamendi and colleagues (2012) described a predominance for 'necessary touch' when conducting tasks or physical care over non-necessary touch when caring for the dying. Similarly, a preference for, or a pre-occupation with technical elements

of nursing work or the patient's physical needs can enable the nurse to withdraw from the source of his/her anxiety (Brisley & Wood, 2004).

### ***Rationalising death***

For others, rationalising a death helps to enforce the emotional distance between the nurse and a dying patient. Nurses evaluate patients according to their various social characteristics such as age, level of education, and their role in life such as mother or father (Glaser & Strauss, 1964), react accordingly, and respond to their own death anxiety (Peterson et al., 2010; Rachman, 2004). Identified first in the 1960s by Glaser and Strauss (1964), rationalising a patient's death/impending death, as a way of coping with one's own discomfort with death and dying, is a common thread in other literature (Kubler-Ross, 1969; Peterson, et al., 2010; Rachman, 2004). It is particularly relevant to this study.

## **2.7 Summary**

The publications included in this chapter, as well as in the literature presented in sections 2.2 to 2.5, present a foundation of the extant literature drawing from both empirical and non-empirical origins. Given the dearth of high level research evidence, non-research literature such as guidelines, position statements, and other documentation from key and peak professional bodies is used to inform patient care at the EOL and thus, it would be remiss to exclude these sources. Additionally, the inclusion of a sociological perspective, inclusive of death anxiety, is imperative to understanding the findings generated in this study.

The literature subsequently presented in Section 2.6 presents the theory of anxiety, and more specifically, death anxiety and how it relates to nurses. This literature is imperative as it is used like a 'theoretical lens' to provide an alternate/complementary understanding of the research findings presented later in this thesis. This theoretical lens also assists the research

to shape and strengthen the connection between Phase One and Two of this study. How this is done is detailed in Chapter 3, to follow.

In the following chapter, the methodological approach employed in this study is detailed.

## CHAPTER THREE - RESEARCH DESIGN

### PART B: Suggested Declaration for Thesis Chapter

Monash University

#### Declaration for Thesis Chapter Three

##### Declaration by candidate

In the case of Chapter Three, the nature and extent of my contribution to the work was the following:

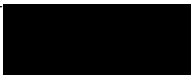
Nature of contribution	Extent of contribution (%)
Concept development, key ideas, development, writing up and critical revisions	80%

The following co-authors contributed to the work. If co-authors are students at Monash University, the extent of their contribution in percentage terms must be stated:

Name	Nature of contribution	Extent of contribution (%) for student co-authors only
Professor Wendy Cross	Critical Revision	N/A
Professor Margaret O'Connor	Critical Revision	N/A
Professor Ruth Endacott	Critical Revision	N/A
Assoc. Professor Cheryle Moss	Critical Revision	N/A
Dr Maggie Doman	Co-writing	N/A

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the candidate's and co-authors' contributions to this work\*.

Candidate's  
Signature

	Date 12/08/2013
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Main  
Supervisor's  
Signature

	Date
--	------

\*Note: Where the responsible author is not the candidate's main supervisor, the main supervisor should consult with the responsible author to agree on the respective contributions of the authors.



### **3.1 Introduction**

This chapter outlines the design and methods used in this study. As previously suggested, mixed methods was selected as the most appropriate method to address the aims of this study. Therefore, each phase will be detailed. Two papers that relate to methodological issues that arose from this study are included.

### **3.2 Mixed Methods**

The origins of mixed methods research are well documented and date back over 50 years (Creswell & Plano Clark, 2011). Over this time, various attributions such as 'integrated' or 'combined' research have been used as a way of emphasising the notion that two approaches to data collection are blended together (Steckler, McLeroy, Goodman, Bird & McCormick, 1992). Similarly, Campbell and Fiske (1959) suggested a 'multitrait-multimethod matrix' approach to research inquiry, which enabled the inclusion of multiple sources of quantitative data in the validation of psychological traits. Cronbach (1975) also advocated a new way of viewing research, arguing that allowing descriptive data to be considered when scientific data on its own does not show a statistically significant outcome will enable researchers to think more constructively about results than they may have otherwise. Madey (1982) has examined the beneficial synergistic effects of integrating quantitative and qualitative methods within the design, data collection, and analysis phases of a single study. Where both qualitative and quantitative methods are used, each method is strengthened by the intrinsic qualities of the other.

Green, Caracelli and Graham (1989) extend this work, focusing on the purpose of mixed methods research and provide an extensive review of published mixed methods studies, including the nomenclature associated with mixed methods. Morse (1991) investigated

methodological triangulation, being the use of at least two methods, usually qualitative and quantitative to address a research problem, where either one on its own would be inadequate and where the two methods could be used simultaneously or sequentially. Morse's work is significant as prior to this, the timing of the two methodological approaches had not been articulated (Plano Clark & Creswell, 2008). Morse also demonstrated a nomenclature system for describing mixed methods approaches that clearly described the theory underpinning the research and the sequential or simultaneous nature of the research (1991).

More recently researchers have continued to consider mixed methods as more than just the use of both qualitative and quantitative methods within the one study. Mixed methods have also been described as the 'third methodological movement' (Tashakkori & Teddlie, 2003), considered better suited to address research problems of a complex nature (Creswell & Plano Clark, 2011). Likewise, mixed methods have been described as an approach that combines elements of qualitative and quantitative research approaches, including viewpoints, data collection and analysis techniques for the purposes of breadth and depth of understanding and corroboration (Burke Johnson, Onwuegbuzie & Turner, 2007).

Contemporary experts in the field argue that mixed methods research is an intuitive way of conducting research that is constantly on display through our lives (Plano Clark & Creswell, 2008). Plano Clark and Creswell (2008) explain how in everyday life, qualitative and quantitative data are used to tell a story, that is a better story than one reliant on one or the other alone. A news report about a cyclone, for example, will not only include important statistics, such as size, category rating, and projected path over populated land, but will also include stories about people whose houses were lost, human suffering, and environmental damage. It is when these two types of data are combined that the news report becomes more powerful and meaningful. These historical developments assist in developing and refining

mixed methods as a complete research design, a complete distinct approach in its own right (Creswell & Plano Clark, 2011).

It is the work of Creswell and others (Creswell, 2009; Plano Clark & Creswell, 2008) that have contributed significantly to the student researcher's understanding and perspective of mixed methods research. Recognising that all methods have limitations, combining methods helps address the limitations of each method individually (Creswell, 2009). Given that the intent of this research was to examine and explore nurses' recognition and responsiveness to dying patients in the acute hospital setting, qualitative and quantitative research methods individually were not adequate to research this problem. Through the use of mixed methods, qualitative and quantitative approaches can be used to complement each other and provide a deeper understanding of the research phenomenon or problem (Creswell, 2009). While it is vital to understand quantitative data on patients dying in acute care wards, this approach alone is unlikely to answer the current research problem. By using qualitative methods as well, the researcher can acknowledge the context and then use qualitative techniques to further explore the phenomena.

### ***3.2.1 Philosophical worldview/Paradigm***

It is clear from the literature that debate continues about the epistemology that underpins mixed methods research. While Sandelowski (2000) suggests that a combination of the positivist paradigm (quantitative) and the constructivist paradigm (qualitative) is difficult because of their separate and different ontological worldviews, others argue that mixed methods may in fact be a third paradigm, capable of bridging the gap between qualitative and quantitative positions (Burke Johnson, et al., 2007).

Morgan (2007) describes a paradigm as the set of practices and shared beliefs that guide the field of inquiry. It influences the questions that researchers pose as well as the methods they

employ to answer them. Pragmatism as a paradigm focuses on the consequences of research and on the primary importance of the question rather than the method; and on the use of multiple methods of data collection to inform the problem/s under study (Creswell & Plano Clark, 2011). This philosophy of pragmatism argues that the consequences/outcomes are more important than the process, recognising that qualitative and quantitative research methods can be used together to maximise the strengths and minimise the weaknesses of each other, in a way that offers the best chance of answering the research question (Burke Johnson & Onwuegbuzie, 2004).

Morgan (2007) proposes an organising framework that assists understanding the unique advantages that the pragmatic approach can offer the researcher, shown below in Table 1:-

Table 1. Mixed Methods Framework			
	<b>Qualitative</b>	<b>Quantitative</b>	<b>Pragmatic</b>
	<b>Approach</b>	<b>Approach</b>	<b>Approach</b>
Connection of theory to data	Induction	Deduction	Abduction
Relationship to research process	Subjectivity	Objectivity	Inter-subjectivity
Inference from data	Context	Generality	Transferability

(Morgan, 2007).

The distinction between induction and deduction is one of the obvious differences between qualitative and quantitative research. Morgan (2007) discusses that abduction, as a pragmatic approach allows the researcher to move back and forth between induction and deduction as needed. For example, a researcher may first use observation (induction) to develop theories and then use quantitative processes to test the theories (deduction). Similarly, where subjectivity and objectivity are usually dichotomous, pragmatism supports the intersubjectivity

that sits between ‘complete objectivity’ and ‘complete subjectivity’ and allows the researcher to move between various frames of reference (Morgan, 2007).

Pragmatism also seeks to place itself between context-specific knowledge and generalised knowledge. Morgan (2007) rejects the notion that research results can either be so specific that there are no implications that fall outside of one particular context, or so broad that they apply to every possible context. Instead, Morgan espouses ‘transferability’ as the pragmatic approach to knowledge in that in each research context. In this approach it is necessary to consider whether knowledge gained from one setting can be transferred to another and the factors that affect this (Morgan, 2007). The manner in which mixed methods were used in this study is presented in Section 3.4.

### ***3.2.2 Utilisation of death anxiety theory***

Theorising assists researchers to consider and identify any theoretical perspective that may guide the entire design of the study; and how theory is used affects its placement in a study (Creswell, 2009). In mixed methods research theories are often found at the beginning of the study, like a lens or ‘bigger picture’ perspective that shapes how the study is conducted, the types of questions asked, and how the data will be collected (Creswell, 2009). The sequential exploratory design of this study meant that there was some flexibility through which the second phase could be informed by the findings of the first.

Death anxiety theory is important to making the connection between Phase One and Two. As detailed in Chapter Two, a nurse’s attitude, coping and behaviour can be influenced by their death anxiety, thus impeding therapeutic relations with their dying patient. Because of this link between death anxiety theory, resultant attitude, and care of the dying patient, Phase Two of this study was designed as detailed in Section 3.6.

While it was not the intention of the researcher to measure death anxiety, death anxiety theory will be used to enable a greater understanding of the findings, as well as give greater depth to the data collection and analysis processes. In Phase One, the data collected during observation will be explored and analysed on 'face value' using the qualitative methods described later in this chapter (Section 3.5.8). To establish more depth, the same data will be viewed via the 'death anxiety' lens for further understanding.

### **3.3 Study Aim**

The aim of this study was to explore nurses' recognition of and responsiveness to dying patients in an acute hospital (non-palliative care) setting; and to understand the nurses' influence, if any, on the provision of EOL care in that setting.

#### ***3.3.1 Research assumptions***

- a) Nurses are able to 'recognise' when a patient is dying through comprehensive patient assessment and interaction with the patient and their family.
- b) Nurses are, at times, unable to provide EOL care, until consensus is reached by the entire health professional team involved in the patient's care.

#### ***3.3.2 Research questions***

- 1. How do nurses recognise dying?
- 2. How do nurses respond to the dying patient?
- 3. How do nurses influence the care a dying person receives?
- 4. What systems and/or processes influence care of the dying person?

A matrix depicting how these assumptions and questions are answered within the parts of this mixed methods study is detailed below.

Table 2. Matrix of Exploration

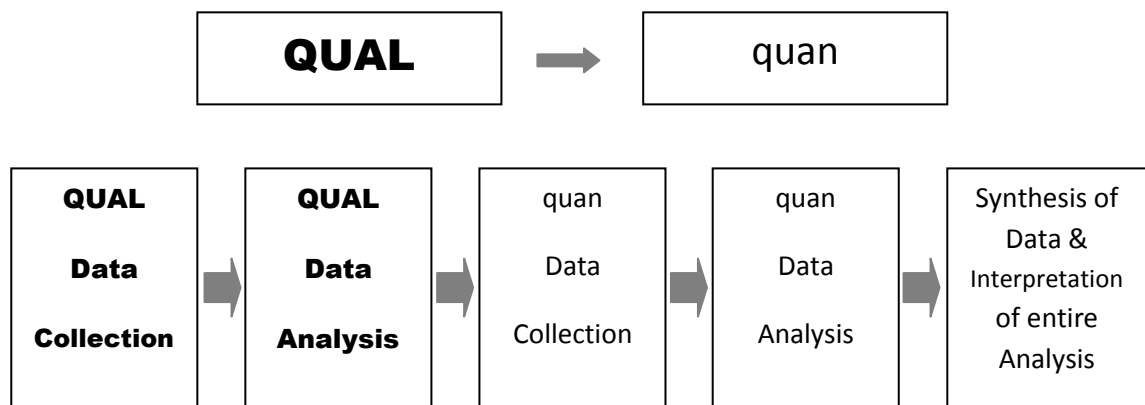
	Phase 1			Phase 2	
	Observation	Focus Group Interviews	Individual interviews	FAT-COD Survey	FAT-COD DOC Survey
RA a) Nurses are able to 'recognise' when a patient is dying through comprehensive patient assessment and interaction with the patient and their family.	✓	✓	✓		This survey was a later addition to the research design and did not relate to the original Research Assumption and Questions. Rather, it developed as a result of the Phase One findings
RA b) Nurses are at times, unable to provide EOL care, until consensus is reached by the entire health professional team involved in the patient's care.	✓	✓			
RQ 1) How do nurses recognise dying?	✓	✓	✓		
RQ 2) How do nurses respond to the dying patient?	✓	✓	✓		
RQ 3) How do nurses influence the care a dying person receives?	✓	✓	✓	✓	
RQ 4) What systems and/or processes influence care of the dying person?	✓	✓	✓	✓	

### 3.4 Study Design

Given that this study is particularly interested in understanding the human influence, that is, how nurses recognise and respond to the dying patient, thus influencing care of the dying, a mixed methods approach, which combines the strengths of both qualitative and quantitative research approaches (Creswell, 2009) was chosen. This approach was considered most appropriate for answering the research questions. Specifically, a sequential exploratory design

was used, where the initial and primary phase of data collection was qualitative in nature (Phase 1), followed by a phase of quantitative data collection and analysis that builds on the findings of the initial qualitative phase (Creswell, 2009). Figure 1 depicts the design.

Figure 1. Sequential Exploratory Design



*N.B. The nomenclature used in this diagram reflects that developed by Creswell.*

(Creswell, 2009)

The qualitative phase was used first so that a theory could be generated (Morse, 1991).

Creswell and Plano Clark also suggest that this design may be useful when the researcher wants to quantify variables that impact on a phenomenon, when the variables are unknown (Creswell & Plano Clark, 2011). In this way, the qualitative and quantitative data complemented each other and were thought to provide a richer meaning than each approach could do in isolation. The subsequent phase of quantitative data collection was used to assist in understanding key data related to the problem in question and provide a basis to generalise the findings to a population (Creswell, 2009).

### 3.5 Phase One – Qualitative Phase

Phase One of this study used several qualitative methods of data collection with which to gather data on how nurses recognise and respond to a dying patient.



### ***3.5.1 Ethical Approval***

Ethical approval was initially gained from XXXXXXXXXX Human Research Ethics Committee (HREC) B in April 2011, with a subsequent amendment approved in June 2011 (Reference 11021B). Ethical approval was gained from Monash University HREC (MUHREC) in June 2011 (Project number CF11/1853 – 2011001039) (See Appendix 1).

### ***3.5.2 Site Selection***

This phase was conducted wholly within one health service in metropolitan Melbourne, Victoria, which serves more than 20 per cent of the population of the city and consists of more than forty care locations (XXXXXXXXXX, 2011). This health service was chosen because of its size, scope of service provision and geographic location, and an accessible research population.

In order to determine which wards/units might be the most appropriate to conduct Phase One data collection, assistance was sought from XXXXXXXXXX to identify potential sites (wards) where the study could be undertaken. The types of wards considered appropriate were those where a large number of deaths occur (Pincombe, Brown & McCutcheon, 2003). The type of care delivered and staff exposure to death and dying in critical care areas and palliative care units made these units unsuitable and were, therefore, excluded from consideration. As a result, two acute wards with the highest rates of death were identified.

### ***3.5.3 Participants and Consent***

All nurses and Nurse Unit Managers were invited to participate in this study irrespective of their role, qualifications, or experience. When non-permanent nursing staff, such as casual or agency staff, were allocated to work in the chosen wards and were involved in the care of a

dying patient, they too were invited to participate. Student nurses were excluded from the study.

Nursing staff were informed of the study in several ways. A flyer was developed and posted within the wards to inform the staff about the study. Also, several information sessions similar to 'ward in-services' were held in each ward to further explain the research. A 'Participant Information and Consent Form' (PICF) was also provided. Consent was obtained from each participant prior to the commencement of the study, and reaffirmed at each subsequent opportunity.

Subsequent to the provision of information and discussion, consent was sought from all nursing staff. Given the nature of shift work, each time the researcher visited either of the participating wards further education and consent processes for participants were necessary. Prior to a nurse consenting to participate in the study, a PICF was provided and the particulars of the study were discussed and any questions answered. With every subsequent visit to the participating wards and prior to any episode of observation, nursing staff who had not yet consented to participate were invited to do so. Additionally, any nursing staff who had previously consented were asked to confirm their willingness to participate. Participants were advised that at any time, they could opt out of the research altogether or perhaps just for the shift, or for any other period. Twenty-five nurses (from both wards) were approached to participate of these eleven were non-permanent staff and none refused.

#### **3.5.4 Method**

Initially non-participant observation was used to gather data, followed by focus group interviews and individual semi-structured interviews. A critique of these methods is provided below.

### **3.5.5 Critique of methods**

#### ***Non-participant Observation***

Non-participant observation was considered the most appropriate method for this phase of the study. When used in the field, this form of social interaction enables the researcher to secure information for scientific purposes (Gold, 1958), collect data on physical and verbal and allow the researcher to see and describe the phenomena in the natural context in which it occurs, (Biros & Baren, 2009; Burns & Grove, 2011; Mulhall, 2003; Schneider, Whitehead, Elliott, Lobiondo-Wood & Haber, 2007). Such an approach also makes it useful for the development of theory (Morse, 2003).

Observation may reveal more than can be elicited through conversation or formal interview, as often individuals may not verbally share information or details that they dismiss as trivial or extraneous (Morse, 2003). It also allows the researcher to see how the participants work within and relate to their physical environment (Mulhall, 2003), making it the ideal method for learning about people's social practices (Moore & Savage, 2002) as the evidence comes from seeing what people actually do, rather than relying on what they say they do (Mulhall, 2003).

Whilst the 'participant-observer' role is well known, it is most strongly associated with ethnographic research and involves the researcher immersing themselves in the research field as part of the team (Bonner & Tolhurst, 2002). In this approach, both the observer and the participants are aware of their research relationship (Gold, 1958). This method is used also when the researcher seeks to understand a social reality by spending time within it and assumes a role similar to those who inhabit the area under study (Bonner & Tolhurst, 2002; Griffiths, 2008). This immersion facilitates the development of relationships (Gold, 1958) given that the data collection phase continues for a prolonged period, with the researcher becoming more immersed in the field over time (Murphy, 2005).

The 'non-participant observer' role, in contrast, keeps the researcher as an independent and non-judgemental outsider, a role which does not form part of the group under observation, but enables a researcher to step in and out of the group at will, interacting and conversing with them and developing productive relationships (Schneider, et al., 2007). The 'non-participant observer' calls for more formal observation than the 'participant-observer' role and, as a result, there is less risk that the observer may 'go native' and lose sight of the research objective (Gold, 1958).

The non-participant observer role, however, can also make use of a researchers' dual identity, such as a researcher and a nurse, enabling a connection to develop on a collegial level. Equally, the researcher is an 'outsider', not part of the working team, either as an employee and not known to the nursing staff in any other way. As a result, the observer does not present with any known pre-conceived opinions or attitudes about the participants. The outsider perspective may also have other advantages, as Bonner and Tolhurst (2002) explain. In their experience, participants feel safe to divulge complex professional and personal information to the observer because they were not part of the team and could not use the information to impact the workplace. The outsider perspective also allows them to notice subtle differences and nuances in activity with different groups of research participants. This has been described as a sensitivity to difference, as the observer might have missed key information when acting as an insider (Bonner & Tolhurst, 2002).

### ***Focus group interviews and individual semi-structured interviews***

Focus group interviews are popular amongst qualitative researchers because they can be used to help explore research questions (Schneider, et al., 2007). In this study, it was determined that focus groups would be an effective way to generate further discussion, and assist clarification and understanding about some of the observed practices and actions. While

focus group research has become very popular amongst qualitative health researchers, this method of data collection can have some limitations.

Morse (2012) warns that the data collected from focus groups comprises opinions given in response to questions asked in a group – these are typically the opinions that participants are only willing to share publicly. Therefore, responses may not be participants' authentic opinions, but socially desirable opinions and attitudes. The dynamics of focus group participants can create a type of coercion which may influence participants' responses (Morse, 2012). In this way, the responses can become 'group think' outcomes (Schneider, et al., 2007) rather than a true reflection of each focus group participant's individual opinion (Morse, 2012).

Another consideration is that the data collected from a focus group can only represent the perspectives or range of views of those who participated, rather than prevalence (Liamputtong, 2009). Given that focus groups were used to complement the data collected via observation, these focus groups proved valuable in improving the researcher's understanding of what was observed. Two focus groups were held, with 6 participants in one and 5 in the other.

Interviews are also useful for enabling researchers to gain a deeper understanding or explanation of other findings (Andrew & Halcomb, 2009). Semi-structured interviews, where guiding prompts or phrases are used, were chosen over unstructured interviews because, as Morse (2012) suggests, semi-structured interviews are best used when the researcher knows what questions he/she wants to ask but does not know what to expect in the response. These interviews also enable the researcher to probe further in response to a participant's comment, but also allow the participant to use 'story telling' to express themselves (Minichiello, Sullivan, Greenwood & Axford, 2004).

Individual interviews are necessary when there may be existing working relationships or unequal power relationships between research participants. This situation makes focus group interviews of several people difficult, but also ethically challenging. The Australian National Statement on Ethical Conduct in Human Research describes how pre-existing relationships between participants, such as supervisors and their employees

*“...may compromise the voluntary character of participants’ decisions, as they typically involve unequal status, where one party has or has had a position of influence or authority over the other.”* (National Health and Medical Research Council, Australian Research Council & Australian Vice-Chancellors' Committee, 2007, p. 59).

Protection of participants is a priority. As a result, focus groups that include individuals in hierarchical or unequal relationships are not advised (National Health and Medical Research Council, et al., 2007).

### **3.5.6 Data Collection**

As detailed in the publication entitled *‘The ‘dis-ease’ of dying: Challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study’* included at the end of this chapter, non-participant observation formed the primary source of data collection.

Participants were observed by the researcher providing care to those patients who were recognised as dying. The commencement of observation was ‘triggered’ by a participant identifying that a patient was dying. Some ‘episodes of observation’, defined as an ‘episode’ or ‘block of time’ in which observation took place, were triggered by a telephone call by the nurse informing the researcher that a patient was ‘dying’. A telephone referral form collected data on the reason the referral was made. Following this, impromptu visits were also undertaken. If at the time of the impromptu visit a patient was recognised by nursing staff as ‘dying’, an episode of observation was initiated.

Twenty episodes of observation involving the dying patient and their allocated nurse were undertaken, lasting between 2-3 hours depending on the amount of activity occurring at the time. Each episode of observation involved the researcher observing nursing care and interaction not only with the dying patient but also the family and with colleagues. The researcher made a moral decision not to impose on 'family time' and was not present at the death of any of the patients.

A process of latent documentation was used where all observations were documented after the period of observation was complete, once removed from the ward area. That is, the researcher left the ward and found a quiet location to record her observations using a laptop computer. A second record of 'reflections' in which observations were reflected upon and explored was also maintained during the data collection period.

When undertaking observation, the researcher dressed in a manner similar to the nursing staff, so that she did not attract the public's attention, but with university identification clearly displayed and visible to clinicians.

Given that this study involved observation of nurses caring for dying patients, there are numerous considerations for the researcher, exacerbated by the presence of dying patients. These considerations are detailed in the publication titled '*Qualitative observation in a clinical setting: Challenges at end of life*', included at the end of this chapter.

Subsequent to the completion of the non-participant observation, focus group interviews and individual semi-structured interviews were conducted respectively with nursing staff and Nurse Unit Managers. The purpose of these interviews was to enable the researcher to seek clarification and a deeper understanding of what was observed. In both the focus groups and individual interviews 'guiding questions and phrases' derived from the observation findings and were used as prompts both to facilitate the flow of the interview and to elicit meaningful



data from the participants (Schneider, et al., 2007). This approach ensured the responses were not influenced by the researcher, as may have occurred with a more specific line of questioning.

The researcher elected to conduct individual interviews with the Nurse Unit Managers, rather than include them in the focus group interviews for two reasons. First, it was thought that the Nurse Unit Managers may have a different perspective than nursing staff and, second, because of the existing hierarchical relationship that exists between the Nurse Unit Manager and the nursing staff from each ward. Not only would interviewing Nurse Unit Managers and nurses together potentially result in nurses being influenced or intimidated by the presence of their manager, but it may also lead to a conflict of interest, where one person's individual interests or responsibilities have the potential to influence another's (National Health and Medical Research Council, et al., 2007).

While it was the researcher's intention to also interview medical staff from both of the participating wards, none of the medical staff were willing to participate.

### ***3.5.7 Data Saturation***

Data saturation is a concept most closely associated with grounded theory. It is used by researchers as a way of justifying the number of participants or the extent of data collection, during the qualitative data collection process (Minichiello, et al., 2004). The point of data saturation is considered to have been met when few or no new data are being generated (Padgett, 2008).

In relation to non-participant observation, this was defined as the point at which there were no longer any new insights available through observation; in other words, the researcher did not observe any action or behaviour that offered new insights or information, or that had not

already been identified and observed. This point was assessed through personal reflection and by reading and re-reading both the observation notes and the reflective notes.

The focus groups were considered similarly. While the same guiding questions/prompts were used in both focus groups, the degree of similarity between the responses in each focus group was high. The researcher determined that there was not likely to be any added benefit in conducting more than two focus groups.

### ***3.5.8 Data Analysis***

Phase One consisted of data in the form of observation notes, observation reflection notes, focus group transcripts, and individual interview transcripts. Initially, each type of data were analysed separately using qualitative content analysis (Schneider, et al., 2007). Each document was read and re-read in its entirety and examined for themes and sub-themes that emerged from the raw data. Colour coding was initially used to identify thematically relevant data within each manuscript. Following this, a table summary, adapted from Moretti and colleagues (2011) was developed, and showed how themes were derived from the raw data.

The results from the focus groups and interviews were then further analysed to ascertain how they contrasted or confirmed the observation findings. The advantage of using the focus group and one-to-one interview data in this way was that it assisted in confirming/dispelling some assumptions and themes derived from the observation data. Similarly, the perspectives of nursing staff were compared to those of the Nurse Unit Managers and highlighted the similarities and differences between the perspectives of those nurses who carried out care for the dying patients and those who maintained a management role within the ward environments.

### **3.5.9 Rigour**

Historically, rigour is a term associated with quantitative research, but the meaning and application of rigour in qualitative research has taken on a different meaning. Rigour in qualitative research was highlighted by Lincoln and Guba (1985) who suggested that the concepts of 'validity' and 'reliability', which measure rigour in quantitative research, are inappropriate to measure rigour in qualitative research. Rather, rigour in qualitative research is the careful adherence to the principles of qualitative inquiry during the conduct of the project (Morse, 2012), that considers the carefulness of data collection, and the thoroughness of analysis (Burns & Grove, 2011).

Prior to commencing this study, the researcher developed documentation and determined processes that would ensure rigour in studying the research problem. For example, the researcher determined how observation would occur, what process would be used for recording data, what interaction, if any, the researcher would have with those within the observation field, and how/when observation would be terminated. The process for analysis of the data was also determined prior to the commencement of the study.

The decision to use focus groups and individual interviews subsequent to the completion of the observation was so that the findings from the observation could be further explored. This enabled the researcher an opportunity for clarification and understanding of observations from the perspective of the participants. As a result, the researcher was more confident that the findings were an accurate reflection of what occurred.

In the analysis phase, a systematic approach, adapted from Moretti and colleagues (2011) was used to analyse the qualitative data. Using this approach, the researcher and supervisors analysed the data separately, then compared their analysis, working together until consensus

was reached. This process also helped to ensure the process of analysis was rigorous and trustworthy.

### **3.6 Phase Two – Quantitative Phase**

While a number of key findings were derived from Phase One (see Chapter 4), it was beyond the scope of this study to explore all findings, so the decision was made to focus on one key finding from Phase One, being 'attitude' towards care of the dying. The death anxiety literature presented in Chapter 2 suggests that an individual's attitude and behaviours can be influenced by death anxiety. Certainly, the Phase One findings suggest that attitudes and /or death anxiety may be influencing behaviour in this group of nurses. Further, nurse participants suggested that doctors may have had a negative attitude towards care of the dying.

Despite what is known about the link between death anxiety and attitude however, death anxiety itself was not measured, and it is equally possible that an individual's attitude toward any phenomena/issue, including care of the dying may be formed independent of death anxiety. As the findings of Phase One were more reflective of 'attitude' and not death anxiety, then the next logical step was to explore attitudes, rather than death anxiety. Consequently, this phase of the study was specifically designed to further explore attitudes towards care of the dying, in both (a) a nursing population and, (b) a final year (pre-service) medical student population which may or may not be influenced by an individual's death anxiety.

Surveys were used to investigate attitudes towards care of the dying. Nurses were the primary focus of this phase. However, a pilot survey of final year medical students was also undertaken concurrently, using a modified version of the same survey tool used with nurses. Given however, that the attitudes of doctors were not the primary interest of the researcher, it was determined that a convenience sample of final year (pre-service) medical students from

Monash University would be used, rather than practicing doctors. It was decided that medical students were likely to be both easier to access and recruit, and have enough relevant clinical experience to contribute meaningfully to this study. This was considered the most efficient method to access and involve individuals with medical training and with exposure to death and dying.

### **3.6.1 Ethical Approval**

Ethical approval was sought from Monash University HREC (MUHREC) for both surveys.

Consent was also obtained from administrators of the Monash University MBBS program to use final year medical students. Health service approvals were also necessary for three metropolitan health services in Melbourne, through which the nurse survey was distributed to nurse employees. Whilst it was initially submitted to MUHREC as ‘low risk’ as an anonymous, voluntary online survey, MUHREC determined that it would require a full ethics application because of the sensitive nature of the topic. The various requirements for ethical approval are detailed below.

Table 3. Phase Two Ethical Approval

	MUHREC	Metropolitan Health Services, Melbourne			Monash MBBS Program
		A	B	C	
<b>Nurse Survey</b>	Full Ethics	Full Ethics	Low Risk	Ethics approval not required	N/A
<b>Final year (pre- service) medical student Survey</b>	Full Ethics	N/A	N/A	N/A	✓

### ***Nurse Survey (FATCOD) Amendments***

After commencement of the Nurse survey (described in detail later in this chapter), several new strategies were introduced to improve the survey's response rate. These strategies included:

1. Approval to use hard copy surveys (as well as electronic) and to use existing planned nurse education events such as 'study days' and 'in-service' to distribute surveys at one Metropolitan Health Service;
2. Approval to advertise the survey nationally to members of the Australian College of Nursing (ACN) via ACN electronic newsletters;
3. Approval to advertise the survey nationally to members of the Australian Nursing Federation (ANF) via electronic publications.

### ***3.6.2 Survey tool selection and development***

A survey was considered the most effective way of examining attitudes. Following a search of the relevant literature, a number of survey tools/instruments were considered and the most appropriate which met the needs of this phase of the research, was the '*Frommelt Attitude Towards Care of the Dying*' tool (Frommelt, 1991), also referred to as FATCOD.

### ***FATCOD History***

The FATCOD tool was originally developed by Katherine Frommelt and first published in 1991. The stated purpose of this instrument was to assess nurses' attitudes towards the terminally ill and their family members. It was also used pre and post-education to measure the effectiveness of an educational program designed to change attitudes towards care of the

dying (Frommelt, 1991). Frommelt reflected on other available tools that tried to measure various aspects of nurses' attitudes towards their own death, but was unable to find a tool that she felt adequately measured nurses' attitudes towards caring for the terminally ill and their families. As a result, the FATCOD tool was developed and used initially as a pre and post-measure following formal education delivery (Frommelt, 1991).

Consisting of 30 items which are scored on a five-point likert scale ranging from Strongly Disagree (SD) to Strongly Agree (SA), the tool is made up of an equal number of positively and negatively worded statements, that, when totalled, produce a score out of 150. Higher scores reflect more positive attitudes (Frommelt, 1991). Instructions for how to score the tool is included as Appendix 5. When originally developed, the FATCOD tool underwent validity testing and a content validity index (CVI) was computed. The CVI for this tool was 1.00, with an interrater agreement of 0.98. A test-re-test procedure was used to assess the reliability of the tool and a Pearson Product–Moment Correlation Coefficient was computed at 0.94. A Pearson's Coefficient of 0.90 was also computed (Frommelt, 1991).

