

*Nursing the Dying:
A mixed method study*

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DEDICATION

For all students in nursing past, present and future who care for dying patients and their families, it is your stories which inspired me on this journey...

And for Robert, my husband I thank you for always being there, loving me unconditionally and encouraging me to keep going. Words cannot express how deeply I feel about the commitment you made to me so I could achieve my goal. I therefore dedicate this thesis to you with much love.

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STATEMENT of AUTHENTICATION

I, *Amanda Johnson*, declare that this thesis, submitted in fulfilment of the requirement for the award of Doctor of Philosophy, in the School of Nursing and Midwifery, College of Health and Science, University of Western Sydney, is to the best of my knowledge and belief original except as acknowledged in the text. I hereby declare that I have not submitted, either wholly or in part, this work for a degree at this or any other institution.

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Candidate

Signature.....Date.....

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ABBREVIATIONS USED IN THESIS

Abbreviation	Full term
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
CDNM	Council of Deans of Nursing and Midwifery
ICN	International Council of Nurses
NHMRC	National Health and Medical Research Council
PCA	Palliative Care Australia
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

ABSTRACT

Death affects us all. It is an inevitable certainty of living, universally faced by all human beings. Currently, and projected into the future, the vast majority of people in developed countries will die in an acute-care hospital. Nurses, of all the health professionals encounter dying patients and death more frequently than any other group. Caring for an adult dying patient is complex and poses many challenges when undertaken in an acute-care hospital. Understanding those challenges more completely, will enable students and new graduate nurses to be more adequately prepared by their undergraduate programs.

This first Australian study sought to understand what the experience of caring for an adult dying patient and their family means to Australian students and new graduate nurses. A two-phase mixed method study design incorporating a longitudinal element was selected to conduct the research. It is named specifically as sequential explanatory because a quantitative study was conducted initially, followed by a qualitative study.

Phase one of the study involved the conduct of a descriptive survey. A questionnaire was developed to collect data on the current curriculum practices undergraduate nursing programs use to provide education on death and dying. Respondents were accessed via the Council of Nursing Deans. A response rate of 72% was achieved representing each state and territory of Australia. Survey data was analysed using descriptive statistics. The key result of this study described education on death and dying as; inconsistently presented, to have minimal penetration into the overall curriculum and be pedagogically underdeveloped. The main conclusion drawn from

these results suggests significant deficiencies exist in the curricula design and content to support students acquiring the relevant attitudes, knowledge and skills to optimally engage in care of a dying patient.

Phase two of the study consisted of 14 participants recruited from a single Australian university in the final semester of their undergraduate nursing program. A phenomenological interview, informed by van Manen (1990) was held with each participant. Subsequently, six participants from the same cohort were re-interviewed for a second time on completion of their hospital new graduate program approximately 18 months later. Interviews were transcribed verbatim and thematically analysed using van Manen's (1990) approach. Four themes emerged from the phase two interviews. The first three themes came directly from the first interviews and were: *being confronted, being transformed by death, and grieving the loss of a patient*. The fourth theme to emerge was directly related to the second interviews and consisted of: *the buck stops with you: being responsible for the care of the dying*.

Against a backdrop of inadequate preparation by Australian undergraduate nursing curricula three major outcomes have been identified by this two-phase mixed method study. Firstly, this study has shown the need for the participants to be supported while bereaved following the death of a patient. Secondly, the study has highlighted that as a result of this experience, students and new graduate nurses are at risk of developing vicarious traumatisation. Finally, this study shows that the experience of caring for a dying patient and their family provides the capacity for transformative learning to take place which can lead to nurses building a more meaningful practice.

CHAPTER 1

INTRODUCTION

Death affects us all. It is an inevitable certainty of living, universally faced by all human beings. Yet death has become an increasingly secluded part of our everyday life. We have been shielded from the normality of death by sequestering the dying into institutions. The outcome is a lack of exposure to the dying process and death until the adulthood years. When death is encountered it is understood as a tragic and abnormal part of life rather than accepted as a normal consequence of living.

Of all health professionals, nurses encounter dying patients and death more frequently than any other group. As the primary caregiver they play a significant and crucial role in care of the dying. Most nurses value highly this role and feel privileged to provide care at this time. Caring for the dying is a complex entity encompassing the cognitive, emotional, physical, psychological and spiritual dimensions of being human. This requires that nurses practice from a holistic perspective to meet their patients' needs. Furthermore the presence of being with the dying and the intimacy co-created between nurse and patient impacts on the personal and professional lives of individual nurses.

Nurses, in acute-care hospitals now and into the future, face additional challenges in providing care to adult dying patients. These challenges arise largely as a combination of: an escalation in the numbers of people dying from a range of life limiting illnesses across many settings in an acute-care hospital, the nurse's limited personal understanding of death and dying, the lack of knowledge and skills in generalist palliative care and providing care in a setting whose goal is primarily curative and the

tensions this creates. In the absence of any previous Australian studies it is therefore critical to understand the Australian nurse's experience of caring for adult dying patients in an acute-care hospital. Understanding what it means to nurses to care for adult dying patients in an acute-care hospital is crucial as this experience affects how they practice in the future.

This chapter introduces the reader to this study. It presents the study background establishing the importance of this study in the Australian context. This chapter briefly describes the study design and key terms used in conducting this study. The chapter concludes with an overview of the thesis organisation.

1.1 Background to the study

Currently, and projected into the future, the vast majority of people in developed countries will die in an acute-care hospital (Katz, 2008; Palliative Care Australia [PCA], 2008). Latest estimates predict between 60-90% of all deaths will occur in an acute-care hospital (Becker & Gamlin, 2004; Paice, Ferrell, Coyle, Coyne & Callaway, 2007; Tan et al., 2006; Taylor, 2004). These figures suggest nurses more than ever before will be required to provide care to dying patients with a range of life limiting illnesses in an acute-care hospital (Adriaansen & van Achterberg, 2008; Kwekkeboom, Vahl, & Eland, 2005; Paice, et al., 2007; Sherman, Matzo, Pitorak, Ferrell, & Malloy, 2005). Several reasons contribute to this escalating need and include: an ageing population; an increased prevalence of chronic disease; a protracted dying trajectory due to increased medical intervention and society's preference for dying in hospital (Bakitas, Bishop & Caron, 2010; Clark, 2004; Costello, 2006; PCA, 2008; Seale, 2000a, 2000b). Understanding what this

experience means to nurses in acute-care hospitals is critically important to ensure they are adequately prepared to assume this expanded role to include generalist palliative care knowledge and skills.

International studies have explored this experience from the perspective of nursing students, (see for instance Allchin, 2006; Van Rooyen, Laing & Kotzé, 2005) new graduate nurses, (see for instance Brisley & Wood, 2004; Hopkinson, Hallet, & Luker, 2005; Tan et al., 2006) and nurses with several years of experience, (see for instance Costello, 2006; Dunn, Otten & Stephens, 2005; Mok, Lee, & Wong, 2002) and found caring for dying patients and their families in an acute-care hospital to be both challenging and confronting. In numerous studies, students and nurses attributed their feelings of confrontation and being challenged to inadequate preparation by their initial nursing program (Adriaansen & van Achterberg, 2008; Allchin, 2006; Hopkinson et al., 2005; Kelly, 1999; Paice et al., 2007; Quint, 1967). Furthermore, these studies provided evidence of the way students carried the sustained and unresolved impact of this experience into their subsequent nursing practice post graduation. However, against the back drop of the international studies conducted, understanding what it means to Australian nurses to care for adult dying patients in an acute-care hospital was unknown.

1.2 Study Purpose

The purpose of this study was to understand what the experience of caring for an adult dying patient and their family in an acute-care hospital means to Australian students and new graduate nurses. The specific aims of this study were to:

(1) describe the current curriculum practices Australian undergraduate nursing programs use to provide education on death and dying.

(2) understand the students' and new graduate nurses' experience of caring for an adult dying patient and their family in an acute-care hospital.

1.3 Study Design

A two-phase sequential explanatory mixed method longitudinal study design was selected to explore the Australian student and new graduate nurse's experience of caring for an adult dying patient and their family. The decision to use mixed method design was based on several factors. Firstly, this study required a methodological approach capable of collecting data from multiple perspectives in a single study. Collecting data from both an epistemological and ontological perspective would enable the experience to be accessed in a more comprehensive manner than compared to the previously conducted international single studies. Single method studies present only one perspective of the phenomenon being investigated and therefore the understandings gained are incomplete. A mixed method design therefore had the potential to further build upon the nursing knowledge already known in this field by gaining a deeper and more holistic understanding of the experience (Gillis & Jackson, 2002; Whitehead & Elliot, 2007). Secondly, the experience of caring for an adult dying patient and their family is complex and multidimensional, necessitating a study design capable of revealing the many layers embedded within the experience and making them visible to others.