Since 1991, the FATCOD and its variations (FATCOD Form B, FATCOD Form B-J and FATCOD Abbreviated Version) have been used extensively and in a variety of ways. Of the 23 studies identified in the literature that use the FATCOD in its original form or subsequent iterations, 21 utilised nurses as participants (Brajtman, Fothergill-Bourbonnais, Fiset & Alain, 2009; Brajtman, Fothergill-Bourbonnais, S, Alain & Fiset, 2007; Braun, Gordon & Uziely, 2010; de Kock, 2011; Dobbins, 2011; Dunn, Otten & Stephens, 2005; Frommelt, 1991; Halm, Evans, Wittenberg & Wilgus, 2012; Iranmanesh, Axelsson, Haggstrom & Savenstedt, 2010; Iranmanesh, Dargahi & Abbaszadeh, 2008; Kinoshita & Miyashita, 2011; Lange, Thom & Kline, 2008; Mallory, 2003; Matsui & Braun, 2010; Miyashita et al., 2007; Wessel & Rutledge, 2005).

Of these 21 studies, 13 used the FATCOD in combination with other tools/instruments (Brajtman, et al., 2009; Brajtman, et al., 2007; Braun, et al., 2010; Dobbins, 2011; Halm, et al.,



2012; Iranmanesh, et al., 2010; Iranmanesh, Dargahi, et al., 2008; Kinoshita & Miyashita, 2011; Lange, et al., 2008; Matsui & Braun, 2010; Miyashita, et al., 2007; Morita et al., 2007; Wessel & Rutledge, 2005), with the remaining 8 using only the FATCOD (Ali & Ayoub, 2010; Alvaro, 2009; Barrere, Durkin & LaCoursiere, 2008; de Kock, 2011; Dunn, et al., 2005; Frommelt, 1991; Iranmanesh, Savenstedt & Abbaszadeh, 2008; Mallory, 2003).

In 7 of the studies using nursing participants, the FATCOD was used as a pre and post measure of the effect/impact of an education program (Alvaro, 2009; Barrere, et al., 2008; Dobbins, 2011; Frommelt, 1991; Halm, et al., 2012; Mallory, 2003) (Appendix 3).

### ***FATCOD tool for a nursing population***

The FATCOD, in its original form, was considered appropriate for use with a nursing sample population. Even though the FATCOD had already undergone validity and reliability testing it was decided to undertake further validity testing, given that the tool had not been previously used with an Australian nursing population. Using Polit et al.'s (2007) method, face validity was tested using a reference group of nursing professionals who would not fall into the sample population. These nurses could attest that on 'face value' the tool did measure the concept it was designed to test. The reference group comprised four senior nurses with significant experience in the acute care hospital sector.

Content Validity (S-CVI) was also assessed with this tool, using an item-level CVI 4 point scale (Polit, et al., 2007) in which the same reference group rated each element of the tool in terms of its relevance to the goal of assessing attitudes towards care of the dying patient. Polit et al. (2007) suggest that 0.80 demonstrates 'acceptable' content. This tool demonstrated a S-CVI of 0.95, meaning that the tool does measure what it purports to measure (that is, it is reliable).

### ***FATCOD-DOC tool development for a final year (pre-service) medical student population***

There was no published literature found to suggest that the FATCOD tool, in its original form or otherwise, had ever been used for a sample population of doctors or medical students.

Following formal approval from Katherine Frommelt (via personal email) a modified version of the FATCOD tool was developed and titled 'FATCOD-DOC'. Modifications and testing were necessary to ensure the tool was appropriate and measured what it was designed to measure.

These modifications involved changing the wording in 9 of the 30 items in the FATCOD to make them fit with the role and perspective of a doctor/student doctor, rather than a nurse.

For example, Item 6 was changed from '*The **nurse** should not be the one to talk about death with the dying person*' to '*The **doctor** should not be the one to talk about death with the dying person*'.

### ***FATCOD-DOC Validity and Reliability***

The newly developed FATCOD-DOC tool was analysed for reliability and validity. A reference group of doctors was put together and used to test face validity and content validity, using the same methods described above. The reference group, who were senior doctors, who would not be part of the actual sample population reported that on 'face value' the tool did measure what it was designed to test. The groups used a similar 4 point scale to assess each item on the tool for content validity (S-CVI) and their results indicated a score of 0.83, which is higher than the minimum acceptable score of 0.80 for content validity (Polit, et al., 2007).

The FATCOD-DOC tool was computed to have high internal consistency, with a Cronbach alpha coefficient of 0.86. See Table 4 below.

Table 4. FATCOD-DOC Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.86	.88	30

Given that this tool is newly developed it is not possible to compare this measure of internal consistency against other studies. However, other studies that have used the original FATCOD tool have indicated an alpha coefficient of 0.72 (Iranmanesh, et al., 2010), 0.77 (Iranmanesh, Savenstedt, et al., 2008) and 0.89 (Wessel & Rutledge, 2005) and one study that used the FATCOD-Form B-J, a Japanese variation of the original FATCOD, demonstrated an alpha coefficient of 0.89 (Wessel & Rutledge, 2005). On the basis of this comparison, the FATCOD-DOC tool scores well and has high internal consistency.

The item total statistics for all 30 FATCOD-DOC items were analysed and are shown in Table 5 below. These data indicate that each of the thirty items in the FATCOD-DOC scale are highly correlated with the total score, meaning that each individual item is measuring the same as the FATCOD-DOC scale as a whole.

Table 5. FATCOD-DOC Item Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Q1	118.47	123.982	.551	.852
Q2	118.50	127.017	.170	.859
Q3	119.83	124.764	.238	.858
Q4	118.60	124.317	.447	.854
Q5	119.17	117.040	.654	.846
Q6	118.50	123.293	.437	.853
Q7	119.03	121.068	.412	.853
Q8	119.60	121.007	.346	.856
Q9	119.03	116.309	.561	.848
Q10	118.50	124.328	.338	.855
Q11	118.47	126.533	.317	.856
Q12	119.43	121.289	.445	.852
Q13	119.53	116.947	.647	.846
Q14	118.97	118.033	.571	.848
Q15	119.10	117.403	.551	.849
Q16	118.47	123.361	.608	.851
Q17	118.63	124.585	.322	.856
Q18	119.40	124.317	.175	.862
Q19	119.53	123.430	.222	.860
Q20	119.43	125.771	.130	.863
Q21	118.73	117.582	.741	.845
Q22	119.13	121.223	.396	.854
Q23	118.47	122.671	.589	.851
Q24	119.03	124.033	.336	.855
Q25	118.67	125.333	.198	.859
Q26	119.63	121.826	.269	.859
Q27	118.53	125.292	.422	.854
Q28	118.67	126.713	.190	.859
Q29	119.13	122.051	.393	.854
Q30	118.73	120.202	.483	.851

### **3.6.3 FATCOD Nursing Survey**

A large nursing sample group was necessary in order to draw conclusions about the attitudes of nurses towards care of the dying and how this may impact upon care. Several sampling options were considered, such as accessing members via existing professional organisations or health service workplaces. The priority was to source a nursing sample population that would be most reflective of a greater nursing population. Therefore, the decision was made to access several health service employee populations and specifically invite registered nurses working in the acute care areas (excluding palliative care) to participate. Three metropolitan Melbourne health services were chosen as sites for recruitment because existing research relationships exist between these health service organisations and Monash University, School of Nursing and Midwifery.

It was not possible to estimate the number of registered nurses working in these health services. While Annual Reports may indicate the number of nurses in each health service, this number may be representative of FTE (full time equivalent) or actual persons and a breakdown of nurses in the acute sector is not known.

#### ***Inclusion and Exclusion Criteria***

Exclusion criteria:-       (i) never cared for a dying patient  
                                     (ii) not working in acute care

Inclusion criteria:-       (i) cared for a dying patient  
                                     (ii) currently working in an acute care setting (excluding palliative care areas).

Registered nurses working in palliative care wards were excluded on the basis of their existing expertise and, similarly, those working in critical care areas were excluded because of the immediate nature of the care provided in critical care areas (Pincombe, et al., 2003).

### ***Recruitment and Consent***

Potential participants were contacted via an email which explained the purpose of the survey sent by a health service representative. This email contained information about the study in the body of the email as well as an Explanatory Statement supplied as an attachment. The Explanatory Statement contained all information mandated by the ethical approval process. Participation in the online survey implied consent to participate.

### ***Data Collection***

The online survey was housed at [www.surveymonkey.com](http://www.surveymonkey.com). Once data was entered into the survey, it was not possible for it to be retrieved. Hard copies of the survey were also used at one Health Service in an attempt to increase the participation rate. The hard copy surveys and Explanatory Statement were distributed directly to potential participants and later collected.

### ***FATCOD Survey Analysis***

Data downloaded from SurveyMonkey and hard copy survey data were entered into SPSS (Statistical Package for the Social Sciences) Version 20. The survey analysis comprised of:-

- (i) reporting the demographic characteristics of the respondent population;
- (ii) calculation of the Mean score (QAverage) and total scores for all items;
- (iii) an analysis of the QAverage in relation to respondent demographic characteristics;  
and
- (iv) qualitative content analysis of the open-ended responses.

### ***3.6.4 FATCOD-DOC medical student survey***

Final year (pre-service) medical students from Monash University School of Medicine were recruited for this survey. Although they are students, consultation with the MBBS Program

Executive, confirmed that these final year medical students had sufficient clinical experience in acute care settings to be able to respond to the survey.

### ***Inclusion and Exclusion Criteria***

Exclusion criteria:- (i) never cared for a dying patient  
(ii) never worked in acute care

Inclusion criteria:- (i) cared for a dying patient  
(ii) has worked in an acute care setting (excluding palliative care).

These criteria were designed to reflect the inclusion and exclusion criteria determined for the registered nurse sample population and to exclude palliative care and critical care areas for the same reasons (Pincombe, et al., 2003).

### ***Recruitment and Consent***

359 final year (pre-service) medical students, in their final year of education were emailed by a representative of the Bachelor of Surgery/Bachelor of Medicine (MBBS) Executive at Monash University. The email provided information about the study, an invitation to participate in the body of the email, and an Explanatory Statement as an attachment. The Explanatory Statement contained all of the information mandated by the ethical approval process. The email also contained a link to the anonymous online survey housed at [www.surveymonkey.com](http://www.surveymonkey.com).

Potential participants were asked to consider the inclusion and exclusion criteria and determine if they could participate in this study. Participation in the online survey implied an individual's consent to participate. Once data was entered into the survey, it was not possible for it to be retrieved.



### ***Data Collection***

The online survey was housed at [www.surveymonkey.com](http://www.surveymonkey.com). Once data was entered into the survey, it was not possible for it to be retrieved.

### ***FATCOD-DOC Survey Analysis***

Data downloaded from SurveyMonkey were entered into SPSS Version 20. The survey analysis comprised of:

- (i) reporting the demographic characteristics of the respondent population;
- (ii) calculation of the Mean score (known as the QAverage) and total scores for all FATCOD-DOC items;
- (iii) an analysis of the QAverage in relation to respondent demographic characteristics;  
and
- (iv) qualitative content analysis of the open-ended responses.

### ***3.6.5 Rigour***

The rigour of both surveys was assured through the face validity and content validity testing described earlier in this chapter. This assured the researcher that the survey questions would be answered in the same way if given to the same person on two or more different occasions (assuming their opinion did not change) (De Vaus, 2002; Punch, 2003).

### ***3.6.8 Ethical Considerations***

A number of ethical considerations arose throughout this phase of the study.

### ***Phase One***

The use of observation as a method of qualitative data collection proved to be ethically challenging, in terms of protecting the rights of participants and others who are present in the observation field. These challenges are detailed in the publication entitled '*Qualitative observation in a clinical setting: Challenges at end of life*' included at the end of this chapter.

The impact that participants (and others who work in the setting) can have upon the researcher was also a potential issue in this study. The ways in which the 'observed' can create ethical dilemmas for the researcher is discussed in detail at the end of this chapter in the publication '*How the observed create ethical dilemmas for the observers: Experiences from studies conducted in clinical settings in the UK and Australia*' included at the end of this chapter. This paper reflects on experiences from this study and that of a colleague in an unrelated study conducted in the United Kingdom.

### ***Phase Two***

There were several ethical considerations in constructing the survey and determining how it was to be implemented. It was imperative that surveys were ethically sound before implementation, and designed and constructed in way that reflects the researcher's ethical responsibilities towards survey participants which included 'doing no harm' (De Vaus, 2002). Of primary concern was the risk of distress to any survey respondents in response to the survey content. To address this concern, the Explanatory Statement specifically showed that the survey was voluntary and anonymous, and that those who suspect that they might find it distressing, should refrain from participating. Furthermore, respondents were advised to cease completing the survey if they became distressed at any time.

The identity of respondents was also protected by opting not to collect identifying data such as name, IP address, or other identifiable demographic variables. Also, all demographic

questions contained within the surveys were optional and could be skipped by the respondent.

### 3.7 Summary

In this chapter, the study methodology was identified as mixed methods and used a 'Sequential Exploratory Design' in which the qualitative component of data collection was the primary focus and where the purpose of the quantitative data collection was to contribute to a greater understanding of the qualitative data. Two publications have been included that relate to this chapter.

The first publication titled '*Qualitative Observation in a clinical setting: Challenges at end of life*' explored the methodological and ethical challenges associated with undertaking qualitative observation in the clinical setting at EOL. The authors reflected on the experiences of using non-participant observation to explore the nursing care delivered to dying patients in acute hospital wards. They also discussed the challenges of observation as a method of data collection defining the participant group and undertaking research that indirectly involves vulnerable populations, such as dying patients and their families. Other related factors to consider when working within the observational field such as the researchers' dual roles, cost versus benefit, impact of culture, religion and ethnicity, and the determination of research limits/boundaries were also discussed.

The second publication titled '*How the observed create ethical dilemmas for the observers: Experiences from studies conducted in clinical settings in the UK and Australia*' is a publication written in collaboration with a colleague in the United Kingdom who also used observation as a data collection method for her doctoral studies. This paper details how, despite comprehensive and robust ethical approval processes which focus on protecting participants and ensuring researchers meet their responsibilities, there are other less overt and often

understated ethical challenges that can arise when conducting observational research in a clinical setting. Reflecting on this study and another observational study conducted by Maggie Doman, a co-author, the challenges of blurring role boundaries, the risk of collecting redundant data and the impact of reverse power relationships between researchers, clinicians and managers are explored. This paper suggests that the preparatory work undertaken with clinicians and managers onsite prior to the commencement of data collection should also highlight the sometimes overlooked ethical issues associated with participatory research like those detailed in this paper. Consideration of these factors can help ensure that participants and managers understand the scope and limitations of the research and consider the ways in which the observed can influence the researcher and the findings.

# Publication: Qualitative observation in a clinical setting: Challenges at the end of life



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## Research Article

# Qualitative observation in a clinical setting: Challenges at end of life

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## Abstract

This paper explores the methodological challenges associated with undertaking qualitative observation in the clinical setting at end of life. The authors reflect on their experiences of using non-participant observation to explore the nursing care delivered to dying patients in acute hospital wards. The challenges of observation as a method, clearly defining the participant group and involving vulnerable populations, such as the dying patients and their families, will be discussed. Consideration is also given to defining and working within the observational field, the researchers' dual roles, cost versus benefit, impact of culture, religion and ethnicity, and the determination of research limits/boundaries, with reflections from the authors' own experiences used to exemplify the issues.

## Key words

clinical setting, death, dying, end of life, non-participant observation, observation, qualitative.

## INTRODUCTION

Those who embark on research in the clinical setting face a multitude of challenges, many of which are set in place to ensure the safety and rights of the individuals involved. Researchers take responsibility for designing methodologically sound research that is ethically sensitive, particularly where vulnerable populations are concerned. Dying patients, and those receiving palliative care, can be considered inherently vulnerable, thus requiring a high degree of moral and ethical awareness throughout the research process.

This paper explores the methodological challenges experienced by the authors who undertook a study, utilizing non-participant observation to explore the nursing care of dying patients in an acute hospital (non-palliative care) setting. The experiences of the researchers in undertaking this study are used to exemplify the challenges of observation in a clinical setting, and might help to inform or assist others who plan to conduct similar research. It is not the intention of the authors to report on the findings of their research, but to explore the deliberations they worked with as they undertook this study, to reveal the thinking and preparation that went into achieving a methodologically-robust research project that acknowledged the vulnerability of dying patients and their families. The responsibilities and thoughtfulness associated with a methodological approach of this nature will be discussed.

With the world population aging, and chronic illness now the leading cause of death (Davies & Higginson, 2004; Thompson *et al.*, 2006), the challenges facing health professionals are changing. The new reality in Australia, which reflects similar situations in other developed countries worldwide, is that 50–60% of the population will die in while an inpatient in a health facility (Jennings 2005; Talon *et al.*, 2007; Department of Health, 2009; Hillman, 2009). Of those who die in hospital, many will continue to receive active treatment, aimed at cure, right up until death (Verbeek *et al.*, 2008; Aleksandrie & Hanson, 2010a). Care of the dying patient, in particular those who die in general acute hospital beds, has received little research attention (Powell *et al.*, 2004).

## BACKGROUND: QUALITATIVE STUDIES IN END-OF-LIFE CARE

In the 1960's Glaser and Strauss undertook what is now regarded as "seminal research", exploring the area of death and dying. One particular study explored the impact of patient death on clinicians and found that nurses developed self-protective strategies to enable them to cope with the loss, falling back on their professional stance, and focusing on another patient or on specific tasks as a way of avoiding the death (Glaser & Strauss, 1964). While these strategies might not be desirable or ideal, Glaser and Strauss found that they helped the nurses maintain composure and efficiency in their roles, particularly when the nurses were aware that the next patient to be admitted will need their expertise (Glaser & Strauss, 1965).

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More recently, Bernuzzi *et al.* (2008) reported that the death of a patient in the acute hospital setting is often seen as failure of treatment, and clinicians have difficulty in accepting that death is the likely outcome, and similar to Glaser and Strauss' work, their focus remained on tasks and care that contributes to curative treatment (Thompson *et al.*, 2006). The literature also highlights that clinicians have difficulty in diagnosing dying, or recognizing that the patient has entered into the dying phase (Verbeek *et al.*, 2006; Pugh *et al.*, 2010; Bloomer *et al.*, 2011), a situation that further compounds the delivery of inappropriate care for dying patients in the acute hospital setting. There is also considerable evidence that care pathways, such as the Liverpool Care Pathway, have contributed to the improvement of clinical care for the dying, and resulted in increased staff satisfaction (Jack *et al.*, 2003; Murphy *et al.*, 2007; Ingleton *et al.*, 2009); however, a number of questions still remain unanswered; for example, how nurses identify patients as dying, how they respond to them, and how they care for the patient and family.

### CONDUCTING QUALITATIVE OBSERVATION RESEARCH: LITERATURE AND RESEARCHERS' REFLECTIONS

The remainder of this paper examines the authors' experiences and reflections on using observation as a research method in a clinical setting, while also relating it to the literature.

The research exemplified in this paper was undertaken in two medical wards of a metropolitan health service in Melbourne, Australia, which were shown to have the highest rates of death. Critical care, palliative care, and oncology wards were excluded from consideration. Ethical approval for the study was granted by the human research and ethics committee of the health service, with subsequent approval granted by the university.

Several data collection methods were possible in this study; however, given the principal researcher is also an acute care nurse, the preference was to use a "clinician's eye" and undertake observation to attempt to answer the research questions. There are also typically limitations with the other methods; in particular, the influence of "social desirability" on participant self-reports in both interviews and focus groups, which can impact upon the results (Minichiello *et al.*, 2004). Undertaking observation in a ward or other clinical area, however, is not without complication, particularly if there is confusion over whom or what is being observed and why.

### OBSERVATION AS A RESEARCH METHOD IN END-OF-LIFE CARE

Murphy and Dingwall describe observation as the closest to a gold standard in qualitative research (Murphy & Dingwall, 2007), and where the goal of the research is descriptive, observation in the field enables the researcher to obtain information (Gold, 1958) and to see what people actually do (Caldwell & Atwal, 2005). It is a systematic method of data collection where the researcher gathers data through their

senses within the real world context in a way that enables the researcher to "see it for themselves". In this case, the principal researcher wanted to use a "clinician's eye" to undertake observation in an attempt to meet the research aim, and gather information about the care delivered to dying patients in the acute hospital setting. By observing the nursing care first-hand and in context, observation can provide the most significant clues to putting a puzzle together that was otherwise difficult to solve (Morse, 2003). Observation also allows the researcher to see how the participants work within and relate to their physical environment as it occurs (Mulhall, 2002; Caldwell & Atwal, 2005), and, in this way, it is an ideal method for learning about people's social practices (Moore & Savage, 2002), where the evidence comes from seeing what people actually do, rather than listening to what they report that they do (Mulhall, 2003).

In order to ensure that the researchers captured data in unedited and uncensored form, observation was chosen as the most appropriate method to examine end of life in this study. Observation allows the researcher to collect data aspects of nursing care, such as physical and verbal behavior, actions, and reactions, and also allows the researcher to see and describe the phenomenon in the natural context in which it occurs (Mulhall, 2003; Schneider *et al.*, 2007; Birss & Baren, 2005; Burns & Grove, 2011), making it useful for the development of knowledge and theory (Morse, 2003).

While it could be argued that interviewing the nursing staff might also be a suitable method of data collection to answer the questions in this study, interviewing relies on the participant's accurate and truthful recollection of the events, where participants can describe their actions in interviews, but this does not account for difference between what people actually do and what they say they do (O'Leary, 2005). Interview is at risk of the participant dismissing some information as trivial or extraneous or undesirable, and therefore, not sharing it (Morse, 2005).

Historically, however, the complex ethical nature of studies utilizing observation as a research method has discouraged researchers from using this method (Morse, 2003), but with due consideration and attention to detail, they can be overcome, facilitating worthwhile research outcomes. There is a challenge, however, in turning a skill that clinicians use every day into a rigorous and robust research method, capable of shedding new light on a phenomenon previously not understood. Challenges also exist in ensuring the research protocol can credibly capture the data required, minimize researcher bias, facilitate trust and rapport with participants that assists with ensuring people behave naturally, protect confidentiality and anonymity, while minimizing the impact on those being researched (O'Leary, 2005).

### Approaches to observation

There are several approaches to observation that can be used, depending on the role adopted by the researcher. "Participant-observer", an approach rooted in anthropology, has always been the central technique of ethnographic research (Minichiello *et al.*, 2004), and involves the researcher immersing themselves in the research field, clearly



playing a role in the setting apart from that as researcher, such as that of a nurse in a ward (Bonner & Tolfurst, 2002; Minichiello *et al.*, 2004), where both the observer and the participants are aware of their research relationship (Gold, 1958). This method is used when the researcher seeks to understand a social reality by spending time with those who inhabit the area under study (Bonner & Tolfurst, 2002; Gribb, 2008), so that a relationship can be developed (Gold, 1958). Often the data collection phase continues for a prolonged period, becoming more immersed in the field over time (Murphy, 2005), but this long-term immersion does increase the risk that the researcher can lose perspective and "go native" (Gold, 1958).

In contrast, the "non-participant observer" role keeps the researcher as an independent and non-judgemental outsider, who does not form part of the group under observation, but can step in and out of the group at will, interacting and conversing with the group, and developing productive relationships with the participants (Schneider *et al.*, 2007). The "non-participant observer" calls for more formal observation than the "participant-observer" role, and enables the researcher to make use of their dual identity, such as a researcher and a nurse. This dual identity can enable a connection to develop on a collegiate level between the nurse as a researcher and the nurse participants, and also maintaining the researcher's position as an "outsider", who is not part of the working team as an employee.

The advantage of the researcher's position as an outsider is that the researcher might not present with any known pre-conceived opinions or attitudes about the participants. The outsider perspective can also have other advantages: Bonner and Tolfurst (2002) reported on their experiences of conducting researcher using participant observation, where participants felt safe to divulge complex professional and personal information to the observer, because they were not part of the team and could not utilize the information to impact the workplace. The outsider perspective also allowed them to notice subtle differences and nuances in activity with different groups of research participants, described as a sensitivity to difference that the observer might have missed as an insider (Bonner & Tolfurst, 2002).

The dual identity, however, can also pose some challenges for the researcher. Researchers who are also clinicians need to be cognizant of the potential tension this dual identity can create, which might result in situations where the researcher has to choose one identity and its associated obligations over the other, in the best interests of the study participant or patients, and perhaps to the detriment of the study itself. As a "non-participant observer", there might be times when the researcher observes practice that compromises patient safety or well-being, and as a registered nurse, the researcher is duty-bound to intervene for the patient's sake (Australian Nursing and Midwifery Council, 2005), and sometimes to the detriment of the research objectives (Payton, 2006). This choice is made more difficult by the fact that deciding what is a significant enough threat to their safety or well-being that it requires intervention is not clear (Parahoo, 2006).

It is important that the participants understand that the researcher's responsibility to "act" as a nurse, in the event of

compromised patient safety, is of course no more or less than the obligation of any other nurse working in the ward, and thus, this obligation is nothing to be feared. Similarly, the researcher can encounter situations where those who are being observed might call upon the researcher, who is also a nurse, to act in a nursing capacity, when this not only contravenes ethical approval, but also arrangements with the health service, particularly when the researcher is not an employee.

### Hawthorne effect

The potential impact of the Hawthorne effect must always be considered when undertaking descriptive research of this nature. The Hawthorne effect refers to the tendency for people to behave differently when they know they are being studied (Chiesa & Hobbs, 2008), in an attempt to present a "good face" to the researcher (Payne *et al.*, 2007). The true impact of this effect can vary, and is not always known. Several studies report that the impact of the Hawthorne effect is often overplayed, with no compelling evidence to suggest that the behavior of the participants changed when in the presence of the researcher, with most professionals being too busy to maintain a behavior that is radically different from their normal behavior for any length of time (Mulhall, 2003; Pincombe *et al.*, 2003; Parahoo, 2006; Chiesa & Hobbs, 2008). The longer the researcher spends in the observation field and begins to blend in, the less significant this effect becomes (Turnock & Gibson, 2001; Pincombe *et al.*, 2003; Leonard & Masatu, 2006; Chiesa & Hobbs, 2008).

In this study, it did not appear that the Hawthorne effect was in play, as the principal researcher observed that many activities were howevering on "inappropriate", such as the use of unprofessional and judgemental language used in the end-of-shift handover report. Surely, any changes in behavior on the part of the participants would be to portray a more positive image, not a negative image.

### OTHER FACTORS IMPACTING ON THE SUCCESS OF OBSERVATION AS A RESEARCH METHOD

#### Observation field

Researchers planning to use observation as their data collection technique must give due consideration to the field of observation and the challenges posed by the field. The observation field in this study is a busy medical ward in a large metropolitan hospital, and while a setting like this is considered semiprivate (Murphy & Dingwall, 2007), the researcher has little control over who is in the field at any one time (Mulhall, 2003). Moreover, the unpredictability of observational research often means that it is difficult to say in advance quite what will be observed and when, with any certainty (Mulhall, 2003). However, the use of observation in a healthcare setting does require sensitivity to the changing context of clinical activity. This requires the observer to consider in advance, for example, how they will behave if an emergency situation develops.



## Participants

The researchers anticipated that it might have been difficult to gain ethical approval for this study, given that dying patients and their families are indirectly involved. However, the research protocol and the researchers were very clear about whom the participants actually were, and as a result, a methodologically-rigorous research process was developed that conforms to the Australian National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council *et al.*, 2007). This is particularly important in observational research, where many others might, by circumstance, enter into or be located within the researcher's field of observation, even when they are not considered participants in the study.

In this study, consent was obtained from nursing staff to allow observation of the nursing care they provide to dying patients. The Human Research Ethics Committee of the health service did not, however, require consent from the dying patients themselves, health professionals or other staff, and members of the public who entered the observation field, particularly because the research did not intend to change nursing practice at all. It is acknowledged that ethics committees in other countries might take a different approach to this issue; however, in this case, the researchers were clear about those for whom the research was likely to be of significance. In this case, it was the nurses who were being observed, and those for whom the research is deemed inconsequential, and thus did not need to be consented (Parahoo, 2006; Murphy & Dingwall, 2007). While the researchers were not required to consent the dying patients and their families, information about the research was freely available on both wards to all patients admitted to the ward.

## Vulnerable populations

The goal of this study was to observe nursing care delivered to patients who were recognized or identified by the nursing staff as "dying", so observing this type of care cannot happen unless dying patients are present in the field of observation. Where vulnerable populations are concerned, human research and ethics committees, and the researchers themselves, are obliged to ensure that their rights are protected (National Health and Medical Research Council *et al.*, 2007). In this case, the researchers had to be clear that the participants in this research were the nursing staff, not the dying patients or their families. We argued that the presence of dying patients in the observation field was incidental, not core to this study. This was clearly articulated in the ethics application to the health service human research and ethics committee who granted approval. The researcher, however, still has an obligation to inform those that enter the research field, including patients, their families, health professionals, and members of the public, that a study is occurring in the ward, an obligation that obviously requires caution and particular consideration of how the information is provided, so that it does not cause psychological hurt (Schneider *et al.*, 2007). A ward flyer was developed and made freely available to any and all persons who entered the observation field.

## Being sensitive to the needs of the patients and their families

The participants in our research were the nursing staff. Nevertheless, due consideration and a sensitivity to the needs and wishes of the dying patients and their family are not only ethically fair, but also the humane and "right" thing to do (Lampert, 2009). While privacy can sometimes be hard to define, and encompasses bodily, spatial, and interpersonal privacy (Johnson, 2005), the researcher must use judgement to know when to step back and facilitate some privacy. In this regard, time spent in the research setting, building relationships with participants is an important part of the preparation for data collection. Although the goal is to observe nurses caring for dying patients, this should not be to the detriment of others in the observation field.

It is also imperative that respect for the dying patients and their families remains a primary focus for the researcher: this includes a recognition of their intrinsic value, including having due regard for their welfare, beliefs, perceptions, customs, and cultural heritage (National Health and Medical Research Council *et al.*, 2007). The family's desire to hold vigil at the bedside and tend to the patient's needs, where able, is highly important (Boucher *et al.*, 2010). In this research project, the principal researcher's preference was to maintain sufficient distance from the dying patient and their family to maintain their privacy when the family was present. This was a personal moral decision on the part of the principal researcher not to encroach on family time. Given that the principal researcher did not identify herself as a researcher to the patient and/or family, it is unlikely that the presence of the researcher would have affected the patients' or families' behaviors any more or less than any other person entering the patient and family's private space. Engaging with the ethical and practical challenges inherent in working with very ill patients and their families is fundamental to the success of this type of research.

The researcher was not present at the time of death for any of the dying patients; however, if the researcher had been present, the researcher would have discontinued the observation of the nurse, out of respect for the family. The researcher might have chosen to wait outside the room and ask questions about the nurse's actions when the nurse left the room. While not as ideal as direct observation, it can still assist with the study goal to observe nursing care, and at the same time, facilitate privacy for the dying patient and their family.

## Cultural, ethnic, and religious implications

Despite the fact that Australia is a multicultural society, Western philosophy dominates ethical standards, and when combined with a medically-dominant healthcare system, clinicians and researchers run the risk of ignoring or placing little value on the importance of culture, ethnicity, and religion in death, dying, and end-of-life care (Chater & Tsai, 2008; Cross & Bloomer, 2010; O'Connor *et al.*, 2010). In the case of any dying patient, not only should the nurse aim to provide culturally-sensitive care, so too should the researcher

consider the cultural, ethnic, and religious implications, such as death rites and rituals when undertaking observation that includes dying patients. In our observation experience, there were several occasions where the dying patient was from a culturally- and linguistically-diverse group, and/or their religious beliefs and cultural needs were either unknown or not fully understood by the nurse providing the care or by the researcher. In these particular situations, the nurse deferred to the family spokesperson for instruction about how the dying care should be provided, and in turn, the researcher followed. A failure to observe cultural, ethnic, and religious factors can lead to what is considered intrusive research (Addington-Hall *et al.*, 2009). The nurse and researcher must equally acknowledge the imperative to remain respectful of the patient and family. Recognizing and identifying the patients' values, belief system, religious, and cultural needs is essential if the researcher is to ensure the burden of the research does not outweigh the anticipated benefits to come from it (Chater & Tsai, 2008).

### Impost

While some literature suggests that participation in research of this nature might not yield any direct benefits for those involved (Endacott, 2007), it is very possible that participants might find benefit in participating in this research, in that it prompts self-reflection. In respect of this, however, the researchers must remain ever cognizant of the potential impact of the research (Endacott, 2007; Griffiths, 2008). An appreciation of the multiple vulnerabilities that might exist for the participants in the study as well as the dying patients and their families, is fundamental (Beattie & Vandonbosch, 2007).

Komesaroff (2008) refers to the person's moral space, a philosophical space in which each person constructs understanding and meaning, and where their sense of coherence and unity can be derived. The researcher must acknowledge that their physical entry into another's experience of the world might impact upon their moral space, just as the researcher's moral space might also be altered. For the family

who maintain a vigil with the dying patient, the "impost" of having another person (the researcher) in the sacred space formed around the patient might far outweigh any possible immediate or latent "benefit". For the nurse, the knowledge that they are being observed while providing end-of-life care might be a significant burden at the time, with little immediate benefit.

### Importance of reflexivity

As a final note to researchers, undertaking research can be a challenging exercise, and the researcher needs to work to ensure that not only are they staying true to the purposes of the research and ethical boundaries, but that they also maintain perspective. The use of reflection as a purposeful activity, both formally and informally, can assist the researcher to maintain perspective, and deconstruct their work to create perspective and a deeper understanding (Lathier, 1995; Davies *et al.*, 2004). There were times when conducting the observation was difficult, such as feeling like an intruder into another person's privacy. At these times, the immediate response was to discontinue the observation and exit the observation field. Using a reflective journal after every episode of observation provided a means by which they could consider the context and circumstances that led to the discomfort and examine the feelings associated, so that clarity and perspective were maintained. Progressive reflective journaling is a practice the authors recommend for others undertaking research activities that might be challenging or complex.

### CONSIDERATIONS

Six key points (Table 1) were identified and considered prior to undertaking observational research in end-of-life care.

While it might seem that the present study highlights all the reasons why the nurse researcher should avoid observation as a research method in end-of-life care, the goal is to

**Table 1.** Key points to consider before undertaking observation in end-of-life care

1. Be sure that observational research is the best method for data collection, in particular whether to use participant or non participant observation.
2. Ensure you refer to the relevant human research ethics committee, and abide by any National Ethical Guidelines when designing the research project, particularly when vulnerable populations are involved.
3. Know who the participants are. The participants should be those who can give you the most unique insight into the phenomenon. Those that are easiest to access might not necessarily yield the best data. It might be that there is more than one participant group. Consideration for how vulnerable populations can be protected, as well as the cultural, religious, and ethnic implications for the chosen research setting, is vital.
4. Have a clearly-defined observation field, ensuring how it works, the usual routines and practices, any political issues, and culture are considered. Also consider both internal and external influences that might impact upon the observation field.
5. Reckon about the researcher's "role", and consider the possibility of "role conflict", where the researcher can have competing professional interests. These should be declared from the outset, and continuously reappraised throughout the project. It is also important to be mindful of any unequal power relationship, such as researcher and nurse, or researcher and dying patient.
6. Determine your research limits at the outset. Consulting with staff and a consumer representative (such as the spouse of a former patient, or service volunteer) about where the limits should be. For example, should observation be ceased at the moment of death? Should observation be suspended when the patient is receiving hygienic care, or when death is imminent?



assist fellow researchers to learn from the experiences and wisdom of the authors, borne from utilizing observation in the clinical setting, and reflecting on the related research literature. The authors wish to inform and encourage others who plan to follow this important and underresearched line of inquiry. The success of the research is largely dependent on the preparatory work undertaken prior to commencement. Establishing rapport with the participants, giving respect to their skills, expertise, and care giving, will significantly enhance the research relationship, and in turn, the quality of the data collected.

It is also important that the researcher's dual roles and responsibilities are clarified with the participants, and a clear process of action and reporting is determined prior to the commencement of the observation. As a researcher, remaining mindful of when observation should be ceased, out of respect for the patient or family, is equally important. This is important, as the participants will appreciate that while you are there to observe, there are times when this is simply not appropriate.

## CONCLUSION

As stated at the outset, there is currently a significant gap in the research literature about how to manage research in end-of-life care, in particular using qualitative descriptive methods such as observation, most likely due to the numerous methodological and ethical considerations highlighted here. The authors acknowledge this, and felt compelled to share their experience of this process, so that others, particularly neophyte researchers, can gain some valuable insights into this type of research. Results of research are commonly published in great detail; however, the foundations, thought processes, and numerous methodological issues that underpin the research are often omitted, despite their importance. It is hoped that what is shared here can assist fellow researchers successfully navigate the methodological challenges associated with observational research in a clinical setting, and involving care at the end of life.

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# Publication - 'How the 'observed' create ethical dilemmas for 'the observers': Experiences from studies conducted in the UK and Australia'

## Nursing & Health Sciences

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### Research Article

## How the observed create ethical dilemmas for the observers: Experiences from studies conducted in clinical settings in the UK and Australia

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### Abstract

Observational research has a history of controversy, particularly when the research is conducted in a clinical setting. Existing ethical approval processes focus on protecting participants and the researcher's responsibilities, in particular where vulnerable populations are concerned. In this study, the authors explored the less overt and often understated ethical challenges that can arise when conducting observational research in a clinical setting. Reflecting on two recent studies conducted in different clinical settings, the authors described the challenges of blurring role boundaries, the risk of collecting redundant data, and the impact of reverse power relationships between researchers, clinicians, and managers. From their experiences, the authors suggested that the preparatory work undertaken with clinicians and managers onsite, which typically focuses on how the researchers will maintain the ethical robustness of the research and protect the rights of participants and the vulnerable, should also highlight the sometimes overlooked ethical issues associated with participatory research. This can help ensure that participants and managers understand the scope and limitations of the research, and consider the ways in which the observed can influence the researcher and the findings.

### Key words

clinical research, observation, qualitative research, ethics, vulnerable population.

### INTRODUCTION

Undertaking research in the clinical setting is ethically challenging for many reasons. Of primary concern is that the research remains ethically robust, ensuring the safety and rights of the individuals involved. Ethical approval processes focus on protecting participants, and stipulate the responsibilities of the researcher throughout the research process. However, when observation is used as a method of collecting data, aside from the more obvious ethical issues of consent, observation boundaries, and the particular issues involving research with vulnerable populations, there are several other ethical issues that can arise for the clinical researcher that have not received the same attention in the existing literature.

The purpose of this paper was to explore some of the less overt ethical challenges that can occur when conducting observational research. The authors reflected on their own experiences of using observation in two recent studies. In study A, non-participant observation was used to explore the

care provided to dying patients in an acute hospital ward setting. In study B, participant observation was used as part of an ethnographic study to identify when/how clinicians determined that a child patient required high-dependency care in a paediatric ward setting. The authors found that ethical issues reached beyond those already mentioned in the existing literature, and were often more subtle or understated, but also just as challenging. Excerpts from the researchers' field notes are used in this paper to exemplify the ethical issues described. Before each of these challenges can be explicated here, some background detail on observation and ethical theory is necessary.

### Observation as a research method

Observation as a data collection method is considered the closest to a gold standard in qualitative research (Murphy & Dingwall, 2007), because it is a systematic data-collection method that enables the researcher to generate hypotheses, describe a landscape (Brew & Baron, 2009), and collect data in the real-world context as it occurs (Mulhall, 2003), without the risk of interpretation and distortion that might occur with other qualitative data-collection methods, such as interviews (O'Leary, 2005). Observation can reveal much more information than what one individual might decide is relevant

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(Mulhall, 2003), information which in fact might be significant when considered with other evidence (Morse, 2003).

The researcher can take several approaches to observation in order to collect data in a clinical setting. Participant observation, a technique rooted in anthropology, is central to ethnographic research (Minichiello *et al.*, 2004), and relies on the researcher immersing themselves in the clinical setting, where they are known as both a researcher and a clinician (Borner & Tolhurst, 2002). Using this technique, the researcher becomes an "insider", enabling them to observe participants in their "natural setting" (Allen, 2004) by watching, listening, and questioning, thus gaining better insight into participants' activities, behaviors, and interactions (Brink & Edgecombe, 2005) to facilitate understanding.

Alternately, non-participant observation keeps the researcher as an independent and non-judgemental outsider, who does not form part of the group under observation, and who can step in and out of the observation field, developing relationships and interacting with participants (Schneider *et al.*, 2007). This role enables a researcher to make use of their dual identity, that is researcher and clinician, to develop connections on a collegiate level that will assist in understanding the behaviors and actions observed, while also maintaining their position as an outsider who is not part of the working clinician team (Bloomer *et al.*, 2012).

### Ethics and observation

The medical ethical principles of autonomy, non-maleficence, beneficence, and justice underpin ethical research (Beauchamp & Childress, 2009), and the protection of the rights, safety, and well-being of research participants is the primary focus of ethical review boards (Griffiths, 2008; Resnik & Ness, 2012). The complex nature of gaining ethical approval for observational studies means that some researchers are discouraged from using observation (Morse, 2003; Griffiths, 2008). Some of the common ethical issues associated with observation are widely discussed, such as gaining consent (Mulhall, 2003), research involving vulnerable populations (National Health and Medical Research Council *et al.*, 2007), defining the observation field (National Health and Medical Research Council *et al.*, 2007; Griffiths, 2008; Bloomer *et al.*, 2012; Resnik & Ness, 2012), and participants' responsibilities in clinical research (Resnik & Ness, 2012). However, there are other ethical issues that remain under-recognized (Birns & Baren, 2009).

## METHODS

### Blurred role boundaries

When conducting research in the clinical setting, the dynamics between the researcher and those being researched can impact significantly on the success and objectivity of data collection and the entire project. The way the researcher identifies themselves, relates to others, and dresses can impact upon the way they are perceived by others. Presenting as a clinician can assist with "blending in" to the environment, but it can also result in clinicians forgetting that the

primary purpose of their presence is research. When interactions occur between the researcher and other people who might enter into the observation field, remaining cognizant of the nature of each relationship or interaction is critical. For example, if the researcher offers assistance to a patient in a clinical capacity, she must remain cognizant that the patient has consented to assistance, and not necessarily to participating in the study (Griffiths, 2008).

Similarly, when the researcher is conducting observation in the field, the degree to which the researcher can be involved, participate, or intervene in care activities, because of their dual role as a clinician, has to be guided by clear ethical boundaries. When investigators do intervene as a clinician in the observation field, the impact on the data collection can be significant, because this might mean that the researcher is not able to document details of this period of observation (Marshall, 2001).

In study B, where the researcher was working within the field as a participant observer, the duality of the role complicated data collection even more. There were occasions where participants over-relied on the researcher's skills as a clinician, particularly when the ward was busy, despite the true purpose of the researcher's presence, and previously-articulated fieldwork guidelines:

During the morning (name of registered nurse) was having to spend time on the phone organizing staff, had her back turned to the high-dependency unit (HDU) and did not appear to hear the alarms. I found myself informing (name of registered nurse) of changes with the babies. . . . Because I was near the nurses' station, I realized that I was being relied on to keep an eye on HDU. (Study B)

Although in this study, the role of the participant observer was clearly set out in fieldwork guidelines, and honorary contracts agreed with the managers of the wards, situations commonly arose where the researcher was relied upon as a clinician, rather than being viewed as a researcher. Similarly, the researcher in study A found that her dual identity meant that she was given access to information that went beyond the scope of the ethical approval, challenging the researcher to stay true to the boundaries of the research. An example of this is described in this study note:

I am informed of a new patient in the ward who is dying. The nurse hands me the medical record and suggests that I would like to read it, so I know what's going on. (Study A)

This also highlights another ethical issue for the researcher, that is, ethical approval for this study was given on the premise that the nurses were the consenting participants, not the patients; and ethical approval was not sought to review patient medical records a detail likely to be forgotten when the researcher is recognized as a clinician. Clearly, reviewing the medical record of a dying patient fell outside ethical approval, yet understanding the context or reason for the patient being identified as "dying", as shared by the nurse providing the care, was within the scope of ethical approval. These issues create a type of "ethical labyrinth" through

which the researcher must navigate, making decisions on what is acceptable as part of the research and what is not (Goodwin *et al.*, 2003), which can have considerable implications in terms of the success of the research.

### Collecting redundant data

Despite clear study protocols, there might be challenges for the researcher in staying true to the research aim and resisting coercion that encourages the researcher to address the needs/agendas of others. In study B, the participants were registered nurses directly involved in providing high-dependency care. Despite this the ward manager encouraged all staff to participate, resulting in healthcare assistants and student nurses also consenting. The motivation of the ward manager for this action was not clear, and while their inclusion of clinicians other than registered nurses could offer a different perspective, the healthcare assistants and student nurses fell outside of the study protocol, and as a result, data were not collected from them.

The researcher also has a responsibility to ensure that their focus remains on the research and does not encompass other issues. Spending considerable time in any clinical environment can highlight other issues or problems that might be considered equally worthy of further research, but the researcher must remain cognizant of the purpose, scope, and boundaries of the current study at all times. The temptation created by the other issues noted during data collection can result in researchers collecting the wrong data for the wrong reasons (Griffiths, 2008).

### Serving the participant's agenda

Staying true to the purpose of the study can also be difficult when clinicians working within the observation field want to utilize the researcher's presence to serve another agenda. Those being observed might attempt to influence the findings by either influencing what is observed or using the researcher's time in the clinical environment to provide information in other ways that might influence data collection:

I attended ward X, and the ward manager wanted to tell me about a complaint she had just received which involved the care of a patient who had died in the ward. This patient was being cared for by a junior registered nurse, and when the patient died, the registered nurse sought assistance from a senior registered nurse to prepare the body, but the senior registered nurse didn't assist because she was too busy, and the nurse unit manager (NUM) commented: "See, the workload in this ward can make it just so hard for our nurses to give the kind of care they want to. We are just so busy up here". (Study A)

In this case, the ward's logistics or staffing issues were not the direct focus of the research, but yet the NUM was attempting to use the researcher's presence in the ward as a platform for her own agenda.

In study B, there were times when no children meeting the inclusion criteria were present on the wards. In these circum-

stances, the researcher observed general activities in the ward, making field notes that enabled high-dependency care to be set in the context of the normal ward environment. However, on several occasions, the researcher was invited to observe other care activities in the ward, emphasizing the ward acuity and the demands on nurses' time and expertise, an activity that would serve the ward manager's agenda, not the researcher's. Additionally, approval for participant observation was only granted for children requiring high-dependency care subject to informed consent by the nurse and child/patient/parent, not others on the ward. Griffiths (2008) cogently justified the inclusion of data from non-consenting patients in her study on the basis of "best interests", but the same argument could not be applied in study B. Consequently, the only field notes written in these circumstances related to contextual information, and no patient details/data were recorded.

## RESULTS

### Reverse power relationships

There is a significant amount of published literature that focuses on the vulnerability of some populations in research (Liamputtong, 2006; Beattie & Vandenbosch, 2007; Oye *et al.*, 2007; Blewett *et al.*, 2012), and this literature implied that studies should be designed to ensure that predictable risks and burdens are weighed against foreseeable benefits to the participants. Where populations are considered especially vulnerable, such as minors, those with a psychiatric illness, or those who are highly dependent on medical care or dying, greater caution is required (Liamputtong, 2006; Oye *et al.*, 2007). While not attempting to downplay the diligence and caution required when working with vulnerable populations, there are also times when the researchers themselves are vulnerable.

Gaining and maintaining access to the observation field, and having the support of clinicians and those who provide access, is fundamentally important in ensuring that the research is possible in the desired clinical environment. This access is often a lengthy process of negotiation between managers, nurses, and others that occurs quite separately from the ethics approval (Mellish, 2003), and is dependent on the researcher establishing agreement and a commitment from the clinical setting to allow the researcher access for the duration of the research. If these relationships are compromised in any way, then continued access to the clinical site might be jeopardized. In this way, a reverse power relationship can develop, leaving the researcher vulnerable, and sometimes unable to continue the research.

While some form of "reciprocity" (Cresswell, 2007) between the researcher and staff of the clinical venue might be justifiable, subtle pressures can be exerted on the researcher to ensure a positive outcome or report, in exchange for ongoing access. In study A, gaining access to the clinical environment was highly dependent on a positive working relationship with the ward manager and individual clinicians, and their acceptance of the study. While clinicians seemed to be readily accepting of the study, there were



occasions when access to the clinical area was restricted. The researcher's reflective notes detailed this:

Another patient is dying. . . . When I attempt to gather some information about the circumstances of the patient dying from the nursing staff, they tell me to stay away, because the family is not coping, and the nurses are very busy. I am asked not to enter that area of the ward. (Study A)

When access is denied like this, there is little the researcher can do to gather data, apart from note the rationale given for this exclusion, and abide by it.

In study B, the ward manager was particularly interested in the research, because at the time she was involved in funding negotiations for staffing and equipment to enhance high-dependency care provision in the ward. She asked to use the research protocol as evidence to support her case at a meeting with hospital managers to demonstrate the importance of this issue. While not stated overtly, it was apparent that the ward manager sought to use the researcher's observations to her own ends, and if the researcher had refused to assist, this might have jeopardized the entire study, and potentially breached the terms of ethical approval. Her request was politely refused, because the study was in its early stages, so no findings were available. Instead, some relevant publications were recommended that could offer further support and information.

#### When observations capture unprofessional behavior/conduct

While upholding voluntary informed consent and anonymity/confidentiality are basic tenets of ethical approval in health-related research, researchers who are also clinicians are additionally bound by professional codes and standards (General Medical Council, 2006; Nursing and Midwifery Council, 2008). Prior to commencing fieldwork, identifying potential issues and devising strategies for action, if required, can help to prevent subsequent difficulties and justify the response. Obviously, the researcher wants to maintain a positive relationship with clinicians, but if the researcher observes any action/behavior that might reflect negatively on the clinical environment, this can challenge the relationship. To report on findings that do not reflect positively on clinicians or care delivery cannot only be detrimental to this study, but also to future studies and future access to the clinical setting:

When I arrived, one of the staff stopped me and asked me about the study. She asked me: "So how are we going? Do we pass the test? I hope you say good things about us". (Study A)

If feedback or findings are anything but a positive reflection of the clinicians' work, then further access to the clinical setting for the current and future projects might be limited/denied.

#### DISCUSSION

Data collection in these studies highlights the different perspectives on familiar ethical principles, such as beneficence

and autonomy. In study B, there were two groups of participants: children/parents and clinicians. The clinician group included the ward manager, and it is here where there was some conflict in interpretation of the study's purpose and application of ethical principles. For the ward manager, beneficence was interpreted from a broader societal angle, and merged with the ethical principle of "justice". This reflects a shift in emphasis from "preoccupation with risks" to the "greater appreciation of potential benefits" of research, which is noted by other commentators (Buchanan & Miller, 2006).

The observation of practice – one person watching the behavior of others – is personal. The researcher decides who and what to observe, takes notes, and asks questions. Thus, the interpersonal dynamic between the researcher and the researched will at times come to the foreground. John Stuart Mill (1869), in his essay "On Liberty", raised the importance of personal morality: "it matters not only what men do but what manner of men (sic) they are that do it". Regardless of safeguards assumed through institutional ethics review, due regard must be paid to the manner in which researchers and participants behave "in the field". Goodwin *et al.* (2003) talk candidly of the conflation between ethical conduct, professional responsibility, and personal morality, and in the studies discussed here, personal morality was evident in the decisions that had to be made by the researchers in the field.

The controversial idea of coercion to research studies has been debated in relation to patient involvement in research (Resnik & Ness, 2012); in study B reported here, coercion on the part of others was clearly intended with the added overlay of a power relationship. It was not clear what the motivation was, possibly to ensure success of the study, or perhaps to bring the data collection to a speedier conclusion. The rationale for this sort of behavior is rarely debated in the field, nor does it appear in published accounts of findings.

#### Conclusions

Preparatory discussions that take place before research begins need to include the issues we have highlighted in this paper. For example, clearly stating the purpose (and therefore, the boundaries) of the research should limit fluidity in expectations. The clinician's notion that data collection can underpin their own agenda concurrently with the goals of the research would not develop if sufficiently clear boundaries were in place between the research and any clinical agendas.

While a clinical qualification undoubtedly assists the researchers to understand "the field", the precise role that the researcher takes during data collection must be overtly clear for researchers, local managers, and participants. Conversations between all parties must address the numerous "what if" scenarios that can occur, and sufficiently detail the limitations that are necessary to protect the researcher and the research. Moreover, the researcher undertaking fieldwork in a clinical setting has to be adequately prepared for the "situated" nature of ethical decision-making required (Mattingly, 2005), and have contingency plans in place for when the ethics of an observational research study become unclear.



Approaches, such as reflective practice and debriefing, can assist the researcher to maintain the right perspective, and coupled with ongoing open communication with clinicians in the field, a common understanding can develop, and successful research can result.

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## CONTRIBUTIONS

Study Design: MB, MD, RT.

Data Collection and Analysis: MB, MD, RT.

Manuscript Writing: MB, MD, RT.

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## CHAPTER FOUR - PHASE ONE RESULTS

### PART B: Suggested Declaration for Thesis Chapter

**Monash University**

#### Declaration for Thesis Chapter Four

##### Declaration by candidate

In the case of Chapter Four, the nature and extent of my contribution to the work was the following:

Nature of contribution	Extent of contribution (%)
Concept development, key ideas, development, writing up and critical revisions	80%

The following co-authors contributed to the work. If co-authors are students at Monash University, the extent of their contribution in percentage terms must be stated:

Name	Nature of contribution	Extent of contribution (%) for student co-authors only
Professor Wendy Cross	Critical Revision	N/A
Professor Margaret O'Connor	Critical Revision	N/A
Professor Ruth Endacott	Critical Revision	N/A

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the candidate's and co-authors' contributions to this work\*.

Candidate's Signature		Date 12/08/2013
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Main Supervisor's Signature		Date
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\*Note: Where the responsible author is not the candidate's main supervisor, the main supervisor should consult with the responsible author to agree on the respective contributions of the authors.

## 4.1 Introduction

This chapter presents the key findings from Phase One in the form of an international peer-reviewed publication entitled '*The 'dis-ease' of dying: Challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study*' reproduced on the following pages. This publication presents Phase One and the substantive results as a stand-alone study. Due to limits on word count and publishing restrictions, not every finding from Phase One is presented in this paper hence further detail is provided below, under the sub-headings: 'Use of Single rooms' (section 4.2), 'Professional Distancing' (section 4.3) and 'The influence of institutional systems and processes' (section 4.4). In light of the 'death anxiety' literature presented in Chapter Two, the Phase One results are then reviewed using a death anxiety lens.

# Publication - 'The 'dis-ease' of dying: Challenges in nursing care of the dying in the acute hospital setting'

Original Article

PALLIATIVE  
MEDICINE

## The 'dis-ease' of dying: Challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study

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### Abstract

**Background:** Changes in health care and an ageing population have meant that more people are dying in the acute hospital setting. While palliative care principles have resulted in quality care for the dying, many patients die in an acute care, still receiving aggressive/resuscitative care.

**Aims:** The aims were to explore nurses' recognition of and responsiveness to dying patients and to understand the nurses' influence on end of life care.

**Design:** A qualitative approach was taken utilising non participant observation to elicit rich data, followed by focus groups and individual semi-structured interviews for clarification.

**Setting/participants:** This study was conducted in two acute medical wards in one health service, identified as having the highest rates of death, once palliative care and critical care areas were excluded. Twenty-five nurses consented to participate, and 20 episodes of observation were conducted.

**Results:** Nurses took a passive role in recognising dying, providing active care until a medical officer's declaration of dying. Ward design, nurse allocation and nurses' attitude to death impacts patient care. End of life care in a single room can have negative consequences for the dying. Nurses demonstrated varying degrees of discomfort, indicating that they were underprepared for this role.

**Conclusions:** When patients are terminally ill, acknowledgement of dying is essential in providing appropriate care. It should not be assumed that all nurses are adequately prepared to provide dying care. Further work is necessary to investigate how the attitudes of nurses towards caring for dying patients in the acute hospital setting may impact care of the dying patient.

### Keywords

End-of-life care, attitude to death, nursing, terminally ill, palliative care

### Background

Advances in health care and technology have meant that the way people die has changed dramatically.<sup>1,2</sup> Populations of developed countries are living longer<sup>3,4</sup> and chronic illness is the leading cause of death.<sup>5</sup> In Australia, population changes have meant that the number of people requiring end of life (EOL) care is increasing<sup>6</sup> and that people are

more likely to die in institutional settings.<sup>2,7</sup> Australian projections of demand for care at the EOL also suggest that the trend towards institutional care will increase as the number of people dying grows in absolute terms, concurrent with a decrease in informal carers.<sup>8</sup>

In 2010, an international white paper ranked the quality of death in 40 countries,<sup>9</sup> and despite Australia ranking second, there is still a growing need to consider care in

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non-specialist palliative care settings. Some people will experience quality care based on individual needs, but others receive inconsistent, or fragmented care.<sup>9</sup>

Many factors influence the care provided in acute hospitals: the dominant medical paradigm in the Australian health system influences care by focusing on short-term episodic care<sup>10</sup> and interventions and treatments aimed at cure.<sup>11,12</sup> This creates an environment where death is seen by clinicians as a failure,<sup>13,14</sup> or where death is denied.<sup>15</sup>

There is significant evidence that demonstrates the merits of palliative care principles,<sup>8,16–18</sup> and the benefits of care pathways for the dying, such as the Liverpool Care Pathway and various iterations.<sup>13,19–21</sup> Fewer studies have focused on the challenges of caring for the dying in non-palliative care settings, reporting that the EOL care provided in an acute hospital ward is less than ideal.

Nurse perspectives suggest that caring for dying patients, alongside the acutely ill, is challenging.<sup>22</sup> Care of the dying has a lesser priority and is under-resourced in terms of staffing and facilities, particularly when dying patients compete for attention with the acutely ill.<sup>23</sup> Poor communication and prognostication difficulties also negatively impact care.<sup>16</sup>

Nurses spend more time at the bedside of patients than any clinician;<sup>24</sup> they are expected to have developed skills and knowledge to enable them to provide physical as well as psychological care and meet the needs of the patient and family.<sup>25</sup> Many nurses feel under-skilled and uncomfortable providing EOL care.<sup>24</sup> Moreover, before nurses can provide appropriate care at the EOL, dying must be recognised as a challenge in itself because dying manifests in every patient differently,<sup>26</sup> and many clinicians have difficulty in recognising impending death.<sup>26</sup> This article reports on the results of a study designed to explore the issues for nurses caring for dying patients in the acute hospital setting.

## Aims

The aims of this study were to explore nurses' 'recognition of' and 'responsiveness to' dying patients in the acute hospital (non-palliative care) setting and to understand the nurses' influence, if any, on the provision of EOL care in acute hospital settings.

## Method

A qualitative approach was taken to elicit rich data. Initially, overt non-participant observation was undertaken to enable the researcher to use a 'clinician's eye',<sup>27</sup> to view what occurs in the acute hospital ward. Subsequently, two focus groups were conducted with ward nursing staff and individual semi-structured interviews were conducted with nurse managers (NMs), to seek clarification and a deeper understanding of the observations.

## Setting

This study was undertaken in two acute medical wards of a metropolitan health service in Melbourne, Australia. The two wards had similar patient demographics, the average length of stay was 7–10 days, and average patient age was reported to be mid-70s. These wards were chosen because the health service identified them as having the highest rates of death, once palliative care and critical care wards were excluded. Palliative care wards were excluded on the basis of existing expertise, and critical care areas were excluded due to the immediate nature of the care they provide.<sup>28</sup>

## Participants

Following ethical approval, nursing staff were informed of the study and invited to participate. All nurses were eligible, irrespective of their role, qualifications or experience; however, student nurses were excluded. When agency or casual (non-permanent) nurses were involved in caring for a dying patient, they were also invited to participate. No nurses refused to participate. Participants were advised that at any time they could opt out of the research in its entirety, or for the current episode of observation. Of the 23 nurses (from both wards) who participated, 11 were non-permanent staff.

## Data collection

When undertaking observation, the principal researcher dressed similar to the nursing staff, with university identification clearly displayed, so that she did not attract the general public's attention, yet was clearly identifiable to clinicians. Episodes of observation were triggered by a telephone call, informing the principal researcher that a patient was 'dying', based on the nurse's perception. Other impromptu visits at various times/days were undertaken; if a patient was identified as dying, an episode of observation was initiated.

Each episode of observation involved the principal researcher watching nursing care and nurses' interactions with the dying patient, family and colleagues. The principal researcher made a moral decision not to impose on the death of any of the patients. Latent documentation, where notes were made after cessation of each episode of observation<sup>29</sup> was used to record observation data.

The potential impact that being observed may have influenced behaviour<sup>30</sup> was considered, but some participants displayed some actions/behaviours that may be perceived as less than 'ideal'; hence, it was considered that participants were more likely to be behaving normally.

## Data saturation

Observation ceased when the principal researcher reached data saturation, where no new insights were encountered or



no new actions/behaviours/practices were observed. This point was determined through personal reflection, reading and rereading the observation field notes and consultation with fellow researchers.

### Focus groups and individual interviews

Subsequent to the observation, one focus group interview was conducted in each ward, with six nurse participants in each group, scheduled to fit within ward restraints, and all rostered staff were invited to participate. The rationale for recruiting in this fashion was that it would provide a mix of nursing staff like that rostered on any shift, rather than a deliberate selection. Subsequently, individual interviews were also conducted with the NM of the two wards to enable clarification of observed activities and practices.

### Methodological limitations

Some methodological limitations became evident, retrospectively. Despite encouragement, nurses rarely initiated a phone call to trigger an episode of observation. Additionally, non-permanent staff members were included in the observations because they were a regular part of the nursing workforce, but elucidating differences in education or training related to death and dying between permanent and non-permanent staff could have been useful. Finally, more focus groups may have provided different information given the different focus group participant populations.

### Analysis

Observation data were analysed using qualitative content analysis and a colour coding system to divide the data into themes and sub-themes.<sup>21</sup> Subsequent analysis using a table summary design adapted from Moretti et al.<sup>22</sup> enabled researchers to similarly code the focus group and interview transcript data, which assisted the researchers to apply a consistent logic to data analysis.

### Findings

Twenty observation episodes were undertaken, lasting for between 2 and 3 h. There was no intention to compare the two wards; therefore, data are presented as 'Observation', 'Focus Group' or 'NM Interview'. Informal conversation with nurses during the observation is noted as 'RN comment during observation' (Registered Nurse, RN).

The researcher's initial impression of both wards was of clinicians working at a hectic pace, in noisy wards, full of activity. The rooms with four beds were open plan, providing excellent surveillance from the nurse's station, but single rooms and two-bedded rooms were less open, and often

had closed doors/curtains. The patient population appeared elderly, and in contextualising the environment and typical patients, one nurse offered,

We have too many old people and they are here too long. The life expectancy of a female is 84, so that means most of the patients are on 'negative time' and they need to get out and enjoy what time they have left. (RN comment during Observation)

The following core themes were derived from observation data, and affirmed through the focus groups and interviews: (1) recognition of dying, (2) nursing care challenges, (3) the impact of single rooms and (4) clinician preparedness and coping.

#### Recognition of dying

During observation, it became apparent that recognition of dying was difficult, that is, nurses had difficulty differentiating between an acutely ill patient and a dying patient, most often deferring to, or waiting for, medical staff to make the distinction. When nurse participants were asked to consider how they recognise when a patient is dying, responses included

... a general loss of tone over the whole body, but it is particularly evident on the face. People who are dying have trouble controlling their mouth and it tends to just gape open ... they stop using their accessory muscles, and stop working to breathe ... they just want to lie down. No one has ever asked me that before ... Interesting question. (RN during Observation)

Start to lose consciousness; they no longer respond as a normal patient would ... their obs [vital signs] are 'off'. They are no longer responding in a healthy or even medically unstable patient way ... it an irreversible process. (RN during Observation)

This demonstrated that some nurses may have an opinion that a patient was dying, or a sense that they were not responsive to rehabilitative care, but in the absence of a decision from a medical officer, acute rehabilitative care often continued, and in one case, this caused distress to nursing staff after a patient's death:

Attended /nm handover to find out one of the patients is now deceased. Staff expressed some distress over her death, stating 'We were very cruel to that lady. Every day we insisted that she get up and have a shower and get out of bed, when clearly she was dying'. (Observation)

The lack of formal acknowledgement by a medical officer and the passivity with which nurses continued to provide acute care obviously distressed this group of nurses.