The two phases of this study comprised a descriptive survey and phenomenological interviews. A brief description of each phase follows. Phase one of the study involved

a descriptive survey of Australian undergraduate nursing curricula. The purpose of this phase was to collect preliminary data to generate a description of current curriculum practices. This information supported the implementation and interpretation of the phase two of the study. A response rate of 72% ($n=26$) was achieved. All states and territories of Australia were represented in the results. A more detailed discussion on the survey methodology and the results obtained are located in chapter four.

Phase two of the study was framed by the qualitative paradigm and implemented following completion of phase one of the study. The purpose of phase two was to elicit the students' and new graduate nurses' experience of caring for an adult dying patient and their family. Phase two of the study involved the conduct of phenomenological interviews informed by van Manen (1990). Fourteen participants were interviewed at two time intervals. Firstly as a final semester student, and approximately 12 - 18 months later as a new graduate nurse following the completion of a hospital new graduate program. Six participants were re-interviewed for a second time. Thematic analysis, informed by van Manen was undertaken on each of the transcribed interviews. Four themes emerged to describe the Australian student and new graduate nurse's experience of caring for an adult dying patient and their family. A longitudinal element was incorporated into the mixed method study design as it was considered the best means by which to determine whether time and multiple and repeated exposure to dying patients made a difference to the participant's experience. This element provided an opportunity to gain a deeper understanding of a previously unexplored aspect of this experience. A more detailed discussion of the methodology used in phase two of the study is located in chapter five. Chapter six presents the four

themes to emerge from this study. Discussions of the phase one results are located in chapter four and the phase two findings are detailed in chapter six.

1.4 Significance of the Study

In the absence of any Australian studies and the escalating demand for nurses in acute-care hospitals to care for adult dying patients with a range of life limiting illnesses, it was critical to understand Australian students and new graduate nurses' experience. Furthermore, investigation using a two-phase mixed method longitudinal study design offered a new methodological approach in this research field.

Furthermore, while unique to the Australian context, it is anticipated that this study will also contribute to advancing the international body of knowledge in this field.

The major findings generated from this study have implications for nurse education and practice with regard to the design and implementation of relevant undergraduate nursing curricula and new graduate programs.

1.5 Definitions of terms and key concepts

Acute-care hospital in this study embraces both Australian private and public hospitals comprising a range of clinical environments.

Care of the dying constitutes the provision of comfort and supportive care activities to alleviate an individual's suffering and promote quality living while dying for both the individual and their family. This entails meeting the individual's physical, emotional and spiritual needs.

Dying patient in this study represents an adult patient necessitating end of life care interventions, regardless of the underlying pathology of the illness, located in any clinical environment of an acute-care hospital.

Family for the purposes of this study constitutes those individuals considered by the dying patient to be significant to them. This term encapsulates all individuals who share biological, legal or social ties to the dying patient.

Hospital new graduate program refers to a transitional support program conducted by a private or public hospital for new graduate nurses for a period of up to 12 months following graduation.

New graduate nurse is the term used to describe a qualified nurse during the first 12 months of practice who has graduated from an Australian tertiary institution.

Palliative care approach denotes a core set of knowledge and skills able to be provided by all health professionals across a range of clinical settings. This is the term commonly used in the Australian health care system. Other terms used interchangeably in the United Kingdom (UK) and United States of America (USA) are: end-of-life care, fundamental palliative nursing; generalist palliative care and supportive care.

1.6 Organisation of the Thesis

The thesis is comprised of seven chapters. The first chapter has introduced the reader to the study and provides an overview of the thesis including the study background, research purpose and aims, significance of the study and key terms.

Chapter Two critically examines the literature and describes how care of the dying has evolved over time. This chapter includes a critique of previously conducted international research studies on undergraduate nursing curricula and student and new graduate nurses' experiences of caring for dying patients in acute-care hospitals. The final section of this chapter reveals the extent of this issue globally and discusses the relevance of this study to the Australian context.

Chapter Three details the study design of mixed method methodology used to conduct this study. The fundamental assumptions underpinning mixed method research and their application to this study are examined. Methods of data collection, data analysis and ethical considerations of the study overall are discussed. The final section of this chapter presents a discussion on the strategies used to maintain rigor and quality in phase one and two of the study.

Chapter Four presents a discussion on the selection of the quantitative paradigm to guide the conduct of phase one of the study. The method of descriptive survey is described including survey instrument development. This is followed by an outline of the data collection and analysis procedures used to conduct this survey on Australian undergraduate nursing curricula. The final section of this chapter presents the survey results and a discussion on the main conclusions drawn from this study.

Chapter Five presents a discussion on the selection of the qualitative paradigm selected to guide the conduct of phase two of the study. A detailed description of van Manen's (1990) hermeneutic phenomenology and how this methodology was used for data collection and thematic analysis in this study are detailed. The chapter concludes with a discussion on the strategies used to enhance quality in the study's findings.