### Nursing care challenges

Providing ideal care for the dying, while also caring for other acutely ill patients appeared to be challenging; at times, nurses resorted to a 'task focus' to get the work done:

The afternoon nurse entered the room, refilled syringe driver, filled in some paperwork, then left without speaking with the dying patient or his family. No eye contact, no words spoken. Curtains drawn. Shortly after, during repositioning of the patient, the two nurses who were doing this talked to each other, but did not talk to the dying patient. It appeared that the overall focus of their visit to his room was to do a job and then get out of the room. (Observation)

The frenetic pace also meant that dying patients occasionally received less attention:

[After the death of a patient] The new graduate nurse caring for the deceased patient, had never cared for a patient who died, or prepared a body. The grad nurse did not know what to do, and when she asked for help from a fellow nurse she was told 'I'm busy. Read the policy'. (Observation)

Care of the dying was also reduced to a focus on tasks as noted by one nurse explaining the care she provided:

I gave a full wash, washed her hair, did mouth care, turned the patient, changed the linen and applied moisturiser. I will keep the curtains pulled, and I put some tissues and a vase of flowers in the room to make it nice. I am not familiar with the patient's story prior to this shift, but my priority now is keeping the patient comfortable ... I will also look after the family in this situation ... by giving them cups of tea and making sure they have a chair to sit on. The visitors can stay as long as they like. (RN during Observation)

These examples highlight a shift in priority from acknowledging that the patient is dying to focusing on care tasks. It was also evident that some nurses appeared reluctant to interact with the dying patient's family:

[The nurse] informs the family about nursing care she is about to deliver, but when the family begin to ask about the patient's prognosis and what happens as death approaches, the nurse interrupts and says 'I'll get the doctor to answer those questions for you'. (Observation)

### Impact of single rooms

The design of the wards comprised several wings, each made up of two rooms with four beds, one room with two beds and two single rooms (Figure 1). Consequently, nurse allocation followed a pattern of two nurses taking a room with four beds each, and the third being allocated to the room with two beds and the two single rooms. Typically, care in a single room is favoured by patients and clinicians, justified for the increased privacy and quietness. Nurses

openly lobbied and prioritised single rooms to dying patients, but this need competed with the need for 'isolation' for infectious patients. The rationale for using a single room for a dying patient was

Single room gives privacy to the dying patient ... dignity in death as well as life. But you have also got to consider the needs of the other patients – when they know that there is a dying person next to them. They might be a similar age so that can be a little confronting. Same for families – they can't talk the same in an open room and you can't be as free with offering comfort and talking about end of life things with family members. (RN during Observation)

Single rooms allow families to all grieve together. (Ward RN during Observation)

Conversely, being nursed in a single room was sometimes detrimental to the dying patient:

Some patients are scared and alone and don't want to be in a single room. (RN during Observation)

Patients who end up in single rooms don't always get the quality care they need ... they can be forgotten. (Focus Group)

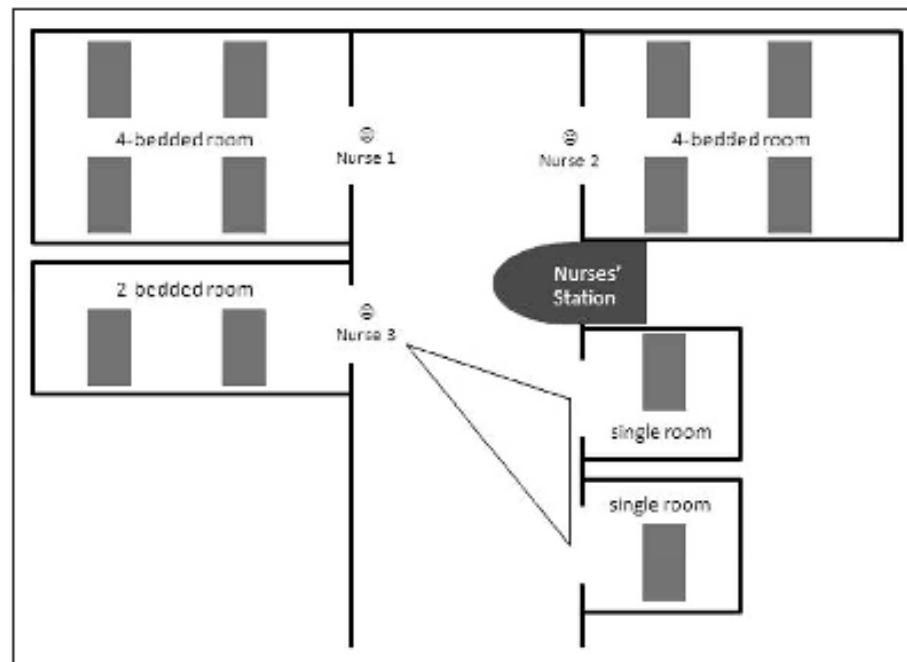
When a single room was not available, it appeared to concern nursing staff. On one occasion, a dying patient in the Emergency Department was refused admission to the ward because no single room was available, and the patient died on a trolley in the Emergency Department.

As described above, dying and/or infectious patients usually occupied the single rooms; therefore, the acuity of these rooms was often higher. Even when patient acuity indicated an alternate allocation, nurses rejected this notion, responding with

We just allocate. Team nursing approach means that it doesn't matter who gets who. (Focus Group)

What was evident during observation was that allocation was often done according to nurse preference rather than patient need. The allocating nurse deemed to take a four-bedded room, another nurse the other four-bedded room, often leaving the most junior/non-permanent nurse for the two-bedded and single rooms, with the sickest or dying patients. This issue was widely discussed, and one nurse commented,

Can I put one more point ... which is a bit sensitive on the ward. As far as, putting them in single rooms ... There's one big problem because usually they have [patients who are on] contact precautions, a bit heavy or difficult. So when it happens nobody really volunteers to take the single rooms ... and the people [nurses] who end up in the single rooms will either be like Bank Agency or they're juniors. And if not that, they lack that continuity of care. And that makes it like, in most cases people ending up in those rooms don't really get the quality. (Focus Group)



**Figure 1.** Ward layout

Hence, there was a perception among the participants that this prioritisation of single rooms for dying patients, together with the hierarchical process of allocating nursing staff by geographic location, impacts the quality and quantity of care received.

#### *Clinician preparedness and coping*

Despite the frequency of death, not all nurses appeared comfortable in caring for a dying patient. One particular nurse, who often chose to care for dying patients reflected that

I am happy to do it. Caring for a patient who is dying is an honour and a privilege. (RN during Observation)

However, her perspective was not indicative of other participants who exhibited hesitation and reluctance to care for dying patients for reasons other than just workload:

The nurse appears stressed and unhappy about being allocated to the dying patient. On questioning her she tells me 'I hate this. I find it really hard. It just makes me uncomfortable'. As I continue to observe her she provides physical care for her patient but doesn't speak to the patient or the family who are present in the room. (RN during Observation)

This issue was discussed with focus group participants, who reflected on the emotional impact that a dying patient can have:

You get these 'hooks', that weren't there before, and before the emotion would just run away, and now it gets caught. (Focus Group)

Others described that even though some emotion was 'normal' in response to a dying patient, the impact persisted beyond immediate grief:

It's not wrong for a nurse to have a tear in her eye but each time you care for a dead patient, there is a certain change, whether it's a degree of reverence, fear, anxiety, something that they feel. (NM Interview)

Even though you debrief, you sense things and can pack things away, and that is how you cope. (Focus Group)

NMs proffered the qualities deemed necessary for a nurse to provide the right care for dying patients:

High social skills, empathetic, worldly, emotional intelligence, able to communicate and choose words well ... sense of humour ... it's ok for a nurse to get emotional about a patient. Most importantly, if it is going to be remembered for ten years you had better get this right and do it well. The time around when a patient dies is remembered by all those people. (NM Interview)

Compassion, empathy, life experience, an empathic relationship with the patient. (NM Interview)



However, these qualities were acknowledged as not inherent in every nurse:

Grads [Graduate Nurses] cannot learn until they have had the opportunity to model of someone that does it well, or model against someone who is absolute worst at it. (NM Interview)

Adding to the difficulty that nurses had with caring for dying patients, focus group participants shared a frustration towards the 'system' and 'practices' that made care more challenging. Even when nurses acknowledged dying, acute care often continued until a medical officer confirmed this, often reluctantly:

The doctors don't want to make those decisions on the weekends, they won't do it... but we need to make sure that, at least, we get some NTR [not for resuscitation] orders before the weekend, because the docs on the weekends won't talk to families about dying and won't make them palliative. (Focus Group)

It's hard to get through to the young doctors what is needed. (Focus Group)

This perspective reinforced observation data. Nurses who were reluctant to talk with the patient or family about dying deferred to medical officers, who then deferred to more senior medical officers where possible.

... really, the quality of care that the patient gets when they are dying depends on who the doctor is. (Focus Group)

## Discussion

This qualitative study provided a unique insight into the 'dis-ease' experienced by nurses when they provide care for patients who are dying in the acute hospital setting. This study showed that time from formal diagnosis/recognition of dying to death appeared to be short, and while other studies such as the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT) study suggest that accurate prognostication can be difficult,<sup>10</sup> this research suggests that other factors also influenced care. This study described what happens when a nurse recognises that a patient is dying, and explored the ways in which they respond; more importantly, it highlighted the unequal power relationship inherent in the nurse-doctor relationship and how this influences care of the dying.

In this, like other Australian health-care contexts, nurses are the primary carers, and consequently, the action or inaction of nursing staff has significant implications for patient care and outcomes. The passivity of nurses towards openly recognising dying and how they subsequently responded were surprising. When asked, nurses found it difficult to 'describe' dying, with some suggesting 'intuitive' ways of knowing, others focusing on physiological parameters, and

in many other instances throughout the observation period, it was evident that nurses clearly 'knew'. Despite knowing, nurses remained passive, making little attempt to act on their knowledge to change the focus of care away from ongoing active care. Where a UK study similarly identified that dying was not always recognised in general medical wards and the focus remained on resuscitation and overcoming medical crises,<sup>22</sup> the passivity of participants in this study, and their lack of influence over EOL care, appears to be about more than just the focus of care and care in these wards.

Other issues such as historical origins of nursing as subordinate to doctors, and the consequent subtle power differential between doctors and nurses that stems from issues of gender, status and social class is likely still impacting patient care today.<sup>24</sup> Findings across the themes indicate that nurses who participated in this study perceived that they had little influence over EOL care and as a result, made no attempt to change the focus of care. NMs could identify the skills required by nurses in EOL care, and some nurse participants described strategies they had used to influence and manage doctors' reluctance or refusal from acute to EOL care; their attempts were clearly subtle and understated, aimed at prompting the doctor to come to the decision to alter focus of care himself or herself. Nurses demonstrated a clear preference to rely on doctors to determine when changing the focus of care to EOL care was necessary and appropriate.

Similarly, an equally important finding was that a patient's death can still be uncomfortable, ambiguous and difficult<sup>14</sup> with nurses experiencing distress and anxiety.<sup>16</sup> Death anxiety, which can be described as the apprehension generated by death,<sup>25</sup> manifests in each person differently, but is likely to be amplified in nurses who are providing care that is not accepting of the patient's impending death,<sup>16</sup> and results in behaviours like those witnessed in this study, such as the observed reluctance to interact with the family and patient, deferral of tough conversations with the medical officer and an over-reliance on care tasks. What, when superficially observed, appeared as frantic activity in the hours or minutes before a patient's death is more likely a representation of death anxiety, denial and withdrawal,<sup>26</sup> where nurses focus on care tasks and disengage as a way of coping.<sup>10</sup>

Likewise, the high priority placed on the use of single rooms for the dying suggests a need to hide the dying. The assumption that a death is only 'good' if it occurs in private, and out of sight, is evident in other literature<sup>22,41</sup> and appeared to be deeply ingrained, but meant that nurses gave little consideration to other ways to provide quality care or to the inherent risks of single-room use such as decreased visual acuity or social isolation.<sup>25,27</sup>

## Conclusion

Acknowledgement of dying is essential in providing appropriate care. It should not be assumed that all nurses

are adequately prepared, educationally, socially and emotionally, to provide such care. Further research should investigate how the attitudes of nurses towards caring for dying patients in the acute hospital setting may impact their care.

# Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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## **4.2 Use of single rooms**

The priority placed on single rooms for those patients recognised as dying was a significant finding of this study. While this point has been already included in the main results paper, this finding was not substantially drawn on in the initial research paper. Consequently, a separate/additional discussion paper with the focus on the use of single rooms for the dying is currently under development for later publication in a peer-reviewed journal. The objective of this discussion paper is to not only explore the ways in which single rooms are used in acute hospital settings, but also to generate discussion and reflection amongst readers that challenges the automatic assumption that single rooms are the best option for all dying patients.

## **Publication – ‘Single Rooms: Are they ideal for the dying?’ (under development)**

### Introduction

Over recent decades, we have seen a growing tendency for new and existing hospital developments to decrease the amount of shared patient rooms, opting instead for more single rooms in hospital ward design (van de Glind, de Roode & Goossensen, 2007), a trend that is reflected at policy level within Australian health services (Snow, 2008; van de Glind, et al., 2007). The reasons for this centre around several key factors. Care in a single room is preferred by patients (van de Glind, et al., 2007), can be mandated for infection control reasons (National Health and Medical Research Council (NHMRC), 2010), and is preferred by clinicians for some patient groups with specific other needs.

The Australian National Health and Medical Research Council guidelines (2010) promote the use of single rooms as part of a suite of recommendations aimed at reducing the spread of infection in hospital, of which using single rooms for isolation is one measure. The research literature however, shows mixed results in terms of the impact of single rooms on infection prevention and control. While some literature reports there was insufficient evidence to assess the effects of isolation as a stand-alone measure (Loveday, Pellow, Jones & Pratt, 2006), other research literature has shown no real difference in infection control outcomes between shared patient rooms and single rooms (Dettenkofer et al., 2004).

Nonetheless, the availability of single rooms in healthcare environments means that even if the evidence unanimously supported single rooms as a primary measure for infection prevention and control, competing demands mean that they are simply not



always available for this use. A UK study found that only 12-19% of single rooms were in fact used for infection control reasons, with factors such as patient gender mix in the ward, the need for a single room for terminal care, patient behaviour, safety and observation used as reasons why a single room could not be used for 'isolation' (Wigglesworth & Wilcox, 2006).

While there is also a perception that hospital care in a single room is more personalised (Ulrich et al., 2008), and patients report greater satisfaction with care in a single room (Press Ganey Inc, 2009), there is currently not enough research evidence to categorically state that patients themselves benefit from single rooms in terms of health outcomes (van de Glind, et al., 2007). As 'person-centred' care is idealised as an approach to care that centres of the person and not their healthcare needs (Manley, Hills & Marriot, 2011), there is insufficient evidence to demonstrate that care in a single room improves patient outcomes (van de Glind, et al., 2007), and whether this care is provided in a single or shared room should be irrelevant.

#### Purpose of this paper

Importantly, clinicians value single rooms for some patients groups, such as those who are dying. This discussion paper seeks to explore the clinician's motivations and rationale for prioritising single rooms for dying patients, reflecting on the consequences of single room care at the end of life. The authors hope to generate discussion amongst clinicians, clinical managers and policy makers about the impact of single room care, and the potential consequences of such care for the dying patient.

#### Data Sources

The Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Google Scholar were searched for literature published in English since 2000, in order to retrieve the most up-to-date information. Keywords used in the data searches were 'single room/s', 'isolation', 'death', 'dying', 'acute care/acute hospital' and 'death

anxiety'. Articles retrieved from these searches were selected based on their relevance to the use of single rooms for care of the dying patient in the acute hospital environment. Other literature, such as government guidelines/standards/recommendations, commissioned reports and seminal works were included if they were found to contribute to the topic under discussion.

## Background

Australia, like other developed countries, has an ageing population (Australian Bureau of Statistics, 2011; Economist Intelligence Unit, 2010) chronic illness is now the leading cause of death (Thompson, McClement & Daeninck, 2006), and as the Australian population ages, the number of deaths each year is expected to dramatically increase (Australian Bureau of Statistics, 2010). While it was once 'normal' for people to die at home, supported by the family and the community (Hillman, 2009; Howarth, 2011), societal changes, such as employment patterns and changes to family demographics (Australian Bureau of Statistics, 2009-10) have resulted in a shortage of family members to take on the role of informal carer, and the inability of family members to cope with demands of the carer role (Becker et al., 2007). This reluctance to take on the carer role is also attributed to a desire to preserve social boundaries of personal intimacy (Aleksandric & Hanson, 2010; Becker, et al., 2007) by delegating this care to healthcare professionals (Exley & Allen, 2007), which also results in more people presenting to hospital to die. In Australia, hospitals and other care institutions are now the most common place to die (O'Connor & Aranda, 2003) with around two thirds of deaths occurring in hospital (Australian Institute of Health and Welfare, 2010), and single rooms used whenever possible.

In the acute hospital setting, where care focuses on resuscitation and life prolongation (Middlewood, Gardner & Gardner, 2001), the emphasis is on efficiency, routine and promoting health (Pincombe, Brown & McCutcheon, 2003), and death and dying can

seem out of place. When imminent death is recognized a decision is made about the preferred place of dying, and when discharge to home is not an option, the dying are commonly moved to a single room, where available (Porock, Pollock & Jurgens, 2009). What is significant about the practice of moving dying patients to single rooms is that it is commonly accepted as 'normal', and 'ideal' practice (Al-Qurainy, Collis & Feuer, 2009; Edmonds & Rogers, 2003; Pincombe, et al., 2003), yet there is a paucity of evidence to outright support this practice. Conversely, there is evidence to suggest that the use of single rooms in this way may not always be in the best interests of the dying patient.

#### Issues with single rooms

##### *Privacy*

When someone is dying, nurses proffer the need for peace and privacy for the dying patient, extending to their families (Pincombe, et al., 2003). It is obvious that families need enough space to congregate, share stories and remembrance, grieve together and hold vigil, and the amount of space available for the family in a shared patient room is often inadequate. However, the nurses' priority has to be what is best for the patient. Nurses may be working on the assumption that a patient's death is only a 'good death' if it occurs in private (Edmonds & Rogers, 2003; Liaschenko, Peden-McAlpine & Andrews, 2011), yet there is insufficient evidence to link the use of single rooms to 'privacy and dignity' as an outcome measure (van de Glind, et al., 2007). Single rooms may provide speech privacy because they limit 'unintended listeners' (Ulrich, et al., 2008) and enable a greater degree of visual privacy than a curtain can but a recent Australian study of the care of dying patients actually found that the move to a single room resulted in decreased opportunities for visual surveillance for clinicians (Pincombe, et al., 2003). This study also found that single room care left the dying patient at greater risk of being forgotten, receiving less frequent care, and at



greater risk of adverse events (Pincombe, et al., 2003). Also, the location of single rooms adjacent to service areas such as the pan room also meant that ambience was not improved (Pincombe, et al., 2003).

### *Family needs*

Single rooms are better at ensuring family are accommodated, enabling them to gather and spend time with their loved one in, even rooming in, in the hours leading up to death and after death (Wakefield, 2000). Single rooms also enabled family visitation that extended beyond the scheduled visiting hours and without disturbing other patients (Beckstrand, Callister & Kirchoff, 2006; Pincombe, et al., 2003). There is no doubt that when family are present, they can make an important contribution to the emotional support provided to the patient, but family presence also resulted in less frequent nursing care or intervention (Pincombe, et al., 2003). Furthermore, the care that was received was aimed at the patient's physiological care needs, rather than a desire to provide psychological support or 'be with' the patient (Thompson, et al., 2006).

In the absence of family, the move to a single room creates social isolation, a bigger issue than the perceived privacy gained (Porock, et al., 2009). For some dying patients, the fear of dying alone may be greater than the fear of death itself, and as a result, some people would prefer the company of relative strangers at death than to die alone. The sense of community and camaraderie that develops in a shared patient room, where support can come from fellow patients and their visitors makes a shared room a more appropriate place of death for some patients (Porock, et al., 2009). But not all patients who are sharing a room with a dying patient will want to, or have to opportunity to establish any sort of connection, particularly if the dying patient has reduced consciousness in the final hours/days. Irrespective of the extent of the relationship, the death of a patient in a shared room must be acknowledged. Even

when unspoken, the prolonged presence of visitors at the dying patient's bedside, with only a flimsy bedside curtain to offer privacy, the death is still experienced by the other patients, and they must be given the opportunity to ask questions and reflect (Porock, et al., 2009).

### *The influence of death anxiety*

For nurses working in acute hospital wards, where the focus is on cure and treatment rather than death, caring for a dying patient can be distressing (Neimeyer, Wittkowski & Moser, 2004), and incongruous with the rest of the ward. As a result, the motivation for placing dying patients in single rooms may also stem from an underlying death anxiety. Death anxiety is the term used to describe the apprehension generated by death (Abdel-Khalek, 2005), and it may impede therapeutic interactions with the dying patient (Deffner & Bell, 2005). Death anxiety can manifest in nurses as a reluctance to interact with the dying person and avoidance (Thorson & Powell, 1988). Even before death occurs in a physical sense, nurses and other clinicians subtly acknowledge a patient's 'social death', that is the point at which the social being disengages from interaction such as when the patient loses consciousness, as a precursor to physiological death, and they begin to withdraw (Glaser & Strauss, 1964; Sudnow, 1982). This withdrawal is also evident in the allocation of the single room, and in the way the dying person is treated more like a body, and where reference to the person is by their diagnosis, rather than their name.

Nurses with death anxiety also have a strong desire to control their emotional involvement (Hopkinson, Hallett & Luker, 2005) and limit intimate the need to provide intimate care for the dying patient (Wakefield, 2000). On the premise of enabling family involvement, nurses may encourage family members to be involved in routine care such as washing, feeding and mouth care. While it may be espoused as 'therapeutic' for family to be involved in care tasks, the literature supports the notion

that this is in fact another psychological defence mechanism employed by nurses to lessen their own anxiety (Wakefield, 1999). It also enables the nurse to focus on other responsibilities, finding solace in the busyness of nursing work, and focussing on other patients who are not dying (Glaser & Strauss, 1965; Kubler-Ross, 1969).

### *Denying death*

Most certainly, in the context of the acute hospital environment, death anxiety and a desire to deny death are the primary motivators for clinicians to desire to conceal death away from public view. The concept of death denial is not new. Many publications over the decades have detailed both society and clinicians' denial of death (Zimmerman, 2004), but its connection to single room use is not so obvious in the literature. Komaromy (2000) described the efforts of clinicians to conceal death from public view, and while this research was undertaken in a residential care setting, there are remarkable similarities between her work and now. Describing the practice of nursing care of the dying as a 'performance', clinicians ritualize the practice of keeping the dying and deceased out of sight so that staff, and others, did not have to face death (Komaromy, 2000; O'Connor, 2009). Sudnow (1982) also described how nurses avoided allocating any room to the dying patient admitted overnight, preferring instead to hold them in another space and allocating a bed if they made it through the night. While this would certainly not occur now, prioritising a single room for the dying patient still implies a desire to deny death and dying.

### *Discussion*

Despite a lack of scientific evidence that single room care is better for the patient in terms of patient outcomes, a growing trend towards idealising single room care exists, created and justified on the assumption that care provided in a single room is superior to that in a shared patient room. As a result, single rooms are 'hot property', especially when they are desired from an Infection prevention and control or privacy perspectives.

For the dying patient, the assumptions that they want/need a single room in order to have a good death, or that the dying patient will receive better care in a single room are fundamentally flawed. As social creatures, human beings need opportunities for social interaction and company, and placing the dying patient in a single room, may not only lead to social isolation but may also result in dying alone. Similarly, a general discomfort with death by others has resulted in single rooms being used to hide death and dying away from view. Even nurses, who are required to provide care for the dying can be affected by death anxiety, and this manifests in the choice of location for care and the way the care is provided.

Cultural norms in the acute hospital system need to change, and the dying patient's needs should be assessed on an individual basis, acknowledging the potential negative consequences that come with single room care. Caring for a dying patient in a single room does not automatically ensure a dignified death, and it may in fact result in a lonely, impersonal and frightening death.

## Conclusion

As the frequency of death in our acute hospitals continues to rise, consideration for how to care for the dying patient, and where, becomes more important. The assumption that care in a single room is likely to be better than a shared room is not based on evidence. This discussion paper has also highlighted that the clinician's response to caring for a dying patient can be directly influenced by their own comfort/discomfort with death, and this may have direct implications for how the dying are cared for. This issue should be the focus of new research so that the extent to which this impacts upon patient care through the dying phase and after death can be fully realised.

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### 4.3 Professional distancing

Professional distancing was described earlier as a coping strategy/behaviour employed by nurses wishing to limit or avoid any contact not deemed necessary with a dying patient, thereby lessening the nurse's death anxiety (Glaser & Strauss, 1965). When caring for the dying, nurses were observed using professional distancing. The following excerpts from observation notes exemplify this:-

*Interaction with the family is limited to when she (the nurse) needs to attend to an aspect of patient care. (Observation)*

*Nurse refilled the syringe driver, did paperwork, then left without speaking to the dying patient or his family. No eye contact, no words spoken. (Observation)*

These findings have been similarly reflected in other studies. One particular study by Hadders (2007) detailed how nurses in the intensive care setting also demonstrated similar behaviour, focussing on the task at hand and the body, rather than considering the human and the impending loss of life.

#### ***Denying the source of the anxiety***

As reported in the publication entitled '*The dis-ease of dying: Challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study*', nurses demonstrated passivity in recognising when a patient is dying and a preference, whenever possible, for caring for the dying in single rooms. Rachman (2004) however, suggests that these findings may in fact be evidence of denial, a strategy employed by participants to manage their death anxiety. Even when a dying patient was being cared for in a single room, extra measures were often taken to deny that dying was occurring. This is demonstrated by the following excerpt from the researcher's observation notes:-



*The curtains were drawn and a 'do not enter' sign was on the door (Observation)*

In the researcher's latent reflective commentary, this entry was noted:-

*The door to the room was closed with a sign on the door to stop entry. The bed curtains were also drawn. Is that for the patient's benefit or everyone else? (Observation reflection)*

This entry indicated that this may have been a mechanism designed to protect everyone else, rather than the dying patient.

### ***Rationalising death***

Other evidence reflects the use of rationalisation as a way of coping with patient death.

During the early stages of observation, a nurse commented to the researcher:-

*"The life expectancy of a female is 84 years, so that means that most of the patients are already on 'negative time' and they need to get out and enjoy what time they have left."  
(Comment during Observation)*

Similarly, during the focus groups nurses described those situations when a patient's social characteristics made a death harder to accept:-

*"Younger women. We have had a lot...For junior nurses like us, it's a bit confronting. Yeah....Like lately we have had I would say between 58 and 63, we've had quite a few women with terminal cancer. So the age of the patient makes it more difficult... If they are old I cope fine. (Focus Group)*

During an episode of observation, a nurse reflected on the dying patient for whom she was caring. She explained that the old lady, who lived a 'hermit-like' isolated life with no family or social support, had arrived in the ward with an open fungating cancer affecting her face and brain. She commented to the researcher that:-

“...she needs to ‘declare herself’ and go.” (*Comment during observation*)

In this case, the nurse was implying that because of the patient’s age, visible and deadly cancer that was invading her face, as well as her lonely life, and the sooner she died, the better.

One (non-peer-reviewed) opinion piece has been published to generate discussion on this topic. This publication is included as Appendix 10.

#### **4.4 The influence of institutional systems and processes**

During the episodes of observation, there were times when nurses utilised accepted institutional systems and processes that impacted upon care of the dying. Aside from the processes used to allocate the workload of each nurse for the shift and the use of single rooms (identified earlier), the excerpt from the researcher’s observations notes below represents a situation in which the process of admitting patients to the ward impacted directly upon a dying patient.

Upon arriving in the ward I met with the NIC [Nurse in Charge], who told me that ED [Emergency Department] had called to advise of a patient in the ED who had come in from a nursing home following a large stroke. The ED staff member was seeking to admit the patient to this ward. The patient was unconscious; the scan showed an extensive stroke and the patient was not expected to live through the night.

The NIC told me she was arguing with the Bed Coordinator about the admission of the patient. The NIC explained that she didn’t want to take the patient because she didn’t have a single room in the ward to admit the patient to, so she had refused to admit the patient. The NIC said that all of the single rooms in the ward were currently occupied with other patients with ‘legitimate’ reasons for being there, so there was

not opportunity to move/swap beds with other patients to make a single room available. She told me that she had been having this ongoing argument with the ED staff and the Bed Coordinator for the last few hours and was determined not to take the patient. She said, *"I'm not going to take a dying patient if I can't get them into a single room. It's not fair."*

Shortly after, the NIC informed me that the patient died in the ED. (*Observation Notes*)

Whilst this situation demonstrates how systems and/or processes that related to admissions and bed allocation resulted in delaying this patient's admission to the ward, it could also be representative of issues of power and control. As Lupton (2012) explains nurses, like other health professionals, are socialised according to the institutionalised norms, hierarchy and power. While nurses are given primary responsibility for the care of patients, they are also subject to rules within which they must operate (Lupton, 2012). This scenario may be an example of how nurses work within the rules, bureaucracy, institutionalised norms and the imposition of medical staff exerting authority. Despite this, nurses often work against these influences to exercise some professional autonomy (May, 1992). This situation demonstrates the ways in which the nurse worked to control the admission of the dying patient, resulting in the patient dying in the ED.

This scenario can be equally explained using death anxiety theory. The nurse's behaviour may be representative of her desire to maintain distance between herself and the dying person and to protect others from the potential for anxiety related to the presence of a dying person (Glaser & Strauss, 1965).

## 4.5 Summary

This chapter has presented the findings from Phase One which utilised non-participant observation, focus groups, and individual interviews to explore how nurses recognise when a

patient is dying and how they respond to the dying patient in the acute hospital setting. The key findings highlighted that in the acute hospital setting, where the focus is on cure, recognising that a patient is dying and changing care accordingly is difficult for the registered nurse. As a result, nurses often chose to remain passive in this regard. Ward design, workload, and nurse allocation practices and hospital systems/processes further contribute to this difficulty. Nurses working in this environment are underprepared educationally and emotionally to care for a dying patient.

When viewed through a death anxiety 'lens' the findings suggest that death anxiety may also have a significant influence over nurse behaviours and, thus, the care provided to dying patients by nurses. As described in Chapter Two, attitudes and the behaviours of nurses are influenced by their death anxiety, both consciously and unconsciously. In order to avoid intimately engaging with the dying patient, nurses demonstrated professional distancing, prioritised single rooms for dying patients, and focused on care tasks or the technical elements of care. Following a death, nurses often rationalised the death in order to lessen the anxiety and sense of loss, and at times, their attitude towards caring for the dying patient, arising from death anxiety, was perceived as negative. In order to understand this series of behaviours in more detail, Phase Two of this study utilised a survey to measure attitudes towards care of the dying, given that attitude is influenced by an individual's death anxiety. These findings are presented in the following chapter.

## ***CHAPTER FIVE - PHASE TWO RESULTS***

### **5.1 Introduction**

This chapter details the findings from Phase Two of this study. Phase Two utilised an existing survey tool, known as the Frommelt's Attitude Towards Care of the Dying Tool (FATCOD) to measure attitudes towards care of the dying in acute hospital nurses. In addition, the tool was modified, tested, renamed as FATCOD-DOC and then piloted with a population of final year medical students. While the death anxiety literature acknowledges that death anxiety can influence attitude, it is also possible that attitude alone, that is, independent of death anxiety, may also be a factor. Thus, the survey was undertaken with two populations, acute hospital nurses and final year medical students. While two separate surveys were conducted and the results of both are reported in this chapter, the primary focus is on the attitudes of registered nurses towards care of the dying.

The results of both surveys are discussed separately. First, the respondent demographics are presented, followed by an analysis of the thirty items contained in survey tool (FATCOD or FATCOD-DOC). Following, an analysis of relationships between the mean scores and the respondent characteristics is presented. At the end of the survey, participants were invited to provide qualitative comments. These were analysed thematically and the themes are presented in this chapter.

### **5.2 FATCOD Survey Results**

#### ***5.2.1 Respondents***

There were 192 respondents to the FATCOD survey. Determining a response rate was not possible due to the use of a variety recruitment methods including 'snowballing'. Of the survey respondents, 119 completed the online survey, and the remaining completed a hard

copy version. In accordance with the inclusion and exclusion criteria 35 responses were eliminated from analysis for the following reasons: respondents indicated that they did not work in an acute care setting (n=9); respondents had not cared for a dying patient in the acute setting (n=1); or were not employed as a registered nurse (n=4). Other respondents did not progress past the descriptive (demographic) questions (n=7) or failed to answer 20 or more of the 30 FATCOD items (n=14). These exclusions resulted in 157 survey responses which were used for analysis purposes. The demographic characteristics for the respondents are presented in Table 6.



Table 6 FATCOD Respondent Demographic Characteristics

<b>Characteristic</b>	<b>Range</b>	<b>Mean</b>	<b>Std. Deviation</b>
<i>Age</i>	21-65 yrs	43 yrs	11.27
<i>Years as a Registered Nurse</i>	1-48 yrs	17 yrs	12.48
<i>Gender</i>		<b>N</b>	<b>%</b>
Female		144	92
Male		13	8
<i>Current position</i>			
Graduate/Registered Nurse		84	54
Clinical Nurse Specialist/Associate Unit Manager		42	27
Educator/Nurse Unit Manager/Nurse Executive		31	19
<i>Highest qualification</i>			
Postgraduate qualification		80	51
Undergraduate qualification		77	49
<i>Palliative care unit or hospice at your hospital or health service</i>			
Yes		130	83
No/Unsure		26	17
<i>Access to specialist palliative care staff for advice or consultation</i>			
Yes		144	92
No/Unsure		13	8
<i>Use an 'end of life' or 'palliative care pathway' in your ward/hospital</i>			
Yes		59	38
No/Unsure		97	62
<i>Previous death education</i>			
Taken a course on death and dying as part of basic nursing education		48	31
Did not take a specific course, but material on death and dying was included in other nursing courses		87	55
No information or education on dealing with death and dying was included in nursing education		22	14
<i>Feelings about previous death education</i>			
Previous death education adequately prepared him/her to deal with death and dying		68	43
Previous death education did not adequately prepare him/her to deal with death and dying		58	37
Did not answer		31	20

The nurses had a mean age of 43 years and 92% were female. These findings were found to align with 2009 data which indicated that the average age of employed nurses in Australia was 44.3 years and 90.4% were female (Australian Institute of Health and Welfare, 2011).

### **5.2.2 FATCOD Individual item analysis**

How individuals responded to the FATCOD survey was analysed in three ways:

1. Each item was considered individually and the Mean, Standard Deviation, Median and Mode was computed. The results are shown in Table 7. These results indicate that respondents had a highly positive attitude towards care of the dying. Furthermore, the standard deviations across all 30 items did not show substantial variation therefore indicating agreement from respondents.