Chapter Six presents the qualitative findings generated from the thematic analysis undertaken on the phenomenological interviews conducted in phase two of the study. The four themes to emerge from this study are presented. In the discussion on each theme, exemplars are provided to illustrate the participants' experience.

Chapter Seven presents a discussion on the three major findings that were generated following the conduct of this two-phase study. These major findings represent the synthesis of the phase one descriptive survey results and the findings generated from the phenomenological interviews conducted in phase two of the study. The study findings are discussed with reference to existing literature, other research studies and current theory. New knowledge derived from this study is also highlighted. The second section of this chapter presents the implications for education and practice identified as a result of the study findings. The third section of this chapter addresses the strengths and limitations of the chapter. The final section of the chapter concludes with recommendations for future research and overall study conclusions.

1.7 Conclusion

This chapter has provided a brief introduction to the study and discussed the organisation of the thesis layout. The following chapter, **Chapter Two** focuses on the world wide extent of the research issue and discusses the significance of this study to the Australian context. It also provides a critique of the previously conducted international research on undergraduate nursing curricula and students and new graduate nurses' experience of caring for dying patients and their families in acute-care hospitals.

CHAPTER 2

LITERATURE REVIEW

This chapter presents a discussion on the literature reviewed to inform the researcher as to the context in which this study should be conducted. An awareness of the value ascribed to death and dying by Australian society was an important aspect of the literature, which enabled the researcher to fully understand students and new graduate nurses' experience of caring for dying patients and their families. Equally important was gaining an appreciation of the evolution in the way nurses care for the dying in Australia and how this practice will further evolve. The final section of this literature review critiques previously conducted international studies and their contributions to the design of this Australian study.

2.1 Influences which shape nurses' perceptions of death

The dying process challenges the preconceptions individuals hold of life (Haley & Daley, 2008). This is also true for nurses. According to G. R. Johnson (1994), nurses are not a homogenous group, nor do they function in isolation from their personal context. As individuals they enter into nursing programs with a diversity of personal life experiences which have formed their attitudes, beliefs and values towards death and dying (G.R. Johnson, 1994). The interpretation and meaning individuals ascribe to death is shaped through their cultural, historical and social frame of reference developed during childhood (Cline, 1996; Corr, 1998; Strazzari, 2005). Other aspects known to influence an individual's perception of death include: age, gender, social class, race and ethnicity (Cox & James, 2008; Field & Cassell, 1997; Strazzari, 2005). It is this frame of reference which has potential to challenge previously held preconceptions on life when encountering death in a professional

context. Quint's (1967) study identified that the first death experience to which students were exposed had a highly significant influence on the nurse's future attitude towards death and dying. For this reason, Quint strongly advocated that the education and management of this experience was critically important.

A nurse's personal and professional culture may also help or hinder their perceptions of death and the care they provide to the dying. Successive immigration to Australia has led to the existence of a culturally diverse community (Kellehear, 2001). As a consequence wide cultural variations are present between and within different ethnic groups in the Australian population (Lickiss, 2003). Each encounter with a dying patient is therefore uniquely defined by the nurse, patient and family (Haley & Daley, 2008). It is "shaped by the individual and their family's culture, spirituality, mores, and values and beliefs about dying" (Johnson & Bourgeois, 2003, p.133), alongside those of the nurse. This provides another layer of complexity for nurses providing care to the dying, necessitating that they navigate between the cultural practices of their patients, themselves and acute-care hospitals. The presence of multiple cultures and the need to navigate their own cultural practices with others poses significant challenges to many nurses (Allchin, 2006; Zerwekh, 2006).

Finally, nurses' perceptions of death are shaped by participation in their education program and exposure on scheduled clinical placements in the acute-care hospital. Historically, undergraduate curricula have emphasised a curative orientation to care, while palliation as an approach to care has been relatively invisible (Quint, 1967). Students and new graduate nurses are the recipients of greater exposure to dying patients in an acute-care hospital due to the increasing prevalence of people dying

from a range of life limiting illnesses. Acute-care hospitals are dominated by a curative orientation to care frequently not at ease or resourced in providing a palliative approach to care (Becker, 2009a, Taylor, 2004). Evidence from Happell's (1999) study suggests students enter nursing programs with preconceived ideas about the most desirable areas in which to practise nursing following graduation. The practice areas identified as most desirable were frequently those that focussed on highly technical aspects of care that lead to saving lives (Happell, 1999). Other areas which gave emphasis to the more caring aspects of the role, such as caring for the elderly, were relegated as less important and less scientific (Happell, 1999). It could be extrapolated that caring for dying patients could also be perceived this way.

2.1.1 Place of Death

The majority of individuals in western countries will die in acute-care hospitals or long term facilities such as nursing homes or as they are known in Australia, residential aged care facilities (Katz, 2008; McWhan, 1991; PCA, 2008; Pincombe, Brown, & McCutcheon, 2003; Tan et al., 2006; V. Taylor, 2004; Zerwekh, 2006). Statistically it is reported that in the USA the likelihood of an individual dying in an aged care facility will be as high as 75% (Zerwekh, 2006) and similarly in the UK between 60-80% (Higginson, 2005). In Australia the figures reported for the UK and USA are similar and attributed to the limited home based care being available (PCA, 2008; Strazzari, 2005). The Australian figures reflect the increasing presence of chronic life limiting illnesses in the community that lead to a heightened need for medical interventions usually undertaken in a hospital setting (Johnson & Chang, 2008). Increased frequency of hospital admission and subsequent medical intervention is more likely to increase the likelihood of death (Zerwekh, 2006). In previous centuries the primary setting for dying was in the home (Zerwekh, 2006). The change

in setting from home to hospital was the direct result of the medical profession's desire to save lives through scientific and medical advances that culminated in an increased control over the dying process (Kellehear, 2001; Seale, 2000a, 2000b; Strazzari, 2005).

Though most deaths occur in acute-care hospitals (Bakitas, et al., 2010 ; Katz, 2008), dying individuals continue to express a strong preference for dying at home (Bakitas, et al., 2010; Davies, 2005; PCA, 2008; Zerwekh, 2006). However, in the 21st century a number of factors limit this desire becoming a reality. Such factors include the: absence of family or friends to provide care, lack of social and economic support for available caregivers, a preoccupation with medical treatments to sustain life, and an absence of medical and nursing resources to provide palliative care in the home (Zerwekh, 2006). Necessity, along with medical dominance, has led to acute-care hospitals assuming the primary setting for death. As a consequence this has largely removed death and dying from the everyday lives of people (Hockey, 2001; Parker, 1998; Strazzari, 2005). The removal of death from everyday lives also includes those who become nurses, limiting their exposure prior to encountering death in a professional setting (G.R. Johnson, 1994).

2.1.2 Death denying attitude

In previous centuries the dying process predominantly occurred in the home setting, an experience which nurtured a familiarity with death for all family members (Parker, 1998; Zerwekh, 2006). Now that this experience has re-located to the hospital setting, family members are often not exposed to, or able to participate in the dying process (Exley, 2004; G.R. Johnson, 1994). This situation is further compounded by the current move away from formal religions. Today, secular views are most prevalent

in western developed countries (Strazzari, 2005). Exley (2004) believes the prevalence of secular views has eroded the traditional rites and practices associated with dying, grieving and mourning. Erosion of these practices adds to individuals no longer being exposed to, or participating in, death as an integral and inevitable final aspect of human life (The National Palliative Care Program, 2006).

Diminished exposure and participation in the ritual of death has led to a limited understanding of the dying process which leads individuals to frequently avoid, conceal or postpone death (Clark, 2002; Corr, 1998; Sandman, 2005; Strazzari, 2005; Van Rooyen et al., 2005; Zimmermann, 2007). Re-locating the setting of death to a hospital, hospice or facility for the aged further shields individuals from death and limits their understanding of the process (Corr, 1998; Loftus, 1998; Strazzari, 2005). Living longer means that an individual is more likely to be exposed to death in middle adulthood (Exley, 2004) compared to past centuries when death occurred predominantly in childhood, adolescence and young adulthood (Corr, 1998; Degnar & Gow, 1988b). The existence of this context is more likely to support individuals acquiring a death denying attitude in western developed countries.

Australia's National Palliative Care Program (2006) suggests the impact of this death-denying attitude has led individuals and the wider community to experience a loss of capacity and skill in understanding death and dying, grief and loss and knowledge of how to play an active role in the provision of care to the dying. Emanuel, Bennett and Richardson (2007) extends this further by saying that the combination of the loss of skill and opportunity for role modelling has led to communities in the 21st century demonstrating less resilience and ability to cope with death and dying. As members of

these communities potential nursing recruits are also affected by these attitudes. Therefore it can also be extrapolated that they enter undergraduate nursing programs with an already embedded death denying attitude. It is also highly probable that these individuals have little understanding of and participation in the dying process at a personal level (G.R. Johnson, 1994) as a result of the diminished exposure the community now experiences.