Table 7 FATCOD item analysis

FATCOD Item	Item Score (Higher scores reflect more positive attitudes)					Mean	Standard Deviation	Median	Mode
	1	2	3	4	5				
Q1	2	1	3	57	88	4.51	0.70	5	5
Q2	4	7	17	80	47	4.03	0.91	4	4
Q3	3	28	18	75	32	3.67	1.05	4	4
Q4	4	5	16	63	68	4.19	0.93	4	5
Q5	1	6	6	63	80	4.38	0.79	5	5
Q6	2	13	15	77	49	4.01	0.93	4	4
Q7	4	9	4	75	65	4.20	0.93	4	4
Q8	0	7	12	82	55	4.19	0.76	4	4
Q9	2	6	11	82	56	4.17	0.82	4	4
Q10	8	3	4	78	64	4.19	0.97	4	4
Q11	0	7	14	84	52	4.15	0.76	4	4
Q12	0	12	40	80	24	3.74	0.81	4	4
Q13	1	6	14	86	49	4.13	0.78	4	4
Q14	0	4	7	86	59	4.28	0.67	4	4
Q15	0	0	3	68	86	4.53	0.54	5	5
Q16	1	1	1	71	79	4.48	0.62	5	5
Q17	0	3	3	71	80	4.45	0.63	5	5
Q18	5	2	25	84	41	3.98	0.87	4	4
Q19	1	5	13	62	76	4.32	0.81	4	5
Q20	0	5	29	88	35	3.97	0.73	4	4
Q21	0	2	3	87	65	4.37	0.59	4	4
Q22	0	4	8	74	67	4.33	0.70	4	4
Q23	5	1	2	46	103	4.54	0.84	5	5
Q24	0	7	22	78	49	4.08	0.79	4	4
Q25	3	10	8	57	79	4.27	0.96	5	5
Q26	4	18	15	78	40	3.85	1.02	4	4
Q27	1	1	8	79	66	4.34	0.67	4	4
Q28	2	4	10	86	53	4.19	0.77	4	4
Q29	5	16	33	63	37	3.72	1.04	4	4
Q30	3	4	14	86	49	4.12	0.82	4	4
Overall Average						4.18			

2. The mean score across all 30 items for each respondent was also computed. This mean score, referred to as the QAverage, was then used for further analysis of statistically significant relationships between the QAverage and the respondent demographic characteristics.
3. Using only those participants who answered all 30 items ( $n=124$ ), a total score (out of 150) was generated. The total scores ranged from 92 to 149 out of 150 with an average total score of 125.94 ( $SD = 11.65$ ).

### ***5.2.3 Analysis of QAverage and respondent characteristics***

The QAverage scores were compared to the respondent demographic statistics using parametric and non-parametric tests. Parametric statistical tests make a number of assumptions about a population from which a sample has been drawn, including that the data are normally distributed (Clegg, 1990; Pallant, 2011). In the first instance, parametric tests were used to analyse the data. Non-parametric techniques, however, do not rely on the same stringent assumptions about a population and are sometimes considered more suitable techniques for smaller samples (Pallant, 2011). As a result, both parametric and non-parametric tests were used in the analysis.

#### ***Age***

There was evidence ( $R^2 = 0.027$ ) that older nurses, on average, scored a higher QAverage than younger nurses ( $\beta_{\text{age}} = 0.005 \text{ points/year}$ ,  $p = 0.039$ ), suggesting that age affected attitudes to dying.

#### ***Years as a Registered Nurse***

There was no evidence ( $R^2 = 0.13$ ) that the number of years spent as a nurse influenced attitudes to dying ( $p = 0.158$ ).

### **Gender**

There was no evidence of a significant difference in QAverage scores for males ( $M = 4.12$ ,  $SD = 0.37$ ) and females ( $M = 4.18$ ,  $SD = 0.38$ ). Levene's test (equal variances assumed Sig. 0.946) Sig. (2-tailed)  $p = 0.105$ .

A Mann-Whitney U Test similarly revealed no significant difference in the QAverage scores for males ( $Md = 4.03$ ,  $n = 14$ ), and females ( $Md = 4.13$ ,  $n = 149$ ),  $U = 899.5$ ,  $z = -0.85$ ,  $p = 0.40$ ,  $r = -0.07$ .

### **Current Position**

A one-way between-groups analysis of variance was conducted to explore the impact of current position on attitudes to dying. Participants were divided into three groups: [1] Graduate or Registered Nurse; [2] Clinical Nurse Specialist or Associate Nurse Manager; and [3] Educator/ Nurse Unit Manager or Nurse Executive. There was a statistically significant difference at the  $p < 0.05$  level in QAverage scores for the various groups:  $F(2, 154) = 5.4$ ,  $p = 0.005$ . The effect size, calculated using eta squared, was 0.07, which according to Cohen (1988) is considered a medium effect. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for Group [1] ( $M = 4.09$ ,  $SD = 0.36$ ) was significantly different from Group [2] ( $M = 4.29$ ,  $SD = 0.37$ ). Group [3] ( $M = 4.27$ ,  $SD = 0.37$ ) did not differ significantly from either Group [1] or [2].

Using a Kruskal-Wallis Test, a statistically significant difference was revealed in QAverage across the three different categories (Group [1],  $n = 8$ : Graduate and Registered Nurse, Group [2],  $n = 80$ : Clinical Nurse Specialist and Associate Nurse Manager, Group [3],  $n = 25$ : Educator/Nurse Unit Manager or Nurse Executive),  $\chi^2(2, n = 113) = 7.32$ ,  $p = .026$ . Group [2] recorded the highest median score ( $Md = 4.3$ ), followed by Group [3] ( $Md = 4.21$ ) and Group [1] ( $Md = 4.07$ ).

### ***Highest Qualification***

An independent-samples t-test was conducted to compare QAverage with 'highest qualification'. There was no significant difference in scores between those with a postgraduate qualification ( $M = 4.13$ ,  $SD = 0.39$ ) and those with only an undergraduate qualification ( $M = 4.22$ ,  $SD = 0.36$ ). Levene's test (equal variances assumed Sig. 0.335) Sig. (2-tailed)  $p = 0.135$ .

A Mann-Whitney U Test similarly revealed no significant difference in the QAverage scores for those with a postgraduate qualification ( $Md = 4.10$ ,  $n = 84$ ), and those with an undergraduate qualification ( $Md = 4.23$ ,  $n = 80$ ),  $U = 2849$ ,  $z = -1.68$ ,  $p = .09$ ,  $r = -.13$ .

### ***'Palliative Care Unit or Hospice at your hospital or health service'***

An independent-samples t-test was conducted to compare QAverage and 'presence of a palliative care unit or hospice at the hospital'. There was no significant difference in scores between those who reported they did have a palliative care unit or hospice at their hospital ( $M = 4.17$ ,  $SD = 0.37$ ) and those who did not ( $M = 4.23$ ,  $SD = 0.41$ ). Levene's test (equal variances assumed Sig. 0.385) Sig. (2-tailed)  $p = 0.389$ .

A Mann-Whitney U Test similarly revealed no significant difference in the QAverage scores for those who reported that they did have palliative care unit at their hospice or hospital ( $Md = 4.13$ ,  $n = 134$ ), and those who did not ( $Md = 4.23$ ,  $n = 28$ ),  $U = 1734.5$ ,  $z = -.627$ ,  $p = .53$ ,  $r = -.05$ .

### ***'Access to specialist palliative care staff for advice or consultation'***

An independent –samples t-test was conducted to compare QAverage and 'Access to specialist palliative care staff for advice or consultation'. There was no significant difference in QAverage scores between those who reported they did have access to specialist palliative care

staff for advice or consultation ( $M = 4.19$ ,  $SD = 0.38$ ), and those who reported they did not ( $M = 4.10$ ,  $SD = 0.36$ ). Levene's test (equal variances assumed Sig. 0.422) Sig. (2-tailed)  $p = 0.452$ .

Using a Mann-Whitney U Test, no significant difference in the QAverage scores for those who reported they did have access to specialist palliative care staff for advice or consultation ( $Md = 4.17$ ,  $n = 148$ ), and those who reported they did not ( $Md = 4.00$ ,  $n = 15$ ),  $U = 879.5$ ,  $z = -1.32$ ,  $p = .19$ ,  $r = -.10$  was identified.

#### ***'Use of an End of life or palliative care pathway in your ward/hospital'***

An independent-samples t-test was conducted to compare QAverage and 'Use of an end of life or palliative care pathway in your ward/hospital'. There was no significant difference in QAverage between those who reported use of an EOL or palliative care pathway ( $M = 4.21$ ,  $SD = 0.40$ ) and those who did not ( $M = 4.16$ ,  $SD = 0.36$ ). Levene's test (equal variances assumed Sig. 0.286) Sig. (2-tailed)  $p = 0.369$ .

A Mann-Whitney U Test similarly revealed no significant difference in the QAverage scores for those who reported use of an EOL or palliative pathway ( $Md = 4.20$ ,  $n = 62$ ) and those who did not ( $Md = 4.10$ ,  $n = 100$ ),  $U = 2835.5$ ,  $z = -.912$ ,  $p = .36$ ,  $r = -.07$ .

#### ***'Previous death education'***

A one-way between-groups analysis of variance was conducted to explore the impact of 'previous death education' on QAverage. Participants were divided into three groups being [1] took a course of death and dying as part of my basic nursing education ( $M = 4.25$ ,  $SD = 0.42$ ); [2] did not take a specific course on death and dying, but material on the subject was included in other nursing courses ( $M = 4.12$ ,  $SD = 0.35$ ); and [3] no information dealing with death and dying was included in my nursing education ( $M = 4.26$ ,  $SD = 0.37$ ). There was no statistically significant difference in how these groups scored on the QAverage  $p = 0.07$ .



A Kruskal-Wallis Test revealed no statistically significant difference in QAverage according to previous death education ([1],  $n = 49$ ; [2],  $n = 92$ ; [3],  $n = 22$ ),  $\chi^2 (2, n = 163) = 4.05$ ,  $p = .132$ . Group [3] recorded the highest median score ( $Md = 4.24$ ), followed by Group [1] ( $Md = 4.23$ ) and Group [2] ( $Md = 4.10$ ).

#### ***‘Feelings about previous death education’***

An independent-samples t-test was conducted to compare QAverage and ‘Feelings about previous death education’. There was no significant difference in scores between those who felt that their previous death education did adequately prepare them to deal with death and dying or not ( $M = 4.18$ ,  $SD = 0.36$ ) and those who did not ( $M = 4.18$ ,  $SD = 0.39$ ). Levene’s test (equal variances assumed Sig. 0.851) Sig. (2-tailed)  $p = 0.940$ .

A Mann-Whitney U Test similarly revealed no significant difference in the QAverage scores for those who felt that their previous death education did adequately prepare them to deal with death and dying ( $Md = 4.10$ ,  $n = 73$ ) and those who did not ( $Md = 4.17$ ,  $n = 59$ ),  $U = 2072.5$ ,  $z = -.371$ ,  $p = .71$ ,  $r = -.03$ .

The tables following represent the findings of analysis conducted for the respondent demographic characteristics of the FATCOD, including the Independent samples t-tests (Table 8), Analysis of Variance tests (Table 9), Regression Analysis (Table 10) and Non-Parametric Analysis (Table 11).

Table 8. Independent samples t-test for respondent demographic characteristics, FATCOD

	Levene's test for Equality of variances		t-test for Equality of Means			
	F	Sig.	t	df	Sig. (2-tailed)	Mean Difference
Gender	.05	.946	-.629	155	.53	-.069
Highest Qualification	.94	.34	-1.50	155	.14	-.09
Palliative Care Unit or Hospice at your hospital or health service	.76	.39	-.86	154	.39	-.07
Access to specialist palliative care staff for advice or consultation	.65	.42	.76	155	.45	.08
Use an end of life or palliative care pathway in your ward/hospital	1.15	.29	.90	154	.37	.06
Feelings about previous death education	.04	.85	.08	124	.94	.01

Grouping Variable: QAverage

Table 9. Analysis of Variance for respondent demographic characteristics, FATCOD

		Sum of Squares	df	Mean Square	F	Sig.
Position	Between Groups	1.461	2	.731	5.424	.005
	Within groups	20.743	154	.135		
	Total	22.205	156			
Previous death education	Between Groups	.744	2	.372		.072
	Within groups	21.460	154	.139		
	Total	22.205	156			

Table 10. Regression analysis for respondent demographic characteristics, FATCOD

		ANOVA					
	R Square	Model	Sum of Squares	df	Mean Square	F	Sig.
Age	.027 <sup>a</sup>	Regression	.605	1	.605	4.340	.039 <sup>b</sup>
		Residual	21.473	154	.139		
		Total	22.078	155			
Years as RN	.013 <sup>a</sup>	Regression	.287	1	.287	2.013	.158 <sup>c</sup>
		Residual	21.408	150	.143		
		Total	21.696	151			

a. Dependent Variable: QAverage. b. Predictors: (Constant), Age. c. Predictors: (Constant), Years as RN

Table 11. Non-parametric tests for respondent demographic characteristics, FATCOD

<b>Mann-Whitney U Test</b>					
	Md	<i>n</i>	<i>U</i>	<i>Z</i>	Asymp. Sig. (2-tailed)
<i>Gender</i>					
Male	4.03	14			
Female	4.13	149	899.5	-.85	.40
<i>Highest Qualification</i>					
Postgraduate	4.10	84			
Undergraduate	4.23	80	2849	-1.68	.09
<i>'Palliative Care Unit or Hospice at your hospital or health service'</i>					
Yes	4.13	134			
No	4.23	28	1734.5	-.627	.53
<i>'Access to specialist palliative care staff for advice/consultation'</i>					
Yes	4.17	148			
No	4.00	15	879.5	-1.32	.19
<i>'Use of an end of life or palliative care pathway in your ward/hospital'</i>					
Yes	4.20	62			
No	4.10	100	2835.5	-.912	.36
<i>'Feelings about previous death education'</i>					
Adequately prepared	4.10	73			
Not adequately prepared	4.17	59	2072.5	-.371	.71
<b>Kruskal-Wallis Test</b>					
	Md	<i>n</i>	Chi-Square	df	Asymp. Sig.
<i>Current Position</i>					
Graduate/Registered Nurse					
Clinical Nurse Specialist/Assoc. Nurse	4.07	8			
Manager	4.3	80			
Educator/Nurse Unit Manager/Nurse Exec	4.21	25	7.318	2	.026
<i>'Previous death education'</i>					
Took a course of death and dying as part of my basic nursing education	4.23	49			
Did not take a specific course on death and dying, but material on the subject was included in other nursing courses	4.10	92			
No information dealing with death and dying was included in my nursing education	4.24	22	4.050	2	.132
<i>Dependent Variable: QAverage</i>					

#### **5.2.4 Survey open-response question**

At the end of the survey, all respondents were invited to provide more detailed responses, of which 43 elected to do so. Thematic analysis of these responses revealed four core themes: (1) workload, (2) nurse experience and education, (3) emotions and attitude, and (4) positive/rewarding experience.

##### **Workload**

Many respondents expressed frustration and negativity about how aspects of their workload impacted on the care they provided to the dying patient. For example:

*“Lots of care and time required which is where the main frustration lies for nurses, as we want to give more but can’t!” (Respondent 105)*

*“I just wish we had the opportunity to spend the time needed to be with the patient and the family to give them the adequate care and attention they need.” (Respondent 40)*

Other comments suggest a tension between what these nurses desired to do for the dying patient and what they were able to do in the context of their workload and time constraints.

*“Difficult to give the care required to a dying patient in context of acute medical setting as not enough consideration given by senior staff who allocate patient loads.” (Respondent 105)*

*“Palliative care nursing requires time and staff should be allocated that time to give the appropriate level of care.” (Respondent 101)*

These comments suggest that nurses knew what they ought to be doing, but seemed not to have the time or control over what they actually did. Others commented that despite realising

the incredible burden for families in needing to let go of their loved one, the time constraints of their role limited their ability to be supportive.

*“I don’t believe we always have enough time to provide holistic care to the dying patient and their family...” (Respondent 22)*

*“The problem.... at night shift is the lack of time for staff to spend with family and the dying person.” (Respondent 23)*

For another, the continuous running of a busy ward, especially in ensuring throughput, seemed to be in contrast to the care nurses wanted to provide.

*“Letting go of your loved one is such a hard, hard thing to do and I don’t think anyone should be rushed.... I wish we could give families and friends more time...to say goodbye to their loved one before the body has to be moved to make way for the next patient.” (Respondent 11)*

### ***Nurse Experience and Education***

The comments about experience and education were succinct. Several nurses noted that despite educational preparation, a nurse may never be prepared or ready to care for the dying patient until s/he has the clinical experience.

*“Experience on the job in this intimate life process has been the best education tool I have come across.” (Respondent 57)*

*“No matter how many courses nurses have on death and dying you can never be really prepared for that moment.” (Respondent 69)*

*“Dying people don’t wait for nurses to complete their graduate year and do further palliative care education.” (Respondent 117)*

Others suggested that the nurse's personal experiences, such as the death of their own family member, can assist the nurse in knowing how to care for the dying patient.

*"I feel that personal experiences regarding death make the nurse more empathetic to patients and families preparing for death." (Respondent 97)*

For those who have not been exposed to death and dying, either professionally or personally, the experience can be challenging for them. Younger nurses or newer staff, in particular, were noted as requiring more support:-

*"I feel that there should be more resources for nurses in relation to death & dying, as some younger or newly qualified staff have never had the experience and it becomes overwhelming for them." (Respondent 32)*

Despite the acknowledgement that supporting those with less experience or exposure to death and dying is important, another respondent commented:-

*"...wards cannot afford to roster graduate nurses away from dying patients until they are experienced." (Respondent 117)*

Other respondents expressed firm opinions about the strong need for ongoing education, especially in undergraduate curricula, but also as part of ongoing education.

*"Undergraduate nursing education programs need to spend more time delivering content on care of the dying patient." (Respondent 117)*

*"As an old school nurse I am very concerned about the lack of knowledge and experience graduate nurses often have towards death and dying." (Respondent 8)*

*"It should be a mandatory part of the nurse's annual professional development study." (Respondent 20)*

### **Emotions and Attitude**

There is no doubt that the death of a patient is a highly emotive time. Respondents considered the challenges of managing their own emotions that manifest as a result of caring for the dying patient.

*"I strongly believe that most RNs working in the 'general' acute sector (i.e. not specialty areas)... have a fear of really 'connecting' with the patient and family." (Respondent 8)*

Acknowledging their emotions, some respondents contemplated whether it was acceptable or not to share these emotions with family members.

*"I think it's important that the family see that the death sometimes affects the nurse also. After all, we are human." (Respondent 17)*

*"I am not afraid of being hurt by their passing, nor of crying with their family." (Respondent 11)*

But the impact of an individual patient's death on a nurse varies, with one response suggesting this depends on how well nurses cope with death and another commenting on the emotional cost, but also the value of the experience.

*"...peoples [sic] deaths and their families effect [sic] you in different ways...not all nurses can deal well with death." (Respondent 69)*

*'...looking after a dying patient can be both distressing and emotioanly [sic] exhausting however it can also be the most rewarding experience...' (Respondent 74)*

The expression of emotion from the nurse as well as their general demeanour is suggested to impact on the family too and will be a significant part of the memory of the death.



*“My belief is that nurses interactions with pt/families [sic] during this time can assist the pt/family [sic] and can be reflective in a good or bad experience for them. I speak from experience as someone who has gone through the process as well as a nurse providing the care. Poor attitude or lack of compassion, perceived [sic] or not, is held strongly in the memory of the survivors and may tarnish their reflection of the event itself.”*

*(Respondent 62)*

### **Positive/rewarding experience**

This theme encompasses the respondents' reflections on the experience of caring for a dying patient. Several respondents, in fact, spoke of how caring for the dying patient is a positive or rewarding experience, indeed a 'privilege'.

*“Palliative Care is one of the satisfying and gratifying elements of the job.” (Respondent 116)*

*“I always feel it is a privilege to care for a dying patient.” (Respondent 118)*

*“I think it is an incredible privilege to care for someone in the last days of their life.” (Respondent 11)*

*“My personal experience of nursing the dying patient and looking after thier [sic] relatives has always been a very rewarding experience and I have learnt more about life and nursing from those times.” (Respondent 91)*

*“I have been involved in the care of several patients who have died, and it was a special time caring for the patient and their family.” (Respondent 17)*

These themes reveal not only that caring for a dying patient is a highly emotive issue, but also that there is a sense of inadequacy, that is, not enough 'caring' in the nursing provided.

Resource limitations, systems and processes, and inadequate emotional and educational

preparation of nurses impact negatively on patient care, and, subsequently, may result in nurses either viewing their care as inadequate, or in their reluctance to care for the dying.

### **5.3 FATCOD-DOC survey results**

The FATCOD-DOC survey was not intended to form part of the main focus of this research.

The impetus for administering the additional survey emerged from the Phase One results, which indicated that some of the nurses expressed statements that doctors were unhelpful in their involvement in caring for dying patients. This is likely to have impacted patient care through their interactions with nursing staff who were providing care to dying patients. As a result, the existing FATCOD tool was modified for use with a medical student population, in order to further test these comments. As this was intended to be exploratory only, recruitment was limited to a single site: from one university's medical school.

There were 43 responses out of a possible 359 indicating a response rate of 11.9%.

Descriptive statistics were collected in order to illustrate the sample population and their responses; however, these questions were optional to prevent them acting as a deterrent from continuing the survey. The respondent demographic characteristics, irrespective of whether they completed the entire survey or not, are presented in Table 12.

Table 12. FATCOD-DOC Respondent Demographic Characteristics

<b>Characteristic</b>			
<i>Age</i>	Range 21-41 yrs	Mean 25 yrs	Std. Deviation 3.93
<i>Ward type when last cared for a dying patient</i>			
Medical		<b>n</b> 34	<b>%</b> 79.1
Surgical		5	11.6
Missing		4	9.3
<i>Access to specialist palliative care staff for advice or consultation</i>			
Yes		23	53.5
No		14	32.6
Missing		6	14.0
<i>Use an 'end of life' or 'palliative care pathway' in your ward/hospital</i>			
Yes		16	37.2
No		21	48.8
Missing		6	14.0
<i>Previous death education</i>			
I have taken a course/subject on death and dying/palliative care as part of my MBBS		23	53.5
I did not take a specific course/subject on death and dying/palliative care, but material on the subject was included in other subjects		14	32.6
No information dealing with death and dying was included in my medical education		1	2.3
Missing		5	11.6
<i>Feelings about previous death education</i>			
I feel that my previous death education prepared me to deal with death and dying		20	46.5
I feel that my previous death education did not prepare me adequately to deal with death and dying		13	30.2
Missing		10	23.3

### 5.3.1 Individual item analysis

Consistent with the FATCOD, how individuals responded to the FATCOD-DOC survey was also analysed in three ways:-:

- Each of the thirty items were first considered individually and the Mean, Standard Deviation, Median and Mode for answered items was calculated. The results are shown in Table 13.

Table 13. FATCOD-DOC Item Analysis

FATCOD-DOC Item	Item Score (Higher scores reflect more positive attitudes)					Mean	Standard Deviation	Median	Mode
	1	2	3	4	5				
Q1	0	0	0	13	19	4.59	0.50	5	5
Q2	0	1	2	8	21	4.53	0.76	5	5
Q3	1	5	13	12	1	3.22	0.87	3	3
Q4	0	0	2	15	15	4.41	0.61	4	5
Q5	0	4	5	16	7	3.81	0.93	4	4
Q6	0	4	1	7	20	4.34	1.04	5	5
Q7	0	3	4	15	10	4.00	0.92	4	4
Q8	1	6	7	14	4	3.44	1.05	4	4
Q9	1	2	5	12	12	4.00	1.05	4	4
Q10	0	1	2	9	20	4.50	0.76	5	5
Q11	0	0	0	13	19	4.59	0.50	5	5
Q12	0	2	12	13	5	3.66	0.83	4	4
Q13	0	5	11	12	4	3.47	0.92	3.5	4
Q14	0	3	2	16	11	4.09	0.89	4	4
Q15	0	3	6	12	11	3.97	0.97	4	4
Q16	0	1	0	13	18	4.50	0.67	5	5
Q17	0	0	5	9	18	4.41	0.76	5	5
Q18	0	0	7	10	15	4.25	0.80	4	5
Q19	0	5	11	7	9	3.63	1.07	3.5	3
Q20	1	4	9	10	8	3.63	1.10	4	4
Q21	0	0	6	11	15	4.28	0.77	4	5
Q22	0	3	7	13	9	3.88	0.94	4	4
Q23	0	0	1	11	20	4.59	0.56	5	5
Q24	0	1	8	15	8	3.94	0.80	4	4
Q25	1	0	3	10	18	4.38	0.91	5	5
Q26	1	9	5	11	6	3.38	1.18	4	4
Q27	0	0	0	15	17	4.53	0.51	5	5
Q28	0	2	1	14	15	4.31	0.82	4	5
Q29	0	3	7	14	8	3.84	0.92	4	4
Q30	1	0	2	14	15	4.31	0.86	4	5
Overall Average						4.08			

These results indicate that respondents had a highly positive attitude towards care of the dying, with the overall average at 4.08 out of 5. While the overall average score was high, the variation in standard deviation, however, suggests not all respondents were in agreement for the thirty items.

2. The QAverage was also computed and was used for further analysis to look for statistically significant relationships between the QAverage and demographic characteristics.
3. Using only those participants who answered all 30 items ( $n=31$ ), a 'total score' (out of 150) was generated from each participant's scores for all 30 items. The total scores ranged from 91 to 150 out of 150 with an average total score of 122.47 ( $SD = 12.86$ ).

### ***5.3.2 Analysis of QAverage and respondent characteristics***

QAverage scores were analysed similarly to the FATCOD data, in relation to the respondent characteristics using parametric and non-parametric tests. As stated previously, parametric statistical tests were used in the first instance, but given the smaller sample non-parametric techniques were also used because of their suitability to smaller samples (Pallant, 2011).

Despite the use of both parametric and non-parametric tests, there was no statistical evidence to suggest that any of the respondent characteristics affected how respondents answered.

#### ***Age***

The relationship between QAverage and respondents' age was investigated using Pearson product-moment correlation coefficient. With normality not violated, there was evidence of a positive correlation between age and QAverage scores,  $r = .22$ ,  $n = 31$ , indicating that older respondents scored more positively; however this relationship was not statistically significant  $p < 0.05$ . Similarly, a Spearman rho was also calculated. This also showed a positive

correlation between age and QAverage scores,  $\rho = 0.23$ ,  $n = 31$ , but it was not statistically significant  $p = .22$ .

### ***Ward Type***

An independent-samples t-test was conducted to compare the QAverage against ward type, being medical and surgical. There was no significant difference in QAverage based on whether respondents selected medical ( $M = 4.1$ ,  $SD = 0.45$ ) or surgical ( $M = 3.93$ ,  $SD = .35$ ;  $t(29) = .78$ ,  $p = 0.44$ , two tailed) for ward type. The magnitude of the differences in the means (mean difference = .17, 95% CI: -0.27 to 0.60) was small (eta squared = .021).

A Mann-Whitney U test also revealed no significant difference in the QAverage for those respondents who selected medical ( $Md = 4.13$ ,  $n = 27$ ) and surgical ( $Md = 3.83$ ,  $n = 5$ ),  $U = 48$ ,  $z = -.808$ ,  $p = 0.42$ ,  $r = -0.14$

### ***'Access to specialist palliative care staff for advice or consultation'***

An independent-samples t-test was conducted to compare the QAverage against whether or not respondents affirmed that they had access to specialist palliative care staff for advice/consultation or not. There was no significant difference in the scores for those who did have access to specialist palliative care staff for advice/consultation ( $M = 3.99$ ,  $SD = 0.41$ ) and those who did not ( $M = 4.26$ ,  $SD = 0.43$ ;  $t(30) = -1.73$ ,  $p = 0.10$ , two-tailed).

A Mann-Whitney U test also revealed no significant difference in the QAverage for those who affirmed that they has access to specialist palliative care staff for advice ( $Md = 4.03$ ,  $n = 21$ ) and those who did not ( $Md = 4.30$ ,  $n = 11$ ),  $U = 79$ ,  $z = -1.450$ ,  $p = 0.147$ ,  $r = -0.26$ .

### ***'Use of an end of life or palliative care pathway'***

An independent-samples t-test was conducted to compare the QAverage with those who affirmed that an EOL or palliative care pathway was used at their hospital/health service or not. There was no statistically significant difference in the scores for those who did use an EOL

or palliative care pathway ( $M = 3.98$ ,  $SD = .46$ ) and those who did not ( $M = 4.15$ ,  $SD = .41$ ;  $t(30) = -1.07$ ,  $p = 0.30$ , two tailed).

A Mann-Whitney U test similarly revealed that there was no statistically significant relationship between those who affirmed that an EOL or palliative care pathway was used at the hospital/health ( $Md = 4.02$ ,  $n = 12$ ) and those who did not ( $Md = 4.15$ ,  $n = 20$ ),  $U = 97$ ,  $z = -0.896$ ,  $p = .370$ ,  $r = -0.16$ .

### ***Previous death education***

A one-way between-groups analysis of variance was conducted to explore the impact of respondents' previous death education on QAverage. Respondents either selected [1] I have taken a course/subject on death and dying/palliative care as part of my MBBS; [2] I did not take a specific course/subject on death and dying/palliative care, but material on the subject was included in other subjects; or [3] No information dealing with death and dying was included in my medical education. There was no statistically significant difference at the  $p < 0.05$  level in QAverage scores for the three groups:  $F(1, 29) = 0.82$ ,  $p = 0.45$ .

A Kruskal-Wallis Test also failed to reveal a statistically significant difference in QAverage scores between the three different groups ([1],  $n = 20$ ; [2],  $n = 11$ ; and [3]  $n = 1$ ,  $\chi^2(2, n = 32) = 2.31$ ,  $p = 0.315$ . Group [3], that is, the one person who stated that no information dealing with death and dying was included in their medical education scored the highest median ( $Md = 4.57$ ), with group [2] ( $Md = 4.03$ ) and group [1] ( $Md = 4.1$ ).

### ***Feelings about previous death education***

An independent-samples t-test was conducted to compare the QAverage the responses of those who reported that their previous education on death and dying had adequately prepared them to deal with death and dying and those who responded that it has not. There was no statistically significant difference in the scores for those who responded that their



previous death education had adequately prepared them to deal with death and dying ( $M = 4.12$ ,  $SD = .35$ ) and those for whom it had not ( $M = 4.01$ ,  $SD = .52$ ;  $t(29) = 0.62$ ,  $p = 0.54$ , two tailed).

A Mann-Whitney U Test revealed no significant difference in QAverage for those who felt that their previous death education had adequately prepared them to deal with death and dying ( $Md = 4.05$ ,  $n = 18$ ) and those who did not ( $Md = 4.10$ ,  $n = 13$ ),  $U = 99.5$ ,  $z = -0.701$ ,  $p = 0.483$ ,  $r = -0.125$ .

The tables to follow represent the findings of analysis conducted for the respondent demographic characteristics of the FATCOD-DOC, including the Pearson  $r$  and Spearman  $\rho$  results (Table 14), Independent samples  $t$ -tests (Table 15), Analysis of Variance (Table 16), and Non-Parametric Analysis (Table 17).

Table 14. Pearsons  $r$  & Spearman  $\rho$  for respondent demographic characteristics, FATCOD-DOC

Pearson product-moment correlation coefficient		
Age and QAverage	Pearson Correlation	.215
	N	31
	Sig. (2-tailed)	.245
	Spearman rho	
	Correlation Coefficient	.227
	N	31
	Sig. (2-tailed)	.219

Table 15. Independent samples t-test for respondent demographic characteristics, FATCOD-DOC

	<b>Levene's test for Equality of variances</b>		<b>t-test for Equality of Means</b>			
	F	Sig.	t	df	Sig. (2-tailed)	Mean Difference
Ward Type	.45	.508	.784	29	.439	.167
Access to specialist palliative care staff for advice/consultation	.008	.928	-1.727	30	.095	-.267
Use an end of life or palliative care pathway in your ward/hospital	.079	.780	-1.071	30	.293	-.167
Feelings about previous death education	2.083	.160	.619	29	.540	.097

*Grouping Variable: QAverage*

Table 16. Analysis of Variance for respondent demographic characteristics, FATCOD-DOC

		<b>Sum of Squares</b>	<b>df</b>	<b>Mean Square</b>	<b>F</b>	<b>Sig.</b>
Previous death education	Between Groups	.305	2	.152	.820	.451
	Within groups	5.393	29	.196		
	Total	5.698	31			

Table 17. Non-parametric tests for respondent demographic characteristics, FATCOD-DOC

<b>Mann-Whitney U Test</b>					
	Md	<i>n</i>	<i>U</i>	<i>Z</i>	Asymp. Sig. (2-tailed)
<i>Ward type when last cared for a dying patient</i>					
Medical	4.13	25			
Surgical	3.83	5	48	-.808	.419
<i>'Access to specialist palliative care staff for advice/consultation'</i>					
Yes	4.03	21			
No	4.30	11	79	-1.450	.147
<i>'Use of an end of life or palliative care pathway in your ward/hospital'</i>					
Yes	4.02	12			
No	4.15	20	97	-.896	.370
<i>'Feelings about previous death education'</i>					
Adequately prepared	4.05	18			
Not adequately prepared	4.10	13	99.5	-.701	.483
<b>Kruskal-Wallis Test</b>					
	Md	<i>n</i>	Chi-Square	df	Asymp. Sig.
<i>'Previous death education'</i>					
Took a course of death and dying as part of my MBBS	4.10	20			
Did not take a specific course on death and dying/palliative care, but material on the subject was included in other subjects	4.03	11			
No information dealing with death and dying was included in my medical education	4.57	1	2.309	2	.315

*Dependent Variable: QAverage*

### 5.3.3 Survey Open-response Question

At the end of the survey, all respondents were invited to provide more detailed responses, of which five elected to do so. Given the small number of responses, extensive thematic analysis was not possible. Those responses that were received were similar in their expression of inadequacy on nurses' lack of educational and preparation for dealing with death.

*“During our 5 year course at XXXXXX we only received 1 (excellent) day of palliative care teaching. This is no where [sic] near enough as we are put on clinical placements before learning how to deal with the dying patient. This is very stressful and upsetting to many students. Please help!” (Respondent 24)*

*“The palliative care day was helpful in preparing me to deal with dying patients.”  
(Respondent 40)*

Despite the positive feedback received by the above respondents in relation to the palliative care education they did receive, others saw it differently, keenly stressing its inadequacy.

*“This is a very difficult area to teach in medical school and a lot of the times it is through our placements that we are exposed to the process of death and dying.” (Respondent 22)*

Similarly, others suggested that formal teaching/education does not necessarily result in a doctor who is prepared for the real management of dying.

*“Even if we are prepared through formal teaching, in the real life situation, it never feels like we can handle it.” (Respondent 39)*

*“To some extent, I don't think anything will prepare you for the first death you experience as a medical student (or should I say deaths in each setting e.g. PEA arrest and failed resuscitation, palliation of colorectal cancer in geriatric unit, death of a child, death in the emergency department.” (Respondent 43)*

One respondent suggests that *how* a doctor manages a patient death and how he/she behaves is equally important to other course content. The amount of formal education devoted to these skills should take precedence over other issues that seem less relevant to the beginning practitioner.

*“The emphasis on the management and appropriate professional behavior [sic] should be taught much earlier in our course over other non-clinical related humanitarian subjects which has no real clinical relevance for the vast majority of us by the time we graduate. There is no point for us to know about the possible ethical dilemmas of someone being treated half way across the world when we still feel inadequate about dealing with a dying patient in our own wards.” (Respondent 22)*

Another respondent indicated that despite the inadequacy of education or preparation for dealing with death and dying, as a medical student in the clinical setting, support was available from more experienced colleagues.

*I think doctors I have worked with have been supportive and conscious of the fact that first times e.g. with certifying deaths can be confronting.” (Respondent 43)*

## **5.4 Comparison of qualitative responses**

What was immediately apparent when the two survey respondent populations when compared was that despite their distinct differences, not only in terms of profession, but also experience, both populations scored ‘highly positively’ on the FATCOD and FATCOD-DOC survey, indicating highly positive attitudes towards care of the dying. Despite these positive scores, however, the open-ended comments made by respondents to both surveys provided some contrast and a compelling need for further consideration.

Workload, time constraints, and the highly emotive work of caring for the dying were reported as a significant source of distress/stress for the nurse respondent population. However, the medical student population did not raise these issues. This is most likely due to the differences in work patterns between nurses and doctors. Where nurses are primary carers for patients, spending more time at the bedside than any other clinician (Hamric & Blackhall,

2007), doctors (or final year medical students), in contrast, may be responsible for a much larger number of patients and spend less time at the bedside of any one patient. It is likely that the caring nature of nursing work (Dempsey, et al., 2009) and the intimate care relationship that is established between the nurse and patient (Carter et al., 2008), extending to their family, increases the emotional impact of a patient's impending death on a nurse.

What was common to both respondent groups was that they conveyed the difficulty of caring for a patient who is dying. Despite some education, whether it is formal classroom education or less formal, it was seen to be inadequate to prepare doctors or nurses for caring for the dying. The comments made by nurses to the open-ended response question elicited some facets of their attitudes and experience of caring for a dying patient and these may seem to be in contrast to a highly positive score on the FATCOD. However, it is equally important to note, that despite the emotional burden, lack of education or experience, workload and time constraints identified by nurse respondents, they also spoke of caring for the dying patient in terms of it being a rewarding experience, a positive outcome not raised by final year medical students.

## **5.5 Summary**

In summary, the findings of the FATCOD and FATCOD-DOC surveys have been presented. Both respondent populations scored highly on the survey tools indicating a highly positive attitude towards care of the dying patient. These results contrast to the findings from Phase One of this study. Equally important, the open-ended responses to these surveys are not as positive as the survey scores and some of the issues raised in their comments more closely reflect the findings from Phase One. These issues will now be explored in further detail in Chapter Six.

## CHAPTER SIX – DISCUSSION

### 6.1 Introduction

The aim of this mixed method study was to explore nurses' *recognition of* and *responsiveness* to dying patients in the Australian acute hospital (non-palliative care) setting and to understand the nurses' influence, if any, on the provision of EOL care. While a smaller pilot group of final year medical students were included in the quantitative phase of this study, the study primarily focussed on nurses.

The findings from Phase One demonstrated that nurses had difficulty in recognising dying from a clinical perspective. They also demonstrated a reluctance to overtly acknowledge that a person was dying, instead remained passive, continuing resuscitative or curative care until dying was 'recognised' first by medical staff. Some nurses were observed to be reluctant and uncomfortable in caring for the dying patient and their comments during the interviews corroborated this finding. This evidence further suggests that they are often underprepared emotionally and educationally in providing EOL care. Furthermore, as suggested previously, it is possible that nurses' death anxiety has significantly influenced their interactions with the dying patient and EOL care.

The Phase Two survey utilised an existing tool to measure 'attitude towards care of the dying'. The survey, however, elicited some findings that did not reflect the Phase One findings. Instead nurses (and final year medical students) scored highly positively, indicating a strongly positive attitude towards care of the dying person. Whilst the quantitative survey findings were positive, indicating a highly positive attitude towards care of the dying, the themes derived from the text comments included by survey participants suggest that, similar to the findings of Phase One, there remains a sense of dis-ease associated with care of the dying, linked to environmental and workload factors and nurse preparedness.



Given that this study utilised a 'Sequential Exploratory Design' (Creswell, 2009; Creswell & Plano Clark, 2011), the structure of this chapter will be presented in the same way. Firstly, the findings from Phase One will be discussed in relation to the literature. Secondly, the same findings will be considered in light of the death anxiety literature theory also presented in Chapter Two. Then the findings from Phase Two will be discussed and compared to other literature. Finally, the findings from the synthesis of Phases One and Two will be discussed, followed by the methodological strengths and limitations of the study.

## **6.2 Observation and interviews**

### ***6.2.1 Recognising dying***

The findings from Phase One indicated that some nurses have difficulty in recognising dying, demonstrating a lack of clarity on how dying is determined. While some relied on physiological parameters such as vital signs and level of consciousness to indicate that a patient was dying, others, instead, referred to how a patient might 'appear'. During the observation and focus group interviews, others spoke of how they relied on formal verbal and/or written recognition from the medical officer to know when a patient was dying. While some participants implied that they might have already known or sensed that a patient was dying, they did not act upon it until there was formal recognition from the medical officer; acute care continued as previously prescribed and for some this was a source of frustration.

The difficulties and complexity associated with recognising dying identified during this study resonate with previously published studies. In an integrative literature review aimed at issues associated with initiating an EOL pathway, Watts (2012) identified four main factors that contribute to difficulties in diagnosing dying: clinical experience, education and training, organisational cultures and professional cultures. Other literature confirms the difficulty in diagnosing dying depends on how dying is assessed (Jack, Gambles, Murphy & Ellershaw,

2003; Pugh, McEvoy & Blenkinsopp, 2010), especially that some people may fit criteria designed to identify when a person is dying and may not be dying (Duffy & Woodland, 2006; SUPPORT Principle Investigators, 1995). This issue contributes to the multiple difficulties faced by clinicians. Findings from two recent studies investigating the use of the Liverpool Care Pathway (LCP) identified that diagnosing dying was difficult for clinicians, particularly when the illness was not of a cancer origin (Pugh, et al., 2010; Verbeek et al., 2006). Another research team found that while most clinicians were able to recognise symptoms associated with dying and when death was imminent, over 35% of patients were not recognised as dying until less than 24 hours prior to their death (Twomey, McDowell & Corcoran, 2007).

Palliative Care Australia (Aleksandric & Hanson, 2010) also acknowledges that diagnosing or recognising dying is challenging for clinicians. They suggest this is largely due to the inability or unwillingness of clinicians to recognise those who are dying, suggesting that the clinician's strongly held desire to treat and cure, together with systems of care and training, limit the clinician's capacity and capability. A lack of understanding of the indistinct boundary between chronic and complex health care problems, ageing and dying is also proffered. Likewise, there is a perspective that clinicians are poorly educated to understand what dying entails (Aleksandric & Hanson, 2010).

Passivity amongst nurse participants in relation to recognising dying may be due to similar factors. The lack of and impossibility of clear cut and universal criteria with which to recognise dying is a likely contributor to the reluctance of nurses to recognise dying. However, nurses' preferences to wait or rely upon medical staff to formally recognise when a patient is dying may also stem from socio-cultural influences, such as the historical and cultural differences that exist between medicine and nursing (Thompson, et al., 2006). Whereas it was traditionally the doctor's role to diagnose and make decisions about care (Porter, 2006), and for nurses to carry out the care as prescribed (Lupton, 2012), this study suggests that nurses

may choose to remain passive, reluctant to articulate their knowledge and contribute to patient management, instead deferring to medical opinion, a finding similarly reflected in other research (Coombs & Ersser, 2004).

Lupton (2012) strongly posits that while there is little published research on the sociological aspects of the power relationship between doctors and nurses. It is likely that this power relationship in which nurses are subordinate to doctors, stems from medicine's dominance over all health professions (Wearing, 1999) and is a contributor to the passivity of nurses. The power differential is due to differences in gender (where doctors are predominantly male and nurses predominantly female), and social class and status (Lupton, 2012). This situation was similarly identified by Coombs et al (2012) who studied clinical decision-making in Intensive Care. This study found that whilst there was evidence of effective and mutually satisfying working relationships between doctors and nurses, there was also evidence to suggest that nurses felt over-powered by medical personnel, with less opportunity to contribute to decision making. Likewise, Allen (1997) highlights how, although nurses were able to assert some influence on doctors, within a formal hierarchy, doctors had higher status.

Howarth (2007) has also reflected on death and dying from a sociological perspective. This study suggests that death has become the exclusive domain of the medical profession, a position that also likely contributes to medical dominance and nurse passivity in EOL care. Regardless of the reason for the passivity, or reluctance of nurses in recognising dying in this study, Palliative Care Australia acknowledge an inability or unwillingness among many health professionals to recognise dying as one of the current challenges impeding care at the EOL (Aleksandric & Hanson, 2010).

### ***Utilising Death Anxiety theory***

When considered in relation to the death anxiety theory presented in Section 2.6, the death anxiety theory suggests an alternate and/or compounding rationale for the passivity

demonstrated by nurses. Death anxiety influences an individual's action and reaction to death (Lehto & Stein, 2009; Yalom, 2009) and when triggered, their primal responses are provoked in the form of defence mechanisms (American Psychiatric Association, 2000) to protect them against the anxiety aroused by death.

The death anxiety theory suggests that a nurses' reluctance and/or passivity in recognising dying may instead be attributed to denial, a known coping mechanism utilised in death anxiety. By denying that a patient is dying, whether a conscious or subconscious choice, the nurse protects his/herself from death anxiety and the negative emotions associated with it. For as long as the death or impending death is ignored or denied, the nurse is not affected and can continue to provide nursing care. In this way, caring for a patient who is perceived as acutely ill is easier than caring for a patient who is dying.

### ***6.2.2 Responsiveness to dying***

The way nurses respond to the dying patient is complex and is an integral determinant of the quality and timeliness of care (Aleksandric & Hanson, 2010; Braun, et al., 2010; Dunn, et al., 2005; Pincombe, et al., 2003). The Phase One findings demonstrated that a nurse's responsiveness to the dying patient was influenced by numerous factors such as nurse preparedness, workplace support, workload, ward design, and nurse allocation.

#### ***Nurse Preparedness***

During the observation it was apparent that not all nurses appeared comfortable with providing EOL care. While some participants reflected on caring for the dying in a positive light, describing the provision of EOL care with words such as 'honour' and 'privilege', others stressed the burden and the degree of emotional work they associated with such care. Focus group participants and the Nurse Managers believed that nurses who care for the dying should have effective communication skills, emotional intelligence, and empathy. It was evident

during some episodes of observation that not all nurses demonstrated these qualities, or were keen to provide care for the dying. The emotional impact of caring for a dying patient made providing EOL care difficult. Although some participants described how an emotional response to the death or dying of a patient was normal, for others, the impact of their grief was prolonged, impacting on their ability to provide care. These findings suggest that the preparedness of individual nurses to provide EOL care as well as the emotional impact it may have on them was considered when allocating nursing staff to this care.

These findings are congruent with previous research and experts who found that there is not only a widespread reluctance to talk about death (Department of Health, 2009; Wasserman, 2008), but acute hospital staff can have negative perceptions of palliative care (Willard & Luker, 2006). The dominant medical paradigm and focus on cure has meant that clinicians sometimes regard a patient's death as a failure of care (Boroujeni, Mohammadi, Oskouie & Sandberg, 2008; Watts, 2012). Furthermore, when nurses feel their workload is too great and they have little control (Jourdain & Chênevert, 2010), these factors contribute to anxiety associated with caring for a dying patient (Abdel-Khalek, 2005; Peters et al., 2012).

Previous studies also support the notion that individuals are afraid of death (Tilden & Thompson, 2009). For clinicians working in acute care settings, providing care for a dying patient can be challenging, not just in a workload or contextual sense, but also because EOL care may contrast with the general goals of care for the ward area. Tilden and Thompson (2009) suggest that the discordance between the goal of 'cure' and acceptance of death creates a significant impediment to quality of EOL care in hospital settings.

### ***Support in the workplace***

The Phase One findings demonstrate that some nurses appear to be stressed and unhappy in being allocated care for a dying patient, suggesting that their emotional needs were not being addressed adequately. Despite those who did verbalise their discontent and/or display their

emotions outwardly, blaming their workload and workplace practices for impacting upon EOL care, many other participants were not vocal about their discomfort, but were observed to be focussed on task-oriented care.

Existing evidence suggests that nurses can and do suffer from death anxiety. Death anxiety is described as the apprehension generated by death (Abdel-Khalek, 2005) or the contemplation of death of self or others (Nyatanga & de Vocht, 2006). Death anxiety is largely repressed by nurses as a way of coping (Lehto & Stein, 2009; Nyatanga & de Vocht, 2006; Yalom, 2009) and because of this repression, many may go unsupported emotionally, with other clinicians unaware of their anxiety. Where some nurses may be able to accept that patient death 'comes with the territory' (Boyle & Carter, 1998), this may not be the case for all nurses, particularly in an environment where care is directed towards cure.

In relation to nurses being task-oriented, concern has been raised in the literature about whether or not caring was being over-shadowed by lists of tasks required to care for patients (Carter, et al., 2008). Care pathways have been demonstrated to improve the quality of care provided to the dying patient in the acute care setting (Department of Health, 2009; Murphy, et al., 2007; Taylor & Randall, 2007), but their prescriptive design has also encouraged a task-oriented approach to care (Edmonds & Rogers, 2003), where activities such as spending time with the family, which are not itemised on the pathway are forgotten. Nevertheless, the focus on task-oriented care observed in Phase One has been identified previously as a coping mechanism used by nurses. Focussing on the tasks rather than the dying patient enables the nurse to shift the focus away from the dying patient who is the source of anxiety (Kubler-Ross, 1969; Pincombe, et al., 2003; Wakefield, 2000; Yalom, 2009).

### **Workload**

During observation, nurses appeared to approach their workload in a way that enabled them to complete set tasks previously described as 'task-oriented' care, rather than using a 'patient-

centred' approach where the needs of the individual determined the care provided (Dempsey, et al., 2009). Nurses were allocated four patients; when one of the four patients was dying, they often received less attention, particularly when they were unconscious and/or placed in a single room. It seemed that the workload, the pace of the ward and the inability of the dying patient to request/seek assistance from the nurses, meant that they received less nursing attention than other patients.

The task-oriented approach to care was demonstrated by nurses planning care delivery according to hour by hour tasks on a 'to do' list. When participants were asked about the care they were providing to the dying patient, the response was commonly a recollection of physical care tasks, such as sponging, linen change, suctioning and so on, rather than a focus on the person and their holistic requirements. What is already acknowledged is that providing appropriate care for the dying in an acute care environment is challenging. Willard and Luker's research (2006) highlighted the challenges to EOL care in an acute hospital and found that nursing staff working in acute care settings across five hospital trusts in the United Kingdom (UK) were preoccupied with active treatment and routine practice. EOL care did not 'fit' with this focus. Another UK study reported how ward nurses perceived care of the dying to be difficult work in an acute hospital environment, amplified when management did not recognise this difficulty (O'Hara, 2011).

### ***Ward design***

The design of the wards observed in Phase One also significantly influenced the way care was provided to the dying. Not only were dying patients and others requiring isolation for infection control reasons allocated to single rooms as a priority, but these rooms were situated adjacent to each other. In terms of allocation, the 'usual' practice observed in this study was that one nurse was allocated to the two single rooms and a two-bedded room in each wing of the ward. Participants were not seen to challenge this usual practice during



observation. One participant's justification for the use of single rooms for the dying was so others did not have to see a patient die. Nevertheless, during the focus groups, the 'ideal' of providing care for the dying in a single room was broached by some participants who suggested that a dying patient in a single room could be forgotten and the quality of care diminished.

Where previous studies justified the use of single rooms in terms of privacy (Boyle & Carter, 1998; Hadders, 2007; Pincombe, et al., 2003; Porock, et al., 2009), others suggested that the strategy of using single rooms is more a reflection of the desire of clinicians to minimise distress to other patients and hide the dying from public view (Porock, et al., 2009). This desire to hide the dying is also acknowledged by Howarth (2007) who provides a sociological perspective on the use of single rooms for the dying. She suggests that those who die in single rooms die in isolation and solitude.

*"... death is perceived as feared – consigned to the dying rooms of the ward. When death occurs in hospitals it is likely to be hidden as the beds of dying people are commonly surrounded by screens..."* (Howarth, 2007, p.124).

### **Nurse Allocation**

Allocation of nursing staff occurred according to the ward layout, taking into account continuity of staffing, rather than the needs or acuity of patients. It became apparent during the observations that a nurse's seniority or assertiveness determined the allocation of rooms, commonly with the single rooms and double room being the last to be allocated. When this ward practice was highlighted in a focus group, participants explained their rationale that a 'team nursing' approach to care meant that it did not matter who was allocated where, however team nursing in this sense, was rarely observed.

While not overtly discussed with study participants, other contributing factors as to the reasons why allocation of care of the dying patient was often left to the most junior (and thus least powerful) nurse cannot be overlooked. Again, death anxiety amongst nurses can manifest as a reluctance to care for the dying person (Thorson & Powell, 1988). In an acute hospital ward orientated towards cure, caring for the dying can be uncomfortable, ambiguous and difficult (Ashby, 2011) and, consequently, nurses' reluctance and discomfort can manifest in their actions. In a qualitative study of nurses coping with death and dying, Peterson et al. (2010) describe how nurses rely on professional distance to cope with dying and in keeping their emotions separate. Similarly, the notion of workload is a likely contributor to allocation practices.

### ***Utilising Death Anxiety theory***

While the discussion presented above explores how nurses respond to the dying patient, in terms of the issues that impede upon nurse responsiveness, death anxiety theory presents an alternative view, which complements the literature already presented and assists in further explaining nurse responsiveness to the dying patient.

As discussed previously, not all nurses were comfortable or prepared to care for the dying patient and the reasons put forward for this included that some nurses lacked the qualities necessary to provide care for the dying. For others, the grief associated with this sort of work impacted their ability and willingness to do it. From a death anxiety perspective, however, the behaviours observed may in fact represent 'avoidance', a defence mechanism employed to counteract death anxiety. Avoidance describes how individuals avoid intimacy and interaction, in this case with the dying patient, as a way of avoiding emotion and pain (Brisley & Wood, 2004; Thorson & Powell, 1988; Wakefield, 1999; Wakefield, 2000).

The nurse's use of avoidance also assists in understanding nurse concerns regarding workload and their allocation practices observed during the observation. Where preferences for

allocation are linked to workload, and justified in terms of the amount of work required to care for the dying patient, the death anxiety theory suggests that this is also representative of avoidance. That is, rather than nurses being reluctant to care for the dying because of the workload, their reluctance is more likely to be due to their preference to avoid the dying patient and control their anxiety.

Avoiding the source of the anxiety also assists the individual in their denial. By avoiding the dying patient, they can continue to deny that death is likely or imminent, thereby assisting to control their own anxiety. For some individuals, denial of a situation deemed threatening such as a dying patient is a common strategy employed in order to cope (Boyle & Carter, 1998). The use of denial as a coping mechanism was also evident in the prioritisation of single rooms for the dying. The segregation of the dying to side or single rooms, which serves to conceal the sick (Lehto & Stein, 2009) has been previously highlighted in the literature as a method utilised by nurses to lessen their own anxiety associated with death and dying and protect others (Degner & Gow, 1988; Porock, et al., 2009) such as other patients from the same anxiety (Lehto & Stein, 2009).

Not only are single rooms enable dying to be hidden away, potentially lessening a nurse's death anxiety, the death anxiety literature suggests that nurses also rely on withdrawal or 'professional distance', and this was evident in the Phase One findings. Professional distance describes how nurses become pre-occupied with technical elements of their work, or concentrate on the patients' physical needs and avoid emotional involvement in patient care (Brisley & Wood, 2004). Where this has previously been suggested to result from a lack of educational or emotional preparation for nurses in care of the dying, the death anxiety literature confirms that the root of professional distancing practices is more likely death anxiety, rather than just a lack of emotional or educational preparation.

### ***6.2.3 Institutional systems and processes that influence care of the dying person***

Institutional systems and processes, accepted as standard practice were also shown to impact on the care provided to the dying person. The process of nurse allocation and the way in which patients are allocated to single rooms has been shown to directly impact upon the care the dying patient receives. Of equal importance, is the influence of controlling and preventing the admission of a dying patient from the Emergency Department into the ward. While the nurse's outward motivation for preventing the admission was the lack of a single room, in viewing the incident using death anxiety theory her behaviour may also be a representation of avoidance and desire for professional distance (Glaser & Strauss, 1965; Thorson & Powell, 1988). By preventing the admission, the nurse was able to control her anxiety associated with the dying patient, despite the likelihood that the dying patient may have had a more comfortable death in a shared bed space in the ward than in the Emergency Department.

## **6.3 Attitudes to death and dying**

In Phase Two of the study a survey was utilised to measure the attitudes of nurses and final year medical students towards care of the dying patient, using a survey instrument known as Frommelt's Attitude Toward Care of the Dying (FATCOD). For the nurse population, the FATCOD instrument, in its original form, was used because it was originally developed for a nurse population (Frommelt, 1991) and for the final year medical student survey population, the survey was modified to suit doctors/final year medical students (and tested) to produce the FATCOD-DOC survey.

The most significant finding from the Phase Two surveys was that both populations scored highly on the FATCOD and FATCOD-DOC indicating positive attitudes towards care the dying.

### **6.3.1 Nurse Survey using FATCOD**

#### ***FATCOD total scores and average scores***

The nurses' attitudes towards care of the dying were measured in two ways. The average of all scores for the 30 FATCOD items, represented as a score out of five was calculated at 4.18.

Other studies of nurse participants that have utilised a similar method of analysis have reported scores of 3.55 (Iranmanesh, Dargahi, et al., 2008) and 4.30 (Lange, et al., 2008).

Alternatively, the average of total scores, represented as a score out of 150 was also calculated in this study to be 125.94. Other studies of nurse participants have also analysed their data in this way and report average total scores of between 94 (Ali & Ayoub, 2010) and 132 (Brajtman, et al., 2009). These scores suggest that the high scores in this study, (which indicate a highly positive attitude towards care of the dying), similarly correlate with other studies of nursing participant populations.

#### ***Relationship between respondent characteristics and FATCOD scores***

The findings in this study demonstrated only one statistically significant relationship between the attitude scores and respondent characteristics. Older nurses scored more positively on the FATCOD. That is, older nurses demonstrated more positive attitudes towards care of the dying than their younger colleagues. However, there was no correlation between 'years as a nurse' and attitude score.

Several studies have found a similar correlation between the age of the nurse and attitude towards dying. Four previous studies were found that showed attitudes towards care of the dying improved with increasing age (Ali & Ayoub, 2010; de Kock, 2011; Iranmanesh, et al., 2010; Lange, et al., 2008). Another, which used the FATCOD as a pre and post measure of the impact of an education program, found that younger nurses were more likely to positively change their attitudes toward care of the dying than those who were older. In that study,

however, 92% of participants were in the same age category (i.e. 18-22years) (Barrere, et al., 2008).

### ***Open-ended responses***

The responses to the open-ended question in the survey yielded 43 responses, which were approximately one quarter of respondents. Thematic analysis resulted in four core themes which were: (1) workload; (2) nurse experience and education; (3) emotions and attitude; (4) positive/rewarding experience. While the nurse respondents' scores against the FATCOD items indicated a highly positive attitude towards care of the dying, the themes derived from the open-ended responses represented something quite different.

#### ***(1) Workload***

In relation to the first theme, nurses commented on their lack of time and how this and their workload negatively impacted on care of the dying patient and their family. This theme correlates to findings from the Phase One observations and interviews suggesting that while survey participants demonstrated a highly positive attitude towards care of the dying patient, a heavy workload and lack of time were an issue for the survey respondents.

Nurse workload in the acute care setting is already highlighted in the research literature and the nature and workload associated with caring for a dying patient is under-recognised (O'Hara, 2011) impacting upon patient care. Ward patients are becoming sicker and their care more complex and these factors directly impact on nurse workload (Quirke, Coombs & McEldowney, 2011). Pincombe, Brown, and McHutcheon (2003) found that when dying patients were cared for with other acute ward patients, workload demands meant that the overwhelming amount of care that was offered to the dying patient was associated with routine and technological care. While they described the care provided to dying patients to be

of a very high standard, the individuality of the patient was disregarded, and nurses were unable to spend more time with them. These findings reflect the findings of this study.

## *(2) Nurse experience and education*

The second theme was that of 'nurse experience and education'. Participants commented that despite education and experience, they may never be prepared for the death of a patient; but for those with less experience, either personally or professionally, dealing with the death of a patient can be very challenging.

Despite previous education relating to EOL care, respondents indicated that there is a need to improve EOL education for nurses in acute care settings. While some identified that they relied upon their own personal experiences with death and dying (in a non-nursing capacity), the need for more education and training for clinicians providing EOL care has already been recognised in the literature (Economist Intelligence Unit, 2010).

In recent years, there has been increasing discussion, both internationally and in Australia suggesting that death, dying, EOL care and palliative care are under-represented in nurse education. More ongoing education and training is necessary (Aleksandric & Hanson, 2010; Economist Intelligence Unit, 2010; Palliative Care Australia, 2008a). For nurses already working in acute care settings, where there is a preoccupation with active treatment (Willard & Luker, 2006), the promotion of further education that not only informs clinicians, but also stimulates discussion and raises the profile of EOL care has significant support (Barrere, et al., 2008; Paice et al., 2006; Palliative Care Australia, 2008a; Palliative Care Curriculum for Undergraduates (PCC4U), 2010). This is further supported by other studies that describe how nurses can feel under-prepared and under-educated in providing EOL care (Ingleton, Gott & Kirk, 2009; Jackson, Mooney & Campbell, 2009). It is apparent that even though nurse



respondents in this study scored highly on the FATCOD, their responses to the open-ended question suggest there is still much room for improvement in this area of education.

### *(3) Emotions and attitude*

Emotions and attitude, the third theme, demonstrated that managing one's own emotions was challenging for nurses providing EOL care. Caring can also make an emotional impression on a family too, by influencing their immediate experience or in the later recollections of the event. While the nurse responses to the open-ended survey questions are not a measure of death anxiety or indication of burnout, the responses by some participants indicated that providing EOL care can and does impact on nurses psychologically and emotionally. Some respondents deferred to issues of workload and the work environment as factors that impacted on EOL care. This may be deliberate, rather than recognising their own psychological response.

Burnout of nurses in the workplace occurs in response to experiences of interpersonal and emotional stressors. These are characterised by emotional exhaustion, a lack of personal accomplishment, and a sense of being overwhelmed by work (Mealer, Burnham, Goode, Rothbaum & Moss, 2009). When nurses feel overloaded, or they lack control over their practice, these factors can contribute to burnout (Jourdain & Chênevert, 2010; O'Mahony, 2011). More specifically, nurses involved with EOL issues, just like the nurses in this study, were found to be more likely to be adversely affected and suffer psychologically from their work (Mealer, et al., 2009). Similarly, Jourdain and Chênevert (2010) also identified that perceived 'hostility' from doctors is another factor contributing to nurse burnout. The implications of burnout are not just the psychological impact on the nurses themselves, but it has also been linked to poorer job performance (O'Mahony, 2011). While it was beyond the scope of this study to measure burnout or other psychological measures, clearly, a nurse's psychological response to caring for the dying patient cannot be ignored.

### *Positive/rewarding experience*

Despite the psychological issues alluded to previously, not all nurses viewed care of the dying negatively. The final theme was 'positive/rewarding experience', which was drawn from the highly positive attitudes towards care of the dying demonstrated in the FATCOD survey.

Studies that have evaluated the use of care pathways for the dying have demonstrated that when the pathways are used as intended, nursing staff reflected positively on their use. Some reported increased confidence and knowledge regarding caring for dying patients (Jack, et al., 2003; Jackson, et al., 2009; Watts, 2012), others shared that they felt more able to speak openly about dying (Duffy & Woodland, 2006) and communication with medical staff had improved (Hockley, Dewar & Watson, 2005). What these studies demonstrate is that when staff are adequately prepared to provide EOL care, it can be a positive and rewarding experience. It is likely that those nurse respondents who commented positively in the open-ended question also feel adequately prepared.

### **6.3.2 Final year medical student survey using FATCOD-DOC**

Final year medical students scored highly positively on the FATCOD-DOC indicating positive attitudes towards care of the dying. At the time this study commenced, no published studies had used FATCOD or a modified version of FATCOD to measure the attitudes towards care of the dying in a medical student or doctor population. More recently, however, Leombruni and colleagues (2012) published research findings from a study that measured pre-clinical second-year medical students' attitudes towards care of the dying in Italy, prior to commencement of an elective short course on EOL care. This course was established because of previous research which indicated that Italian medical students felt inadequately prepared by their curriculum for dealing with the EOL. This finding was congruent with that of Billings and

colleagues (2010) who, using a different approach, also measured the attitudes of medical students towards care of the dying.

Leombruni and colleagues (2012) utilised FATCOD Form B, which was modified from the original FATCOD by the original author so as to be applicable to students from a variety of programs of study (Frommelt, 2003) and it had been translated into Italian. In comparing results of this research to that of Leombruni and colleagues (2012), the Italian study participants scored a mean total score of 112.8 and a mean item score of 3.76. This result was considerably lower than the Australian population of final year medical students. This difference is possibly due to a number of factors.

First, the Australian final year medical students had clinical opportunities for exposure to death and dying as part of the course, whereas the 2<sup>nd</sup> year medical students surveyed in the Italian study were identified as 'pre-clinical' indicating that they had not yet undertaken a clinical placement and are, therefore, not likely to have had exposure to death and dying. Leombruni et al. (2012) also specified that their survey was taken prior to the commencement of an elective education program on EOL care, whereas the majority of this Australian population had indicated they received some education or material related to death and dying.

### ***Open-ended responses***

While only 6 participants chose to respond to the open-ended question, their responses were interesting. Several of the respondents reflected on the education on death and dying contained in their curriculum, suggesting that, while helpful, it had been inadequate to prepare the final year medical student for a dying patient or patient death. Where one day of palliative care education was included and positively regarded, they felt it was insufficient to prepare them for being confronted with the death or dying of a real patient in the clinical

environment. This was a finding consistent with those of previous research with medical students (Billings, et al., 2010; Leombruni, et al., 2012).

## **6.4 Synthesis of findings**

The findings from Phase One of this study identified a number of key findings relating to nurse recognition of and responsiveness to the dying patient including:- nurse passivity in recognition, the preparedness of nurses to care for the dying patient, support in the workplace, workload, ward design and allocation practices that impact upon care of the dying. For the focus group interviews and individual interview results, it was anticipated that nurse 'attitude' toward care of the dying may be a factor influencing care of the dying.

The death anxiety theory presented in Chapter Two indicated that attitude is influenced by death anxiety, and this may have a significant influence on the nurse's preparedness and coping ability. In turn, this influences the care that dying person receives in the acute hospital care setting. This likely connection between death anxiety and the care provided to the dying patient is important. Despite acknowledgement in the existing literature that death anxiety can generate a primal response in the individual with the goal of self-protection, the link between death anxiety and how it influences nurses and the EOL care they provide is equivocal in the existing literature. This study explicates this relationship.

As a result, an investigation of the attitude of nurses toward care of the dying, which can be influenced by death anxiety, was undertaken in Phase Two. Phase Two results showed that, in contrast to Phase One, nurses demonstrated highly positive attitudes towards care of the dying. In comparison to similar studies that have also measured nurse attitudes toward care of the dying, this respondent population performed better. If considered alone, the survey findings would be seen to be in direct contrast to the perspective gained from Phase One that nurse attitudes towards care of the dying may have been negatively influencing care.

However, the themes in the open-ended question also identified issues of workload and time constraints, lack of experience and education that negatively impact upon the individual's care of the dying patient. Other responses to the open-ended question elucidate the emotional burden and the subsequent attitudes of nurses and how they can impact upon care of the dying.

Given that the findings from Phase One contrast with the findings of Phase Two, consideration must be given to the possible reasons for this difference.

#### ***6.4.1 Factors contributing to contrasting findings***

Several factors may have contributed to the seemingly contrasting findings between Phase One and Phase Two.

##### ***Phase One site***

Phase One was conducted in two acute medical wards within one hospital site of a health service. Hence local factors may have influenced EOL, not indicative of other acute hospital wards or the greater Australian nursing population to whom the Phase Two survey was open. Certainly issues related to the staff of the ward, ward design, and allocation practices may not be unique to this setting and it is important to acknowledge that the findings from Phase One are supported by previous studies producing similar findings. However, there may be other organisational issues such as how patients are allocated to wards, the degree of, or lack of involvement, of specialist palliative care clinicians, and the design of this health service's dying pathway. These may have impacted on the nurses in these wards and the observed nursing care.