2.1.3 Changed patterns of disease

Up until the late 19th century, death was often the result of an acute, infective illness frequently of a short duration (Coyle, 2010; Seale, 2000b). Typically the dying trajectory was brief comprising few medical interventions (Corr, 1998; Ferrell & Coyle, 2002). Generally infants, children and mothers were the population groups most commonly affected by these acute, infective illnesses (Corr, 1998; Coyle, 2010; Forest, 2004; Germov, 2005; Seale, 2000a; Strazzari, 2005). Several key advances in health and medicine led to a change in the primary cause of death. These key advances included the: presence of improved nutrition and sanitation; wider use of preventative medicine and health promotion activities; widespread use of vaccinations; discovery and development of antibiotics and other pharmaceutical agents; and earlier detection and treatment of disease (Corr, 1998; Coyle, 2010; Germov, 2005; A. Johnson, Harrison, Currow, Luhr-Taylor, & R. Johnson, 2006; Payne, Seymour, & Ingleton, 2008; Seale, 2000a; Strazzari, 2005).

In the 21st century, the mortality patterns and dying trajectories have altered due to an epidemiological shift in the dominant cause of death (Bakitas, et al., 2010; Clark, 2004; Seale 2000a, 2000b). Infectious diseases as the primary cause of death have been replaced with chronic life-limiting illnesses (Clark, 2004; Johnson & Chang,

2008). Current and projected examples of these diseases include: cancer, heart disease, stroke, neurodegenerative diseases and dementia (Australian Institute of Health and Welfare [AIHW], 2010; Johnson & Chang, 2008; World Health Organization [WHO], 2005). In this current context individuals experience a lengthened disease trajectory, acquire co-morbid conditions and or disability, have an increased need for medical intervention, undergo repeated hospital admissions for treatments and live with an uncertain prognosis (Coyle, 2010; Johnson & Chang, 2008; Payne et al., 2008; Zerwekh, 2006). All of these elements have led to an extension of the dying trajectory with a greater emphasis on sustaining life rather than on the dying process (Zerwekh, 2006). With greater emphasis assigned to living, death has been rejected by contemporary society as a natural, normal process in the life cycle (Emanuel et al., 2007; PCA, 2008; Strazzari, 2005).

The effect of the epidemiological shift on individuals, excluding indigenous populations (Johnson & Chang 2008; Strazzari, 2005), has led to an increased life expectancy (AIHW, 2010; WHO, 2005). However, while not able to access an increased life expectancy it is important to understand the reasons why Indigenous Australians are excluded. Globally Australian indigenous populations experience the lowest life expectancy of all indigenous populations (McMurray & Clendon 2010). This lowered life expectancy is the result of increased experience of chronic disease (AIHW, 2010; AIHW, 2006b). This increased experience of chronic disease is the result of several predisposing factors including: reduced access to health services, poorer use of preventative measures, greater risk taking behaviours, lower income levels, higher levels of poverty, poor housing, greater exposure to violence, and impaired communication when English is a second language (AIHW, 2010; AIHW,

2006b; NHC, 2007). The increased prevalence of these factors, either singularly or in combination, significantly contributes to the adoption of unhealthy life style behaviours: smoking; excess alcohol intake and weight gain in Indigenous Australians (AIHW, 2006b). It is these behaviours and the presence of predisposing risk factors which lead to a higher proportion of Indigenous Australians experiencing higher levels of chronic disease (AIHW, 2010). A further consequence for Indigenous Australians is that they are four times more likely to experience death as compared to non-Indigenous Australians (AIHW, 2010).

The average life expectancy for non-Indigenous Australians has risen to 83.7 years for females and 79.2 years for males (AIHW, 2010), an increase of approximately six years from the last century. This example is comparable with other developed countries (WHO, 2005). It is predicted developed countries will continue to age as society pursues the need to live longer and birth rates continue to decline (Imhof, 2005; Strazzari, 2005). The impact of an increased life expectancy is demonstrated by a higher proportion of individuals aged 65 years or older in the population strata compared to other age categories (AIHW, 2010; Strazzari, 2005; WHO, 2005). In Australia 13.3% of the population is aged 65 years or older (AIHW, 2010).

Populations weighted with individuals aged 65 years or older correlates with a higher incidence of chronic disease and disability (Johnson & Chang, 2008; Strazzari, 2005). In Australia this has recently been reported as 50% of all those aged 65 years or older having five or more long term conditions present.