First, the decision of ward selection may have influenced the findings. Once critical care and palliative care wards were omitted, the two wards were chosen because they were identified by the health service as having the highest rates of death amongst all of the wards in the

health service (spanning several hospital sites). The decision for this selection was modelled on similar research work previously conducted by Pincombe et al. (2003) who also studied care of the dying in the acute hospital setting. It was thought that by choosing the two wards with the highest death rates, it would be possible to observe care of the dying patient more frequently and the phenomenon would be more 'concentrated' in this environment.

In reflecting on this decision, the rationale for choosing these two wards may also have impacted on the observations themselves. Indeed, nurses are confronted by death and dying more frequently than any other health professional (Boyle & Carter, 1998); and a nurse's attitude towards death is constantly evolving as a product of cumulative personal and professional life experiences (Chen, Ben, Fortson & Lewis, 2006; Neimeyer, et al., 2004; Wilson & Kirshbaum, 2011). In the context of these wards where the focus of care remains on cure, the frequency with which death occurs may mean that the care of the dying, the observed nurse actions and behaviour as well as verbal responses from focus groups and interviews, may not be reflective of other environments.

In relation to the ward focus, an issue that creates challenges for clinicians is the misalignment between the ward focus on cure and the need for EOL care (Aleksandric & Hanson, 2010). The use of a care pathway for the dying has also been evaluated in many previous studies and despite their purpose (to transfer the best practice hospice model of care for the dying into the acute hospital setting), studies reported that the use of dying pathways were not without problems. These problems include when to commence the pathway (Duffy & Woodland, 2006; Pugh, et al., 2010; Weiner & Tilly, 2003) and a lack of education associated with pathway implementation and use (Economist Intelligence Unit, 2010; Willard & Luker, 2006). If these factors were influencing ward practices and care of the dying, then this may account as to why the results of Phase One contrasted with the highly positive attitudes towards care of the dying patient measured in Phase Two.

### ***Survey response factors***

The more positive results from the survey could also be due to the nature of surveys. The influence of 'social desirability' on survey responses must also be considered. De Vaus (2002) describes how many survey participants will answer questions so they 'look good' in their own eyes. As a result, the more positive or socially desirable response is over-reported, while the less desirable response is under-reported, in the case of this survey, reflecting a more positive attitude towards care of the dying. Dillman (2000), however, acknowledges that social desirability may positively influence a survey's findings, but suggests that the impact of social desirability is usually more prevalent in surveys that rely on face to face or telephone interview for completion because of the nature of the interaction with the person. Nonetheless, even if social desirability has influenced the findings, there is still considerable similarity between these findings and other similar studies suggesting that the influence of social desirability is minimal.

## **6.5 Summary**

In summary, this mixed methods study has revealed some significant new insights into how nurses recognise when a patient is dying, how they respond to the dying patient and the institutional systems and processes that influence care of the dying patient. The difficulties nurses experience in recognising dying are partly due to the challenges associated with prognostication and the variability in how people die. This point is already extensively highlighted in the literature. In this study, before recognising dying, however, nurses demonstrated passivity in relation to recognising dying, often awaiting a medical diagnosis of dying or formal recognition from a medical officer. While this passivity likely stems in part from the dominant goal and culture of acute hospitals to 'cure' and the dominance of the medical profession over nursing, death anxiety theory has also been shown to shape the findings presented in this study.

Once dying is recognised, how a nurse responds is influenced by a number of factors that ultimately influence the provision of EOL care including death anxiety. In the context of acute hospital care that is directed towards cure, and high acuity, this study demonstrated that nurses are often ill-equipped both emotionally and educationally to provide EOL care to the dying. Despite the availability and/or use of care pathways for the dying, the workload associated with caring for the dying patient as well as other acutely ill patients was a significant issue for nurses in this study. This also indicated that not all nurses felt supported in providing care for the dying. Furthermore, defence mechanisms such as denial, withdrawal, professional distancing and rationalisation used to mask and control death anxiety are also likely contributors to the findings in this study.

Even though the survey of nurse participants indicated a highly positive attitude towards care of the dying in a theoretical sense, what was observed contrasted with this. The results suggested that the reality of providing care for the dying alongside other acutely ill patients in an acute hospital, meant that despite their positive attitude scores on the survey, death anxiety may in fact underpins nurses' behaviour.



## CHAPTER SEVEN – CONCLUSION AND RECOMMENDATIONS

### 7.1 Introduction

This final chapter provides a synopsis of the important findings of this thesis, drawing together the concepts and theory generated out of this study, and concludes with recommendations for practice, education, and research.

### 7.2 Overview of findings

The aim of this study was to *‘explore nurses’ recognition of and responsiveness to dying patients in the acute hospital (non-palliative care) setting and to understand the nurse’s influence, if any, on the provision of end of life care in the acute hospital setting’*. This aim was addressed through four research questions:

1. How do nurses recognize the onset of dying?
2. How do nurses respond to the dying patient?
3. How do nurses influence the care a dying person receives?
4. What systems and/or processes influence care of the dying person?

The findings of this study will now be discussed in terms of how the research aim and questions have been answered.

#### ***Question 1: How do nurses recognise dying?***

It became clear from Phase One of this study that nurses, like other clinicians, can have difficulty in recognising dying. Given that every person dies differently, physiological criteria or parameters alone are not adequate to enable any clinician to recognise dying. Nurses in this study were both observed and reported that they rely on other factors such as a patient’s withdrawal or declaration to signify dying. Most importantly, however, was the finding that

nurses frequently remained passive despite knowing that a patient was dying, continuing to provide acute or resuscitative care as prescribed, until a medical officer formally recognised that death was near.

***Question 2: How do nurses respond to the dying patient?***

Phase One findings indicated that once a patient is formally recognised as dying, nurses prioritised their relocation to a single room. However, issues of workload and time meant that dying patients received little more care than was necessary. Nurses remained 'task-oriented' and attended to the dying patient in order to complete physical nursing tasks. They were not observed as spending time with the dying patient or their family, other than when care tasks were necessary.

The behaviour of nurses also suggested that they were, at times, uncomfortable in providing care to the dying patient. Some participants were vocal about this, while others remained silent, choosing instead to avoid interaction with the dying patient or their family, remaining busy with other nursing tasks and patients. Once placed in a single room, patients had the door to the room and often also the curtain kept closed, perhaps to hide away dying from public view as well as that of the nurses.

Viewing the phenomenon through death anxiety theory has added a greater depth of understanding to this question. Where the analysis attempts to explain nurse behavior, the addition of the death anxiety theory adds further insight and depth in understanding nurse behavior. Even though death anxiety was not directly measured, the addition of death anxiety theory provided a more complete and holistic understanding, providing a plausible and likely explanation for their avoidance, distancing behaviours and reluctance to care for the dying.

Despite the highly positive scores of nurse respondents to the Phase Two survey, some respondents' comments further suggest that in the context of an acute ward, the dying person

no longer 'fit' with the ward culture or goals. Many respondents projected the blame for inadequate care of the dying on issues such as time constraints and workload. While these issues may be legitimate, a sense of discord was significant between how nurses were expected to respond and how they actually did respond.

***Question 3: How do nurses influence the care a dying person receives?***

Overall, nurses demonstrated passivity towards recognising dying, but the findings from the observations suggested that despite this, there were occasions when they acted to influence a medical officer's determination that a patient was dying. By doing so, the nurse was able to effect change such as the cessation of aggressive or invasive curative treatment, commencement of a dying pathway, and relocation to a single room.

Unfortunately, nurse allocation practices and the demonstrated reluctance of some nurses to care for the dying patient often result in the care of the dying patient being provided by the most junior nurse, who seemed the least assertive. Where some nurses, in both phases of this study, were comfortable to care for the dying patient and on occasion, volunteered to do it, they were the exception. For most, caring for the dying made them uncomfortable and they were reluctant to do it. The death anxiety literature suggests that this behavior has likely manifested itself as a result of the participants' death anxiety. The result is the use of defense mechanisms such as withdrawal, professional distancing, and avoidance.

***Question 4: What systems and/or processes influence care of the dying person?***

As described previously, the seniority or assertiveness of each individual nurse to vie for their choice of patient allocation can and did significantly impact upon the care of the dying patient during Phase One observations. Similarly, once a patient had commenced on a dying care pathway, as much as the pathway may have clarified recommendations about aspects of care (such as analgesia), the observations showed that it also reduced interactions with the dying patient and their family to only those times when a care task was due to be completed.

Nurses were not observed as choosing to spend time with the dying patient or their family at other times. Participants in the focus groups and responses to the nurse survey both justified this behaviour in terms of time constraints, acuity of the other patients, and general nursing workload.

The controlling of entry of a dying patient to the ward is also representative of how nurses assert their power through common processes, such as admission and bed management procedures. The impact of this example of a nurse asserting control was that instead of the person dying in a shared patient room, they died in the Emergency Department, arguably a less private or comfortable setting than a ward.

Nurses did suggest that they were not adequately prepared emotionally or educationally to provide EOL care in an acute care ward context and that there was inadequate peer-support or mentoring for less experienced staff that were allocated to care for the dying person. While it was not measured directly, the possibility that death anxiety influenced nurse behaviour must be considered. This study has uncovered information that strongly suggests that death anxiety is not only influencing nurse behavior and EOL care, but that it is not acknowledged or understood by the very people it affects.

## **7.3 Methodological strengths and limitations**

There are several factors that have impacted upon this study, presented below.

### ***7.3.1 Methodological strengths***

This study has a number of methodological strengths that have enabled the elicitation of detailed findings.

First, the mixed methods design, more specifically, the use of a ‘Sequential Exploratory Design’, has enabled the exploration of the phenomenon in question more fully than would be

possible using qualitative or quantitative methods alone. Where qualitative data may provide a detailed understanding of a problem and quantitative data may provide a more general understanding of a problem, when both methods are used, they can provide a more complete understanding of the research problem than either approach by itself (Creswell, 2009; Creswell & Plano Clark, 2011). To date, this is the first study identified that has utilised a mixed methods approach to explore nursing care of the dying.

Second, the decision to utilise focus groups and individual interviews subsequent to the observation has proven a valuable addition to the observation. Not only did it provide an opportunity to clarify what was observed with participants, but it also enabled the development of a greater understanding of *what* was observed, ensuring a more complete and accurate understanding of the phenomena in question and adding rigour to the research.

Third, the introduction of death anxiety theory to provide a greater understanding of findings, particularly in relation to the behaviours observed in Phase One has added significant depth to the findings of this study, particularly in terms of its contribution to new knowledge. While death anxiety was not directly measured, the manner in which death anxiety pervades nursing care was visibly demonstrated.

Finally, because of the nurse participants in Phase One indicating they sometimes had difficulty with medical staff contributing to EOL care, a decision was made to survey a population of final year medical students to measure their attitudes towards care of the dying. At the time that this study was being designed, there were no published studies of doctors or medical students utilising FATCOD or any of the subsequent iterations of the tool. As noted above there has been a more recent study that used FATCOD Form B (Leombruni, et al., 2012); however, the version of the FATCOD used was not specifically designed for a doctor or medical student population. To rectify this, the student researcher sought permission from the FATCOD author to design a new iteration of the FATCOD tool (now known as the FATCOD-

DOC). The development and testing of the FATCOD-DOC tool and subsequent piloting of the tool with a small sample provided greater data and detail to the Phase Two study, which was to measure nurses' attitudes toward care of the dying. It also created an opportunity for further research work with medical populations.

### ***7.3.2 Methodological limitations***

There are methodological limitations associated with this study that could be addressed in future research work. First, when undertaking observational work, the potential for the Hawthorne effect, that is, the tendency for people to behave differently when they know they are being studied (Chiesa & Hobbs, 2008), and to present well to the researcher (Payne, Field, Rolls, Hawker & Kerr, 2007) must also be considered. While there is no way for a researcher to be able to accurately measure this, the evidence suggests that the longer that the researcher stays in the observation field and begins to blend in, the less likely that the Hawthorne Effect will impact upon data collection (Chiesa & Hobbs, 2008; Leonard & Masatu, 2006; Pincombe, et al., 2003; Turnock & Gibson, 2001).

Others studies suggest that the impact of the Hawthorne effect is often overplayed, with most professionals too busy to maintain a behaviour that is different from their normal behaviour for any length of time (Mulhall, 2003; Parahoo, 2006). In Phase One of this study, the researcher observed behaviour and language that was considered by her to be judgemental and at times inappropriate and unprofessional. That participants openly behaved and spoke this way suggested that participants were not modifying their behaviour because they were being observed.

Second, in reflecting on the findings of Phase One and how they contrast with the highly positive attitudes measured in Phase Two, the sites chosen for this study may not be indicative or even similar to other acute hospital wards. The decision to choose wards (excluding critical

care and palliative care) with the highest rates of death and from the one hospital site of one health service may have resulted in a 'skewed' outcome. The close proximity of the two wards within the one hospital, with the same physical design limitations is likely to mean that issues such as lack of access to specialist palliative care clinicians, the use of specific dying care pathways, and other organisational factors may have also impacted upon the findings from Phase One. Future research should be undertaken in a range of acute hospital wards across several hospitals and health services to ensure a more balanced view.

Third, the sample size in both surveys was small. The FATCOD-DOC survey was undertaken as an exploratory pilot study. The issue of sample size in that survey, therefore, was not a major consideration. Likewise, the FATCOD survey undertaken with nurses, also recruited a small sample, despite numerous diverse strategies to improve participation rates. Other ways to improve the participation rate, such as recruiting via other media could be considered in future studies.

## **7.4 Implications**

### ***7.4.1 Implications for practice***

The new knowledge derived from this research highlights some clear deficits in current clinical practice.

- A patient's impending death should represent an opportunity to honour the patient's life and facilitate an appropriate and respectful death, acknowledging the needs of family and significant others. This would be achieved by:-
  - encouraging open and early dialogue amongst the care team regarding the patient's health status so that early recognition of dying is possible;

- encouraging early and on-going communication with the patient and/or their family to ensure their specific needs, such as social, familial, cultural or religious needs are met leading up to and after death of the patient.
- The potential for death anxiety to influence nursing care must be acknowledged. Clinicians and health service managers should ensure that the potential for death anxiety to influence clinical care is made explicit, with processes in place to address this, such as encouraging a team nursing approach to care of the dying, pairing nurses according to experience and confidence in a way that enables collegial support at all times. Similarly, encouraging open dialogue about the challenges of providing EOL care at team meetings and handover is essential to 'normalising' EOL care and supporting those who are providing the care. This is essential to achieving the following elements of care:-
  - establishing and maintaining a therapeutic relationship;
  - engaging in open and honest communication;
  - addressing the patient's and family's emotional needs; and
  - providing comfort through spending time 'being with' the dying person and their family/significant others.

#### ***7.4.2 Implications for education***

Nurses need further and ongoing education that empowers them, as primary carers, to become the leaders in end of life care for their patient. This education should:-

- be inclusive of 'recognition of dying';
- equip nurses to confidently lead and facilitate a quality end of life care experience for the dying patient, their family/significant others, and the nurse;



- provide a 'safe' space for death education of individuals or small groups of supportive colleagues to share, reflect on and learn about their own responses to death and dying;
- Curricula should extend beyond the practical nursing management of a dying person to detail how a nurse can meet a person's social, emotional and spiritual needs as they approach the end of their life, including making time to 'be with' the dying person.

#### ***7.4.3 Implications for further research***

The findings, strengths and limitations of this study suggest several key foci for further research:-

- Further observational work across multiple hospital sites and in a variety of specialty areas is essential so that an even greater understanding of this issue is reached.
- The FATCOD survey should be administered with nursing staff at the Phase One observation sites to determine if the attitudes of nurses from Phase One were different from the greater nursing population already surveyed. There may be other factors specific to the Phase One sites that impacted upon care of the dying.
- Given that the need for EOL care for people in acute care (non-palliative care) settings is likely to continue to rise, it is essential to examine how the cultures of acute care settings influence EOL care and how these cultures can be modified so that the focus of care is less about 'cure' and more about appropriate care for the individual patient.
- There is also an obvious need to further explore and measure the true impact of death anxiety in the acute hospital setting. This is imperative not only for patient care, but for care of the nurse.

- Investigations /interventions that address/treat nurses' death anxiety is essential and ongoing evaluation of these interventions is essential to ensure their feasibility, effectiveness and appropriateness.
- Further work that examines nurses' self-efficacy in caring for the dying in the acute hospital setting and other clinical settings would clarify the confidence and competence with which nurses approach those nearing the end of their life.

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## *APPENDICES*

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## Appendix 1 - Phase One Ethical Approvals



MONASH University

### Human Ethics Certificate of Approval

**Date:** 28 June 2011

**Project Number:** CF11/1853 - 2011001039

**Project Title:** Nurses recognition of and responsiveness to the dying patient in the acute hospital (non-palliative) ward

**Chief Investigator:** Prof Wendy Cross

**Approved:** From: 28 June 2011 to 28 June 2016

#### Terms of approval

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, and a copy forwarded to MUHREC before any data collection can occur at the specified organisation. **Failure to provide permission letters to MUHREC before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.**

2. Approval is only valid whilst you hold a position at Monash University.

3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.

4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or

Unforeseen events affecting the ethical acceptability of the project.

5. **Complaints:** The researchers are required to inform MUHREC promptly of any complaints made about the project, whether the complaint was made directly to a member of the research team or to the primary HREC.

6. **Amendments to the approved project (including changes in personnel):** Requires the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC.

Substantial variations may require a new application.

7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.

8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.

9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.

10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.

11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

Professor Ben Canny  
Chair, MUHREC

**Cc: Assoc Prof Cheryle Moss; Prof Ruth Endacott; Ms Melissa Bloomer**

22 June 2011

A/Prof Wendy Cross  
School of Nursing and Midwifery  
Head of School  
Monash University  
Building 13C  
Wellington Road  
Clayton VIC 3800

Dear a/Prof Wendy Cross

**Study title: Nurses Recognition of and responsiveness to the dying patient in the acute hospital (non-palliative) ward.**

**XXXXXXXXXX HREC Ref: 11021B**

**Revised**

The XXXXXXXXXXXX HREC B reviewed the above application at the meeting held on 17 February 2011. In addition, the HREC is satisfied that the responses to our correspondence on 28 February 2011 have been successfully addressed.

The HREC approved the above application on the basis of the information provided in the application form, protocol and supporting documentation.

**Approval**

The HREC approval is from the date of this letter.

Approval is given in accordance with the research conforming to the *National Health and Medical Research Council Act 1992* and the *National Statement on Ethical Conduct in Human Research (2007)*. The HREC has ethically approved this research according to the Memorandum of Understanding between the Consultative Council and the participating organisations conducting the research.

Approval is given for this research project to be conducted at the following sites and campuses:

XXXXXXXXXX and XXXXXXXXXXXX

You must comply with the following conditions:-

The Chief Principal Investigator is required to notify the Administrative Officer, Research Directorate, XXXXXXXXXXXX of:-

- Any change in protocol and the reason for that change together with an indication of ethical implications (if any)
- Serious or unexpected adverse effects of project on subjects and steps taken to deal with them
- Any unforeseen events that might affect continued ethical acceptability of the project
- Any expiry of the insurance coverage provided in respect of sponsored trials

-Discontinuation of the project before the expected date of completion, giving reasons

-Any change in personnel involved in the research project including any study member resigning from XXXXXXXXXXXX &/or the study team.

At the conclusion of the project or every twelve months if the project continues, the Principal Investigator is required to complete and forward an annual report to the Committee.

Annual report forms will be forwarded to the researcher.

### **Approved documents**

Documents reviewed and approved at the meeting were:

*Participant Information and Consent Form Version 2 16 March 2011*

If you should have any queries about your project please contact XXXXXXXXXXXX or XXXXXXXXXXXX by email XXXXXXXXXXXX.

The HREC wishes you and your colleagues every success in your research.

Yours sincerely

XXXXXXXXXX

Medical Administrator

Cc: Ms Melissa Bloomer, Monash University Peninsula Campus Room E2.44 PO Box 527 Frankston Vic 3199

## **Appendix 2 - Phase One Participant Information and Consent Form**

### **Participant Information and Consent Form**

XXXXXXXXXX and Monash University

#### **Full Project Title:**

Nurses **recognition of** and **responsiveness to** the dying patient in the acute hospital (non-palliative) ward

#### **Principal Researcher:**

Professor Wendy Cross  
Head of School, PhD Supervisor  
Monash University, School of Nursing and Midwifery  
Wellington Road, Clayton, Victoria 3800  
Ph [REDACTED]  
[REDACTED]

**Principal Researcher:** Associate Professor Cheryle Moss  
Associate Professor Nursing, Research and Practice Development, PhD Supervisor  
Monash University, School of Nursing and Midwifery  
Wellington Road, Clayton, Victoria 3800  
Ph [REDACTED]  
[REDACTED]

#### **Student Researcher:**

Melissa Bloomer  
Student Researcher, PhD Candidate  
Monash University, School of Nursing and Midwifery  
PO Box 527, Frankston, VIC, 3199  
Ph [REDACTED] or Mob [REDACTED]  
[REDACTED]

## **1. Introduction**

You are invited to take part in this research project. The research project aims to explore the nurses 'recognition of' and 'responsiveness to' the dying patient in an acute (non-palliative) ward environment.

This Participant Information and Consent Form tells you about the research project. It explains what is involved to help you decide if you would like to take part.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or your local health worker. Participation in this research is voluntary.

If you don't wish to take part, you don't have to.

You may keep this Participant Information Form.

## **2. What is the purpose of this research project?**

The aim of the project is to

- explore nurses recognition of dying;
- explore nurses responsiveness to dying;

in the Australian acute hospital (non-palliative) setting.

With the Australian population ageing, and with chronic illness now the leading cause of death, the number of patients who will die whilst an inpatient in an acute hospital ward is likely to rise. What is unclear is whether nurses can 'recognize' dying, how they 'recognize' dying and how they respond to dying, particularly in the Australian context. While much research has focused on palliative care, the patient/family experience, and the clinical management of dying, and other aspects such as communication, little research has been done to explore this area in the acute setting.

The outcomes of this research project will firstly help us as a professional group of nurses to describe our practice and the issues we face relating to care of patients who are dying in our acute care wards, and secondly, the findings will assist to further inform future nursing care of the dying.

Two (2) wards within XXXXXXXXXX have been identified for this study. These wards have been selected because hospital records reveal that nurses working on these acute wards frequently encounter, and are required to care for dying patients. Critical care areas, oncology and palliative care wards have been excluded from the study.

This study is the first phase of a larger research project. The outcomes of this phase will inform the development of the second and third phases, all of which will take up to three years to complete.

The results of this research will be used by the student researcher, Melissa Bloomer, to obtain a Doctor of Philosophy (PhD) degree. This research is funded by an 'Australian Postgraduate Award Scholarship', and an 'Australian Legion Scholarship'.

### **1. What does participation in this research project involve?**

This research has several parts. The part that is relevant to you is Part 3, which involves the direct observation of nursing staff allocated to care for dying patients.

Nursing staff from this ward will be encouraged to make contact with the student researcher when any patient is recognised as 'dying', at any time of the day or night. The student researcher will come to the ward on receipt of the notification.

The student researcher will act as a non-participant observer, which means that she will not be involved in any activities, and will not assist in care, however, where possible, the student researcher will converse with staff to understand the context and rationale for their decisions and actions, while they are providing care. The student researcher will not converse with the patient or family.

It is anticipated that observation will be performed for several hours at a time, and that observation could occur at any time of the day and night.

Observations and conversations with staff will be recorded as field notes, and all observations will focus on the *actions* observed, and *not the individuals* observed. No observations will be subjected to audio or video recording. You will not be paid for your participation in this research.

### **4. What are the possible benefits?**

It is anticipated that the outcomes of this research will assist to define how nurses recognize dying, and how nurses respond to dying. Little is known about these phenomena, in particular the impact of the nursing role on the dying patient and their family.

There is likely to be no direct benefit to individuals involved in the research at the time, but other studies have shown that participants in nursing research can benefit from reading the results of the study, and personally reflecting on their own nursing work.

### **5. What are the possible risks?**

It is unlikely that this research will present any risks to you as an individual. All data collected during the observations will be de-identified and recorded in terms of the nursing actions or care observed. Notes about a particular individual will not be taken.

As a non-participant observer, the student researcher will not participate in care delivery. She will be completely impartial to the care and activities observed.

If you, at any time, wish to be excluded from observation, then you may do so.

If you become upset or distressed as a result of your participation in the research, the researcher will arrange for counselling or other appropriate support. Any counselling or support will be provided by professionals that are not members of the research team.

### **6. Do I have to take part in this research project?**

Participation in this research project is voluntary. If you do not wish to take part, you do not have to. You are free to 'opt out' at any time during the project for the duration of the research project, or just 'opt out' for a particular shift or time period.

In order to 'opt out', the student researcher must be informed so that the individual nurse can be excluded from further observations.



If you decide to leave the project part way through, the researchers would be unable to destroy any data already collected as a result of observing you in your nursing role, as all information collected is de-identified.

Your decision whether to take part or not, or to take part and then withdraw, will not affect your relationship with XXXXXXXXXX, the researchers or Monash University.

**7. How will I be informed of the final results of this research project?**

At the completion of this phase of the study, a summary report will be made available to the Executive Director Nursing and Midwifery, as well as the Nurse Unit Managers from both wards. Also, a copy of any publications that are produced from this research will also be made available.

**8. What will happen to information about me?**

All hard copy and electronic data will be stored in a locked filing cabinet in the locked office of the student researcher, and will be accessible only to the researchers named on this project. The data associated with this research will be stored for 7 years in accordance with the *National Statement on Ethical Conduct in Research Involving Humans*, 12.11. Seven (7) years after the completion of the pilot study, all electronic files will be deleted and all paper records will be shredded.

Your participation in this study includes the use of the study data for the subsequent phases of this research project. Your information will not be included in any other research projects. This research does not involve the establishment of a data bank.

In any publication and/or presentation, information will be provided in such a way that you cannot be identified.

**9. Can I access research information kept about me?**

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to access the information collected and stored by the researchers about you, however all information collected as part of this study will be de-identified, so it is not possible to identify which information, collected during observation in this study, relates specifically to you. Please contact one of the researchers named at the end of this document if you would like to access your information.

**10. Is this research project approved?**

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of XXXXXXXXXX and Monash University.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)* produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

## 11. Consent

I have read or have had this document read to me in a language I understand, and I understand the purposes, procedures and risks of this research project as described within it.

I acknowledge that the researchers would like to me to participate in this research project, according to the conditions outlined in this document.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I understand that I will be given a signed copy of this document to keep.

Name..... Position .....

Signature..... Date.....

Declaration by researcher\*: I have given a verbal explanation of the research project, its procedures and risks and I have understood that explanation.

Researcher's name (printed) .....

Signature..... Date.....

*Note: All parties signing the consent section must date their own signature.*

## 12. Who can I contact?

The person you may need to contact will depend on the nature of your query. Therefore, please note the following:

### For further information or appointments:

If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project (for example, feelings of distress), you can contact the student researcher:-

**Melissa Bloomer on [REDACTED] or [REDACTED] (any time of night or day)**

or *either* of the following people:

Professor Wendy Cross                      OR                      Associate Professor Cheryle Moss

[REDACTED]

[REDACTED]

### For complaints:

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Name:                      XXXXXXXXXXXX

Position:                      Director, Research Services

Telephone:                      XXXXXXXXXXXX

### Appendix 3 - FATCOD Instrument Use Summary

FATCOD			
Author, Source and Year of Publication	Country	Instrument	Sample, response rate
Halm, Evans, Wittenberg & Wilgus <i>Holistic Nursing Practice</i> (2012)	USA	Combined with other instruments  Used as a pre and post education measure	Convenience sample 31 nurses Response rate 36%
De Kock <i>Unpublished thesis</i> (2011)	South Africa	FATCOD only  Used as a once off measure	Purposive sample 127 Nurses Response rate 67%
Dobbins <i>Teaching and Learning in Nursing</i> (2011)	USA	Combined with other instruments  Used as a pre and post education measure	Convenience sample 37 nursing students Response rate not specified
Iranmesh, Axelsson, Haggstrom & Savenstedt <i>Indian Journal of Palliative Care</i> (2010)	Iran & Sweden	Combined with other instruments  Used as a once off measure	Convenience sample 234 Undergraduate nursing students Response rate 95%
Braun, Gordon, Uziely <i>Oncology Nursing Forum</i> (2010)	Israel	Combined with other instruments  Used as a once off measure	Convenience sample 147 Registered Nurses Response rate 86%
Ali and Ayoub <i>Journal of Medicine &amp; Biomedical Science</i> (2010)	Egypt	FATCOD only  Used as a once off measure	Convenience sample 197 Registered Nurses Response rate not specified
Brajtman, Fothergill-Bourbonnais, Fiset & Alain <i>International Journal of Palliative Nursing</i> (2009)	Canada	Combined with other instruments  Used as a once off measure	Purposive sample 53 Clinical and Theory Educators (Nursing) Response rate 27%
Alvaro <i>Unpublished thesis</i> (2009)	USA	FATCOD only  Used as a pre and post education measure	Convenience sample Intensive care nurses Response rate unclear
Iranmesh, Savensedt & Abbaszadeh <i>International Journal of Palliative Nursing</i> (2008)	Iran	FATCOD only  Used as a once off measure	Convenience sample 100 Undergraduate nursing students Response rate 98%

Iranmesh, Dargahi & Abbaszadeh <i>Palliative &amp; Supportive care</i> (2008)	Iran	Combined with other instruments Used as a once off measure	Convenience sample 120 Registered Nurses Response rate 98%
Barrere, Durkin & LaCoursiere <i>International Journal Nursing Education Scholarship</i> (2008)	USA	FATCOD only Used as a pre and post education measure	Convenience sample 73 Undergraduate nursing students Response rate 71%
Brajtman, Fothergill-Bourbonnais, Casey, Alain & Fiset <i>International Journal of Palliative Nursing</i> (2007)	Canada	Combined with other instruments Used as a once off measure	Purposive sample Undergraduate nursing students Response rates of 72%, 40% and 10%
Lange, Thom & Kline <i>Oncology Nursing Forum</i> (2008)	USA	Combined with other instruments Used as a once off measure	Convenience sample 355 Registered Nurses Response rate not specified
Wessel & Rutledge <i>Journal of Hospice and Palliative Nursing</i> (2005)	USA	Combined with other instruments Used as a pre and post education measure	Purposive sample 33 Registered Nurses Response rate not specified
Dunn, Otten & Stephens <i>Oncology Nursing Forum</i> (2005)	USA	FATCOD only Used as a once off measure	Convenience sample 58 Registered Nurses Response rate 97%
Mallory <i>Journal of Professional Nursing</i> (2003)	USA	FATCOD only Used as a pre and post education measure	Convenience sample 104 Undergraduate nursing students Response rate not specified
Frommelt <i>American Journal of Hospice and Palliative Care</i> (1991)	USA	FATCOD only Used as a pre and post education measure	Convenience sample 34 Registered Nurses Response rate 100%
<b>FATCOD (abbreviated version)</b>			
Morita, Murata, Hirai, Tamura, Kataoka, Ohnishi, Akizuki, Kurihara, Akechi & Uchimoto <i>Journal of Pain &amp; Symptom Management</i> (2007)	Japan	Combined with other instruments Used as a pre and post education measure	147 Registered Nurses Response rates of 62% and 54%

<b>FATCOD Form B</b>			
Leombruni, Miniotto, Bovero, Castelli & Torta <i>Journal of Cancer Education</i> (2012)	Italy	FATCOD Form B only  Used as a once off measure	Convenience sample 193 2 <sup>nd</sup> year medical students Response rate 96.5%
Frommelt <i>American Journal of Hospice and Palliative Care</i> (2003)	USA	FATCOD Form B only  Used as a pre and post education measure	Convenience sample 115 College Students (non-nursing) Response rate not specified
<b>FATCOD Form B-J</b>			
Kinoshita & Miyashita <i>Intensive and Critical Care Nursing</i> (2011)	Japan	Combined with other instruments  Used as a once off measure	Purposive sample 224 ICU Registered Nurses Response rate 78%
Matsui & Braun <i>International Journal of Palliative Nursing</i> (2010)	Japan	Combined with other instruments  Used as a once off measure	Convenience sample 388 Registered Nurses and Care workers Response rate 84%
Miyashita, Nakai, Sasahara, Koyama, Shimizu, Tsukamoto & Kawa <i>American Journal of Hospice and Palliative Medicine</i> (2007)		Combined with other instruments  Used as a once off measure	184 Registered Nurses Response rate 78%

#### **Appendix 4 - Communication with Katherine Frommelt**

**Katherine Frommelt** [REDACTED]

to me

Dear Melissa,

I am giving you permission to use the FATCOD. I am wondering why you want to use the original tool, which was designed for use by nurses only. I revised the tool and made a form B so that it could be used by persons from any discipline, including nurses. Form B also has more demographic information. As far as I know Form B has been used by physicians, although it may have been in one of the foreign countries that it has been used in. It has been used quite extensively---I am not exact but I think that it is now in 23 foreign languages. I know that many nurses have used form B, although you are welcome to use either one.

I am attaching both forms and the Scoring information as well as the Reliability, Validity and CVI information to this e-mail.

I hope this is what you need. Best of luck with your research. I would love to hear about your results.