In western countries, the majority of people will die after reaching the age of 65 years (Johnson & Chang, 2008; Strazzari, 2005; WHO, 2005). In Australia, the AIHW

(2010) recently reported 46% of all deaths occurred in the 65-84 year age bracket with the numbers for those 85 or older rapidly increasing. Those aged 65 years or older generally experience more frequent admissions to acute-care hospitals for the management of their symptoms, ongoing treatments and or issues related to ageing (AIHW, 2007; Caty, Downe-Wamboldt, & Tamlyn, 1982; Imhof, 2005; Katz, 2008) than compared to all other age brackets. The older population group are at greater risk of death than any other age category due to their repeated hospitalisations, the presence of co-morbid conditions and the associated vulnerability that accompanies the ageing process (AIHW, 2007; AIHW, 2010; Caty et al., 1982). Nurses in acute-care hospitals are likely to encounter dying patients aged 65 years or older, suffering with a minimum of five long term conditions, with or without disability present (AIHW, 2010; Bakitas, et al., 2010; Payne et al., 2008; Strazzari, 2005). As a consequence, dying patients in this context present with significant complexity displaying multiple needs compounded by issues associated with ageing that require intervention (Johnston & Smith, 2006; Seale, 2000a, 2000b).

2.1.4 Medicalisation of death

As new scientific knowledge emerged, medicine sought to aggressively cure or at least prolong life with little regard for human suffering (Strazzari, 2005). The result was human bodies were seen as 'biomedical machines' (Turner, 1995) and death was no longer considered a normal part of the life cycle (Illich, 1976; Zerwekh, 2006). Death became reduced to a series of signs and symptoms seen “as [a] disease rather than the natural and expected limitation to life” (Cline, 1996, p. 77). Re-defining death in this way meant that death became re-defined as a medical event inclusive of a more sanitised approach, greater technological involvement, almost exclusive focus on the physical aspects, increased control and greater decision making

by the medical profession (Bradbury, 2000; Ferrell & Coyle, 2002; Johnston & Smith, 2006; Parker, 1998; Strazzari, 2005). The widely held perception was the medical profession demonstrated behaviours of avoiding, postponing or resisting death so as not to feel or be seen as a failure (Clark, 2002; Ferrell & Coyle, 2002; Parker, 1998; Strazzari, 2005).

Simultaneously the wider community also came to expect, through increased cure rates, that lives could be sustained and living extended. As a consequence, communities also viewed death as a failure and were unable to accept death as a natural consequence of the life cycle (Donahue, 1996; Ferrell & Coyle, 2002; Strazzari, 2005). These attitudes were not exclusive to the medical profession or wider community but also mirrored by nurses (Quint, 1967; Van Rooyen et al., 2005).

Nurses also saw, and to some degree continue to see, patient death as a professional failure (Boyle & Carter, 1998). Quint's (1967) study identified that initial nursing curricula socialised nurses almost exclusively in curative care, emphasising acute life saving and technical skills. Quint (1967) believed this arose because the medical profession was heavily involved in teaching nurses at this time, and gave emphasis to the new scientific knowledge and technologies available to achieve cure. Happell (1999) suggests this emphasis on cure, at the expense of care, still exists in educating nurses.

2.1.5 Increased involvement of professional caregivers

In tandem with the hospital replacing the home as the main setting for dying, professional carers have assumed primary responsibility for the provision of care to dying individuals (Corr, 1998; Kurz & Hayes, 2006; Zerwekh, 2006). In the majority of instances these professional carers are nurses (Graham, Andrewes, & Clark, 2005;

Spruyt, MacLeod, & Hudson, 2007; Tan et al., 2006; Thompson, 2005). It is usually nurses who provide the majority of the direct care to a dying patient over a sustained period of time (Kingma, 1994; Kurz & Hayes, 2006; Pincombe et al., 2003; Quint & Strauss, 1964; Sherman, Matzo, Panke, Grant, & Rhome, 2003). In previous centuries where dying occurred in the home setting the role of caregiver was typically ascribed to family members, in particular to females (Cline, 1996; Donahue, 1996). These 'nurses' typically gained their knowledge and skills from direct experience with the dying and with information passed down through the generations (Madsen, 2007). With the increased involvement of professional carers, individuals entering nursing programs are less likely to have been exposed to personal experiences of death involving the care of a family member, as rehearsal for professional death experiences (G.R. Johnson, 1994; Quint, 1967).