Kay Frommelt

4 attachments — Download all attachments

FATCOD, Form A, Original (2009).doc  
37K View Download

FATCOD, Form B, Original (2009).doc  
43K View Download

FATCOD, A & B, Rel and Valid, Sept, 2010.doc  
31K View Download

SCORING INSTRUCTIONS FOR THE FATCOD, 2010.doc  
24K View Download

**Melissa Bloomer** [REDACTED]

To Katherine

Thanks so much Katherine. This information is very useful.

The rationale for using the original FATCOD was that I want to use it for a group of nurses and the terminology of the original FATCOD is already suited to nurses. If I used the Form B with the nursing group, I am not sure that nurses would understand/relate to 'non-family caregiver' as well.

I haven't been able to find any published articles in English where it has been used with doctors, but I will definitely have another look at the published literature.

Thanks once again

**Appendix 5 - FATCOD Original Instrument and scoring instructions**

**Frommelt Attitude Toward Care of the Dying Scale**

**Original Form A**

In these items the purpose is to learn how nurses feel about certain situations in which they are involved with patients. All statements concern the giving of care to the dying person and/or, his/her family. Where there is reference to a dying patient, assume it to refer to a person who is considered to be terminally ill and to have six months or less to live.

Please circle the letter following each statement which corresponds to your own personal feelings about the attitude or situation presented. Please respond to all 30 statements on the scale. The meaning of the letters is:

SD = Strongly Disagree

D = Disagree

U = Uncertain

A = Agree

SA = Strongly Agree

- |     |   |    |   |   |   |    |
|-----|---|----|---|---|---|----|
| 1.  | Giving nursing care to the dying person is a worthwhile learning experience.                              | SD | D | U | A | SA |
| 2.  | Death is not the worst thing that can happen to a person.   | SD | D | U | A | SA |
| 3.  | I would be uncomfortable talking about impending death with the dying person.                             | SD | D | U | A | SA |
| 4.  | Nursing care for the patient's family should continue throughout the period of grief and bereavement.     | SD | D | U | A | SA |
| 5.  | I would not want to be assigned to care for a dying person.   | SD | D | U | A | SA |
| 6.  | The nurse should not be the one to talk about death with the dying person.                                | SD | D | U | A | SA |
| 7.  | The length of time required to give nursing care to a dying person would frustrate me.                    | SD | D | U | A | SA |
| 8.  | I would be upset when the dying person I was caring for gave up hope of getting better.                   | SD | D | U | A | SA |
| 9.  | It is difficult to form a close relationship with the family of the dying person.                         | SD | D | U | A | SA |
| 10. | There are times when death is welcomed by the dying person.   | SD | D | U | A | SA |
| 11. | When a patient asks, "Nurse am I dying?," I think it is best to change the subject to something cheerful. | SD | D | U | A | SA |
| 12. | The family should be involved in the physical care of the dying person.                                   | SD | D | U | A | SA |



SD = Strongly Disagree  
D = Disagree  
U = Uncertain  
A = Agree  
SA = Strongly Agree

13.	I would hope the person I'm caring for dies when I am not present.	SD	D	U	A	SA
14.	I am afraid to become friends with a dying person.	SD	D	U	A	SA
15.	I would feel like running away when the person actually died.	SD	D	U	A	SA
16.	Families need emotional support to accept the behavior changes of the dying person.	SD	D	U	A	SA
17.	As a patient nears death, the nurse should withdraw from his/her involvement with the patient.	SD	D	U	A	SA
18.	Families should be concerned about helping their dying member make the best of his/her remaining life.	SD	D	U	A	SA
19.	The dying person should <u>not</u> be allowed to make decisions about his/her physical care.	SD	D	U	A	SA
20.	Families should maintain as normal an environment as possible for their dying member.	SD	D	U	A	SA
21.	It is beneficial for the dying person to verbalize his/her feelings.	SD	D	U	A	SA
22.	Nursing Care should extend to the family of the dying person.	SD	D	U	A	SA
23.	Nurses should permit dying persons to have flexible visiting schedules.	SD	D	U	A	SA
24.	The dying person and his/her family should be the in-charge decision makers.	SD	D	U	A	SA
25.	Addiction to pain relieving medication should not be a concern when dealing with a dying person.	SD	D	U	A	SA
26.	I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	SD	D	U	A	SA
27.	Dying persons should be given honest answers about their condition.	SD	D	U	A	SA
28.	Educating families about death and dying is not a nursing responsibility.	SD	D	U	A	SA
29.	Family members who stay close to a dying person often interfere with the professionals job with the patient.	SD	D	U	A	SA
30.	It is possible for nurses to help patients prepare for death.	SD	D	U	A	SA

Last 4 digits of your Social  
Security No.

Completion and Return of This Questionnaire Will Be  
Construed as Your Consent to be a Research  
Subject in This Study. Your Anonymity is Guaranteed.

### DEMOGRAPHIC DATA SHEET

Please check the appropriate spaces:

1. Age  
☐ 18-22 years  
☐ 23-27 years  
☐ 28-35 years  
☐ 36-45 years  
☐ 46-55 years  
☐ 56-65 years  
☐ 66 years and over
2. Sex ☐ Male  
☐ Female
3. Highest degree held: ☐ High School Equivalency (GED)  
☐ High School Diploma  
☐ Associate Degree  
☐ Bachelor's Degree  
☐ Master's Degree  
☐ Education Beyond Masters  
☐ Other (Please Specify)
4. Previous education on death and dying  
☐ I took a course in death and dying previously.  
☐ I did not take a specific course on death and dying, but material on the subject was included in other courses.  
☐ No information dealing with death and dying was previously presented to me.
5. Previous experience in dealing with terminally ill persons  
☐ I have cared for terminally ill persons and their family members previously.  
☐ I have had NO experience caring for terminally ill persons and their family members previously.

## SCORING INSTRUCTIONS FOR THE FATCOD

The FATCOD consists of 30 Likert-type items, which are scored on a 5-point scale. The instrument is made up of an equal number of positively and negatively worded items.

Possible responses to each item include SD=Strongly Disagree, D= Disagree, U = Uncertain, A= Agree and SA= Strongly Agree.

Positive items are scored from 1 for Strongly Disagree to 5 for Strongly Agree. For Negative items the scoring is reversed.

Items 1, 2, 4, 10, 12, 16, 18, 20, 21, 22, 23, 24, 25, 27, and 30 are all positively worded statements. (scored from 1 for Strongly Disagree to 5 for Strongly Agree.)

All others are negative. (scored from 1 for Strongly Agree to 5 for Strongly Disagree.)

Higher scores, therefore, reflect more positive attitudes.

Katherine H. Murray Frommelt, RN, BSN, MSN, PDE, CGC, FT

Copyrighted



**MONASH University**

**Human Ethics Certificate of Approval**

**Date:** 22 October 2012

**Project Number:** CF12/3219 - 2012001608

**Project Title:** Attitudes towards care of the dying

**Chief Investigator:** Assoc Prof Wendy Cross

**Approved:** From 22 October 2012 to 22 October 2017

**Terms of approval**

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, and a copy forwarded to MUHREC before any data collection can occur at the specified organisation. **Failure to provide permission letters to MUHREC before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.**

2. Approval is only valid whilst you hold a position at Monash University.

3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.

4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.

5. **Complaints:** The researchers are required to inform MUHREC promptly of any complaints made about the project, whether the complaint was made directly to a member of the research team or to the primary HREC.

6. **Amendments to the approved project (including changes in personnel):** Requires the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC.

Substantial variations may require a new application.

7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.

8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.

9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.

10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.

11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

Professor Ben Canny  
Chair, MUHREC

Cc: Prof Margaret O'Connor; Prof Ruth Endacott; Mrs Melissa Bloomer;

Hagan, Natalie [REDACTED]

19/07/2012

to me, Wendy, Margaret, Ruth

[REDACTED]  
Dear Melissa,

Thank you for submitting the above research proposal and responding to the comments raised by the Nursing Research and Access Committee.

The Nursing Research and Access Committee is happy to endorse this project.

XXXXXX Ethics approval is not required for this project, as per the emails below.

Please feel free to contact me when you are ready for us to send the invitation emails, as I can organise that.

Warm Regards,

**Natalie Hagan**

Postgraduate and Nursing Research Coordinator  
Nursing Education

t XXXXXXXXXXXX e XXXXXXXXXXXX

HUMAN RESEARCH ETHICS COMMITTEE Low Risk Research Subcommittee

**Full Approval**

17 July 2012

Ms Melissa Bloomer  
School of Nursing and Midwifery  
Monash University  
PO Box 527  
FRANKSTON VIC 3199

Dear Melissa

**PROJECT: LRR/12/PH/6**

**TITLE: Registered Nurses' attitudes towards caring of the dying patient**

Thank you for submitting the above project which was first considered by the Low Risk Research Committee (LRRS) on Tuesday 10 July 2012 in accordance with the National Statement on Ethical Conduct in Human Research (2007). Following requested clarification, I am pleased to advise that full ethical approval has now been granted.

The documents reviewed and approved include:

<b>Application:</b>	5 July 2012
<b>Participant Information:</b>	
<b>Introduction to e-mail:</b>	Version1: 5 July 2012
<b>Explanatory Statement:</b>	Version 1: 29 May 2012

<b>Research Tools:</b>	
FATCOD Nurse Survey:	Version 1: 5 July 2012

Please note the following requirements of the XXXXXXXXXXXXXXXX HREC:

1. The principal investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
  - any serious or unexpected adverse events
  - unforeseen events that might affect continued acceptability of the project.
2. Proposed changes to the research protocol, conduct of the research, or research completion data will be provided to the HREC for review in the specified format.
3. The Low Risk Research Subcommittee will be notified if the project is discontinued at a site before the expected date of completion.
4. The principal investigator will provide an annual report to the LRRS and at the completion of the study a final report, in the specified format.

Should you have any queries about the HREC's consideration of your project please contact XXXXXXXXXXXXXXXX, Manager Research Program.

The Committee wishes you every success in your research.

8 August 2012

A/Prof Wendy Cross  
School of Nursing and Midwifery  
Head of School  
Monash University  
Building 13C  
Wellington Road  
Clayton VIC 3800  
Dear A/Prof Cross

**Study title: Attitudes towards care of the dying**

XXXXXXXXXXXXXXX HREC Ref 12237L

The XXXXXXXXXXXX HREC Low Risk Review Panel reviewed the above application and are also satisfied that the responses to our correspondence of 26 July have been successfully addressed.

The HREC approved the above application on the basis of the information provided in the application form, protocol and supporting documentation.

This reviewing HREC is accredited by the Consultative Council for Human Research Ethics under the single ethical review system.

**Approval**

The HREC and Site Specific Authorisation approval is from 8 August 2012.

Approval is given in accordance with the research conforming to the *National Health and Medical Research Council Act 1992* and the *National Statement on Ethical Conduct in Human Research (2007)*. The HREC has ethically approved this research according to the Memorandum of Understanding between the Consultative Council and the participating organisations conducting the research.

Approval is given for this research project to be conducted at the following sites and campuses: XXXXXXXXXXXXXXXX.

You must comply with the following conditions:

The Principal Investigator is required to notify the Administrative Officer, Research Directorate, XXXXXXXXXXXXXXXX of:

1. Any change in protocol and the reason for that change together with an indication of ethical implications (if any)
2. Serious or unexpected adverse effects of project on subjects and steps taken to deal with them
3. Any unforeseen events that might affect continued ethical acceptability of the project

4. Any expiry of the insurance coverage provided in respect of sponsored trials
5. Discontinuation of the project before the expected date of completion, giving reasons
6. Any change in personnel involved in the research project including any study member resigning from XXXXXXXXXXXXXXXXXXXX &/or the study team.

At the conclusion of the project or every twelve months if the project continues, the Principal Investigator is required to complete and forward an annual report to the Committee.

Annual report forms will be forwarded to the researcher.

### **Approved documents**

Documents reviewed and approved by the Low Risk Review Panel:

*Explanatory Statement Version 3 30 July 2012*

*Email Invitation to Participate Version 1 29 May 2012*

If you should have any queries about your project please contact XXXXXXXXXXXXXXXX or XXXXXXXXXXXXXXXX by email XXXXXXXXXXXXXXXX.

The HREC wishes you and your colleagues every success in your research.

Yours sincerely

XXXXXXXXXXXXXXXXXX  
HREC Medical Administrator



**Appendix 7 - Sample wording for Email Invitation to Participate**

**(Registered Nurse)**

Dear Registered Nurse,

*Re: Registered Nurses' attitudes towards caring of the dying patient*

You are invited to take part in this study investigating the Registered Nurses' attitudes toward caring for dying patients.

The aim of this research is to determine how nurses recognise when a patient is dying, and how they respond to dying patients. More specifically, we are interested to see if nurses' attitudes towards caring for dying patients might be a factor influencing the care provided to people who are dying in acute hospital wards.

This survey is open to all Registered Nurses in Australia who:-

- work in acute care, for example medical or surgical wards; and
- have cared for a dying patient

If your main area of nursing work is not acute care, or you have never cared for a dying patient, then you are not eligible to complete this survey.

If you work in critical care areas such as Intensive Care, or you work in palliative care/hospice settings, then you are also not eligible to complete this survey.

Please read the attached Explanatory Statement in full before making a decision.

Please click on this link to access the survey

<https://www.surveymonkey.com/s/Nursesurvey2012>

**(Medical Student)**

Dear Student Doctor,

*Re: Student Doctors' attitudes towards caring of the dying patient*

You are invited to take part in this study investigating the Student Doctors' attitudes toward caring for dying patients. The aim of this research is to determine if Student Doctors' attitudes towards caring for dying patients might be a factor influencing the care provided to people who are dying in acute hospital wards.

This survey is open to all final year medical students at Monash University who:-

- have worked in acute care, for example medical or surgical wards; and
- have cared for a dying patient

If you have never worked in acute care, or you have never cared for a dying patient, then you are not eligible to complete this survey.

Please read the attached Explanatory Statement in full before making a decision.

The survey is available at <https://www.surveymonkey.com/s/StudentDoctorSurvey>



**MONASH University**

School of Nursing and Midwifery

## **Explanatory Statement**

5 September, 2012

**Title:** Registered Nurses' attitudes towards caring of the dying patient

**This information sheet is for you to keep.**

My name is Melissa Bloomer and I am conducting a research project with Professor Wendy Cross, Head of School in the School of Nursing and Midwifery towards a PhD at Monash University. This means that I will be writing a thesis which is the equivalent of a 300 page book based on the findings of this research.

You are invited to take part in this study. Please read this Explanatory Statement in full before making a decision.

### **Why were you chosen for this research?**

This survey is open to all Registered Nurses in Australia who:-

- work in acute care, for example medical or surgical wards; and
- have cared for a dying patient

If your main area of nursing work is not acute care, or you have never cared for a dying patient, then you are not eligible to complete this survey. If you work in critical care areas such as Intensive Care, or you work in palliative care/hospice settings, then you are also not eligible to complete this survey.

### **The aim/purpose of the research**

The aim of this research is to determine how nurses recognise when a patient is dying, and how they respond to dying patients. More specifically, we are interested to see if nurses' attitudes towards caring for dying patients might be a factor influencing the care provided to people who are dying in acute hospital wards.

### **Possible benefits**

There is not likely to be any direct benefit to you in taking part in this study.

### **What does the research involve?**

The study involves completion of an online survey. The survey is completely anonymous and it will not be possible to identify you from the survey results.

**How much time will the research take?**

This survey is voluntary and it will take up to 15 minutes to complete online. It is assumed that if you complete the survey, you are willing to participate in this research. Once you have answered the survey you will not be able to withdraw your responses

**Inconvenience/discomfort**

Apart from the possibility of 'mild discomfort', there are no foreseeable risks to you, but if at any time you feel more than mild discomfort, please discontinue the survey.

Counselling services are available for any participant who requires it as a result of participating in this survey. These services will be made available via your employer. Please contact your employer to arrange counselling.

**Payment**

You will not receive any payment or reward for your participation.

**Participation**

Being in this study is voluntary and you are under no obligation to participate. You do not need to answer all the questions, but once you have answered all or part of the survey, you will not be able to withdraw your responses.

**Confidentiality**

Your identity and contact details have not been disclosed to the researchers, and this survey is completely anonymous. Your identity will not be known.

**Storage of data**

Data collected will be stored in accordance with Monash University regulations, kept on University premises, in a locked filing cabinet for 5 years. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

**Use of data for other purposes**

The data collected as part of this study will not be used for any other purpose.

**Results**

The overall results of this survey will be made available to participating hospitals for circulation at the completion of the study. It is anticipated that the results of this survey will be reported in the theses of the student researcher, and a report of the study may be submitted for publication. The data collected as part of this study will not be used for any other purpose.

If you would like to contact the researchers about any aspect of this study, please contact the Chief Investigator:	If you have a complaint concerning the manner in which this research is being conducted, please contact:
<p>Professor Wendy Cross  School of Nursing and Midwifery  Monash University  Email [REDACTED]  Telephone: [REDACTED]</p>	<p>Executive Officer, Human Research Ethics  Monash University Human Research Ethics Committee (MUHREC)  Building 3e Room 111  Research Office  Monash University VIC 3800</p> <p>Tel: +61 3 9905 2052      Fax: +61 3 9905 3831  Email: <a href="mailto:muhrec@monash.edu">muhrec@monash.edu</a></p>

Thank you.



Melissa Bloomer

## Appendix 9 - Survey Coding Sheets

<b>FATCOD CODING SHEET</b>			
<b>Not analysed</b>	<b>DQ1</b> Do you work in an acute hospital setting?	1 = Yes      2 = No (If no, survey will be terminated)	
	<b>DQ2</b> Have you ever cared for a dying patient?	1 = Yes      2 = No (If no, survey will be terminated)	
	<b>DQ3</b> Please select the hospital where you work most of the time?		
	<b>DQ4</b> Please select the option which best describes your work area	1 = PC/Hospice -terminated    2 = Medical    3 = Surgical    4 = Other	
<b>DQ5</b> What is your sex?		1 = Male      2 = Female	
<b>DQ6</b> What is your age in years?		_____ yrs	
<b>DQ7</b> How many years have you worked as a Registered Nurse?		_____ yrs	
<b>DQ8</b> Which title best describes your position?	1 = Graduate Nurse    2 = Nurse    3 = Clinical Nurse Specialist (CNS)    4 = Assoc. Nurse Manager (AUM) 5 = Nurse Manager (NM)    6 = Nurse Educator (NE)    7 = Executive Management (Exec)    8 = Other		
<b>DQ8 Recoded</b>	1= Grad & Nurse    2=CNS & AUM    3=NM, NE, Exec, Other (CNC)		
<b>DQ9</b> What is your highest qualification?	1 = PhD    2 = Masters    3 = GDip (Graduate Diploma)    4 = GCert (Graduate Certificate)    5 = UGrad (u/graduate)    6 = HT (hospital trained)    7 = Other _____		
<b>DQ9 Recoded</b>	2 = Postgrad (Masters, GDip, GCert)    3 = Undergrad (UGrad, HT and other)		
<b>DQ10</b> Please choose the statement that best fits your previous death education	1 = I took a course in death and dying as part of my basic nursing education 2 = I did not take a specific course on death and dying, but material on the subject was included in other nursing courses 3 = No information dealing with death and dying was included in my nursing education		
<b>DQ11</b> Please choose the statement that best fits your feelings about your previous death education	1 = I feel that my previous death education prepared me adequately to deal with death and dying 2 = I feel that my previous death education did not prepare me adequately to deal with death and dying		
<b>DQ12</b> Is there a palliative care unit or hospice at your hospital/health service?		1 = Yes      2 = No      3 = Unsure	
<b>DQ12 Recoded</b>		1 = Yes      2 = No/Unsure	
<b>DQ13</b> Do you have access to specialist palliative care staff for advice or consultation?		1 = Yes      2 = No      3 = Unsure	
<b>DQ13 Recoded</b>		1 = Yes      2 = No/Unsure	
<b>DQ14</b> Do you use an 'end of life' or 'palliative care' dying pathway in your ward/hospital?		1 = Yes      2 = No      3 = Unsure	

DQ14 Recoded	1 = Yes	2 = No/Unsure			
	SD	D	U	A	SA
1. Giving nursing care to the dying person is a worthwhile learning experience	1	2	3	4	5
2. Death is not the worst thing that can happen to a person.	1	2	3	4	5
3. I would be uncomfortable talking about impending death with the dying person.	5	4	3	2	1
4. Nursing care for the patient's family should continue throughout the period of grief and bereavement.	1	2	3	4	5
5. I would not want to be assigned to care for a dying person.	5	4	3	2	1
6. The nurse should not be the one to talk about death with the dying person.	5	4	3	2	1
7. The length of time required to give nursing care to a dying person would frustrate me.	5	4	3	2	1
8. I would be upset when the dying person I was caring for gave up hope of getting better.	5	4	3	2	1
9. It is difficult to form a close relationship with the family of a dying person.	5	4	3	2	1
10. There are times when death is welcomed by the dying person.	1	2	3	4	5
11. When a patient asks, "Nurse am I dying?", I think it is best to change the subject to something cheerful.	5	4	3	2	1
12. The family should be involved in the physical care of the dying person.	1	2	3	4	5
13. I would hope the person I'm caring for dies when I am not present.	5	4	3	2	1
14. I am afraid to become friends with a dying person.	5	4	3	2	1
15. I would feel like running away when the person actually died.	5	4	3	2	1
16. Families need emotional support to accept the behaviour changes of the dying person.	1	2	3	4	5
17. As a patient nears death, the nurse should withdraw from his/her involvement with the patient.	5	4	3	2	1
18. Families should be concerned about helping their dying member make the best of his/her remaining life	1	2	3	4	5
19. The dying person should not be allowed to make decisions about his/her physical care.	5	4	3	2	1
20. Families should maintain as normal an environment as possible for their dying member.	1	2	3	4	5
21. It is beneficial for the dying person to verbalize his/or feelings.	1	2	3	4	5
22. Nursing care should extend to the family of the dying person.	1	2	3	4	5
23. Nurses should permit dying persons to have flexible visiting schedules.	1	2	3	4	5
24. The dying person and his/her family should be the in-charge decision makers.	1	2	3	4	5
25. Addiction to pain relieving medication should not be a nursing concern when dealing with a dying person.	1	2	3	4	5
26. I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	5	4	3	2	1
27. Dying persons should be given honest answers about their condition.	1	2	3	4	5
28. Educating families about death and dying is not a nursing responsibility.	5	4	3	2	1
29. Family members who stay close to a dying person often interfere with the professionals' job with the patient.	5	4	3	2	1
30. It is possible for nurses to help patients prepare for death.	1	2	3	4	5

<b>FATCOD-DOC CODING SHEET</b>					
Have you ever cared for a dying patient in an acute hospital ward setting? (excluding palliative care and critical care areas)			1 = Yes      2 = No (survey will be terminated)		
When you last cared for a dying patient, what type of ward was it?			1 = Medical    2 = Surgical    3 = Other _____		
What is your age in years?			_____ years		
Please choose the statement that best fits your previous death education		1 = I have taken a course/subject on death and dying/palliative care as part of my MBBS 2 = I did not take a specific course/subject on death and dying/palliative care, but material on the subject was included in other subjects 3 = No information dealing with death and dying was included in my medical education			
If you have had previous death education, please choose the statement that best fits your feelings about your previous death education		1 = I feel that my previous death education prepared me to deal with death and dying 2 = I feel that my previous death education did not prepare me adequately to deal with death and dying			
When you last cared for a dying patient, did you have access to specialist palliative care staff for advice or consultation?				1 = Yes    2 = No	
When you last cared for a dying patient, did you use an 'end of life' or 'palliative care' dying pathway?				1 = Yes    2 = No	
	SD	D	U	A	SA
1. Giving care to the dying person is a worthwhile learning experience.	1	2	3	4	5
2. Death is not the worst thing that can happen to a person.	1	2	3	4	5
3. I would be uncomfortable talking about impending death with the dying person.	5	4	3	2	1
4. Care for the patient's family should continue throughout the period of grief and bereavement.	1	2	3	4	5
5. I would not want to be assigned to care for a dying person.	5	4	3	2	1
6. The doctor should not be the one to talk about death with the dying person.	5	4	3	2	1
7. The length of time required to care for a dying person would frustrate me.	5	4	3	2	1
8. I would be upset when the dying person I was caring for gave up hope of getting better.	5	4	3	2	1
9. It is difficult to form a close relationship with the family of a dying person.	5	4	3	2	1
10. There are times when death is welcomed by the dying person.	1	2	3	4	5
11. When a patient asks, "Am I dying?", I think it is best to change the subject to something cheerful.	5	4	3	2	1



12. The family should be involved in the physical care of the dying person.	1	2	3	4	5
13. I would hope the person dies when I am not present.	5	4	3	2	1
14. I am afraid to become friends with a dying person.	5	4	3	2	1
15. I would feel like running away when the person actually died.	5	4	3	2	1
16. Families need emotional support to accept the behaviour changes of the dying person.	1	2	3	4	5
17. As a patient nears death, the doctor should withdraw from his/her involvement with the patient.	5	4	3	2	1
18. Families should be concerned about helping their dying member make the best of his/her remaining life.	1	2	3	4	5
19. The dying person should not be allowed to make decisions about his/her physical care.	5	4	3	2	1
20. Families should maintain as normal an environment as possible for their dying member.	1	2	3	4	5
21. It is beneficial for the dying person to verbalize his/or feelings.	1	2	3	4	5
22. Medical care should extend to the family of the dying person.	1	2	3	4	5
23. Nurses should permit dying persons to have flexible visiting schedules.	1	2	3	4	5
24. The dying person and his/her family should be the in-charge decision makers.	1	2	3	4	5
25. Addiction to pain relieving medication should not be a concern when dealing with a dying person.	1	2	3	4	5
26. I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	5	4	3	2	1
27. Dying persons should be given honest answers about their condition.	1	2	3	4	5
28. Educating families about death and dying is not a medical responsibility.	5	4	3	2	1
29. Family members who stay close to a dying person often interfere with the doctor's job with the patient.	5	4	3	2	1
30. It is possible for doctors to help patients prepare for death.	1	2	3	4	5

## **Appendix 10 - Non-peer reviewed Publications**

**Bloomer, M., Moss, C. & Cross, W. (2011). Recognising dying in acute care. *Australian Nursing Journal*. 18(7), 43.**

While palliative care services in Australia are among the best in the world, and accessible to those without private health insurance, the current reality is that almost two thirds of those who die in Australia, do so in acute hospital wards. Existing research and literature has focussed on the care of the dying in palliative care units, however there is an urgency to consider the needs of those dying in other settings.

A recent Australian study showed that despite the promotion of advanced care plans, their prevalence in hospital medical charts is less than one per cent. Those admitted to hospital with a life limiting illness (in the absence of a Medical Power of Attorney, or Advance Directive) are provided with active treatment aimed at cure. When this occurs, the dying process, which is a natural part of life, becomes medicalised. Many dying patients receive active treatment aimed at cure, rather than appropriate end of life treatment, where the focus is on comfort, symptom control, family inclusion and a dignified death.

The Liverpool Care Pathway (LCP), developed in the United Kingdom, has recently been implemented in Australia. While several studies show the LCP is responsible for marked improvement in care and management of the dying patient and increased staff satisfaction, some evaluations found that nursing staff had difficulty recognising the signs of active dying/the dying phase, and were thus unsure when to start the care pathway.

Where acute hospital care is focused on cure, nurses are underprepared educationally and clinically to recognise and manage the dying phase. There is a definite need for more attention to be given to death education in continuing education for registered nurses and in undergraduate nursing curricula. Educational strategies should include not only the

physiological signs of active dying, but also the social and psychological signs of dying. This is essential to develop early recognition and the ability to implement appropriate death care pathways to ensure realistic quality patient-centred care is provided for the patient and extended to their family.

**Bloomer, M. (2012). Care in final days. Nursing Review, August, p. 20**

Over recent decades, we have seen a growing tendency for including more single rooms in hospital ward design. Single rooms are often favoured by patients, are highly sought after and rarely empty.

Infection control guidelines mandate single rooms for patients who are infectious to others or immuno-compromised, and the deeply ingrained cultural norms in hospitals result in nurses also lobbying for single rooms for particular patient groups, such as those who are dying.

Australians today have an overwhelming preference to die at home, and to be cared for by family until death. But our rapidly ageing population, and the shortage of family members to take on an informal carer role, has resulted in a significant increase in the number of people who die in hospital.

Family members generally prefer hospital care as it preserves the social boundaries of personal intimacy, allowing for the delegation of care tasks to professionals.

Nevertheless, when acute hospital care is aimed at resuscitation and recovery, caring for a dying patient and their family can be challenging, not only in terms of their physiological care needs, but also in terms of the emotional and social impact that a dying patient can have on those around them. Dying has come to be regarded as a private matter and privacy is considered essential to a “good death”.

Nurses justify single rooms for dying patients based on the need for peace and privacy and because having a patient die in a shared room is distressing for the other patients.

Nurses also demonstrate a strong desire to hide dying away from public view as a way of lessening any anxiety and discomfort associated with death

In terms of privacy, one recent Australian study found that the single room did provide more visual privacy and that they were noisier as a consequence of being located adjacent to toilets, the pan room and other service areas.

Not all dying patients want to be cared for in a single room either, fearing that it could lead to isolation and a loss of identity . For many, the fear of dying alone is greater than the fear of dying itself.

When the dying person does not have family or loved ones to provide support and be with them, a sense of social support and community can come from the presence of other patients in a shared room, and being part of the activity in the shared space. When the dying patient is placed in a single room, this sense of community is lost, creating social isolation and limited opportunity for interaction with others.

Patients cared for in a single room are also at greater risk of adverse events or situations that compromise their dignity as a result of decreased visual surveillance. When a nurse is caring for patients in a shared room there is an ongoing opportunity to visually assess them throughout the shift. In a single room, however, the same is not true. The evidence also suggests that patients in single rooms get a lower proportion of care time than those in shared rooms, and that the care they do receive is associated with routine or technological care.

Another issue is that ward design sees single rooms located adjacent to each other, resulting in an allocation pattern where one nurse may be caring for several patients in separate single rooms. As mentioned, when the single rooms are filled with infectious and dying patients, this

creates a heavy workload. Furthermore, irrespective of the high acuity in the single rooms, the practice is to allocate nursing staff based on the “normal patterns”, rather than patient acuity.

As the number of people dying in hospital continues to rise, single rooms will remain in demand. Assuming that dying patients want or need a single room is short-sighted, and may not be in their best interests.

Cultural norms in the acute hospital system need to change, and the dying patient’s needs should be assessed on an individual basis, acknowledging the potential negative consequences that come with single room care. Caring for a dying patient in a single room does not ensure a dignified death and may in fact result in a lonely, frightening one.

**Bloomer, M.J., Cross, W., O'Connor, M., & Endacott, R. (2013). When your patient is dying... *The Hive*, (2 Winter), 20-21.**

Australia's population is ageing, and despite improvements in medical technology, many patients will die in the acute hospital setting. While Australia is ranked second in the world for 'quality of death' (Economist Intelligence Unit, 2010), only a small proportion of - patients who die in Australia are cared for in a specialist palliative care setting (O'Connor, Peters & Lee, 2007). For those who die in general hospital wards or in critical care areas, where the overall momentum is toward extending life, the quality of end of life care is dependent on many factors (Bloomer, Moss & Cross, 2011).

Clinicians may have a sense of failure associated with the death of a patient, particularly when resuscitative treatments or interventions are continued right up until death. Others describe their emotional and moral distress at continuing resuscitative care, even when they felt there was no hope the patient would survive and a sense of powerlessness in not being able to change the focus of care to end of life care (Bloomer, et al., 2011).

Despite its inclusion in nursing curricula, it was clear that not all nurses felt adequately prepared educationally or emotionally to provide care for the dying patient, which often extends to include caring for their family/loved ones (Bloomer, et al., 2011). Knowing what to say, how to say it and how to provide the support the family/loved ones need is not innate. Previous studies have shown that nurses rely on mentoring and role-modelling to learn how to carry out this important work (Bloomer, Morphet, O'Connor, Lee & Griffiths, 2012). However in the context of acute hospital wards, where patient acuity is high and the pace is fast, facilitating this kind of supported learning can be very difficult.

For the family, death of a loved one can be equally difficult. When resuscitative care

continues, this may create a false sense of hope that death can be denied or delayed, and then when death does occur, it can be harder to accept. Studies suggest that the seriousness of the situation is often not clearly articulated by clinicians who often find it difficult to talk about death or dying. Many rely on euphemisms; others avoid talking about the topic altogether (Bloomer, et al., 2011), leaving the family 'in the dark', unprepared and without the opportunity to say goodbye.

How the family are cared for after a death is also important work that often goes unrecognised. Families may be in shock, grieving and in need of support. When the death occurs after hours, and support personnel such as social work or pastoral care are not available, it is usually the nurse who is responsible for family care (Bloomer, et al., 2012; Stuart, O'Connor, Peters & Bloomer, 2010). While it is already well known that the families of patients who are critically ill or die, may suffer long lasting psychological effects as a consequence of their experience (Pochard et al., 2005), it is important to talk with the family, give them time, space and privacy to be with their deceased loved one, and facilitate specific cultural or religious needs or rituals that may be important. It may be impossible to foresee exactly what is needed, but families will appreciate it if clinicians make an effort to meet their needs.

Caring for a dying patient is a challenge, particularly when they are being cared for in an acute hospital ward where the focus is on resuscitation and cure. For those who are less experienced at this aspect of nursing work, it can also be difficult emotionally. Supporting less experienced colleagues through the provision of end of life care is essential to ensuring that patients receive appropriate care at the end of life, extending to the patient's family.

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