2.1.6 Summary

The dying process is transformed from previous centuries, underpinned by changes to demographic profiles, epidemiological trends, mortality patterns, attitudes towards death and the setting in which death takes place (Seale, 2000a, 2000b; Strazzari, 2005; Thompson, McClement & Daeninck, 2006). Advances in communication, health, medicine, public health, science, technology and transport (Germov, 2005) have also made this transformation possible. For the populations of western developed countries, excluding their indigenous peoples, this transformation translates into the community having an expectation of increased life expectancy and a protracted dying trajectory to be the norm for the majority of individuals (AIHW, 2010; Payne et al., 2008). Individuals also have the expectation they will be the recipients of quality care at the end of life (Mallory, 2003; PCA, 2005a; Thompson et al., 2006)

2.2 The move to a palliative care approach

In response to concerns about the aggressive and cure orientated approach to care dying patients received in hospitals, the hospice movement emerged in the late 20th century to give back 'the dying' their role in society (Clark, 2004; Haley & Daley, 2008). Nurses were often at the forefront of these changes and believed the hospital system failed to adequately address the holistic needs of a dying individual (Haley & Daley, 2008). Initially the movement focussed principally on terminal care provided to dying patients from cancer provided in the last weeks and days of life (Becker, 2009a; Haley & Daley, 2008; Strazzari, 2005). Recently this focus has broadened to include all life limiting illnesses regardless of diagnosis, to commence at any point along the illness trajectory and for individualised care to be implemented to prevent and relieve suffering with the ultimate goal of enhancing an individual's quality of life (Becker, 2009a; Haley & Daley, 2008; Johnson et al., 2006; WHO, 2009). The continued provision of palliative care to only those with a cancer diagnosis, was seen as neither equitable nor sustainable by health service models (Auret, 2007; Yates, 2007). Acknowledgement that this was inequitable and unsustainable has led to palliative care embracing all life limiting illnesses, being implemented at any point along the disease trajectory and determined by patient need rather than prognosis (Fallon, 2004; Ferrell & Coyle, 2002; Johnston & Smith, 2006; Kellehear, 2001; Kurz & Hayes, 2006; Malloy, Virani, Kelly, Jacobs, & Ferrell, 2008; Strazzari, 2005). The implication of this expanded focus means the workforce needs to be skilled in the principles of palliative care across a range of health care settings (Bakitas, et al., 2010; Yates, 2007). Given nurses spend the most time with dying patients; several nursing authors advocate that it is a very high priority for the profession to develop a knowledgeable and skilled workforce (Ferrell, 2007; Kurz &

Kayes, 2006; Paice et al., 2007; Sherman et al., 2005; Thompson, 2005). Yates (2007) and others (Bakitas, et al., 2010; Kurz & Kayes, 2006; Mallory, 2003; Paice et al., 2007; Sheehan & Ferrell, 2010) argue this priority is best served through the provision of relevant education in undergraduate curriculum.

Several authors (Payne et al., 2008; Stjernswärd & Clark, 2004; Yates, 2007) recommend that at least 60% of all deaths would benefit from some level of palliative care intervention. This benefit is largely attributed to the emphasis palliative care places on quality of life through meeting an individual's physical, psychological, spiritual and social needs (Clark, 2004; Haley & Daley, 2008). For dying individuals this means they more actively determine how their death is managed, when acute interventions will be stopped and plan explicit goals to attain a comfort and quality of life (Haley & Daley, 2008; PCA, 2005b; Seale, 2000b). In acknowledgement of this shift in the provision of palliative care Australia, along with other developed countries, strives to embrace the adoption of fundamental principles in palliative care by all health professionals across a range of clinical settings (Becker, 2009b, 2009c; Ferrell, 2007; Palliative Care Curriculum for Undergraduates Project Team [PCC4U], 2005; Sheehan & Ferrell, 2010; Yates, 2007).

In Australia, integrating the fundamental principles and practices of palliative care into the health professional's everyday practice is named a 'palliative care approach' (PCC4U, 2005). This practice reflects the health professional providing uncomplicated, low to moderate complexity palliative care to a patient and their family (PCC4U, 2005; PCA, 2010; Payne, et al., 2008; V. Taylor, 2004; Yates, 2007). Frequently the terms end-of-life care, generalist or fundamental palliative care,

supportive care and terminal care are used interchangeably in the literature with a palliative care approach (Davis & Kuebler, 2007; PCA, 2010; Payne et al., 2008).

Several authors suggest palliative care principles can be embraced by all nurses into their everyday practice and that it is not the exclusive domain of specialist nurses, nor does it require highly complex medical interventions necessitating removal to a specialist unit (Becker, 2009a; Ferrell, 2007; Yates, 2007). Rather these authors advocate differing levels of practice can be instituted effectively by health professionals across a range of clinical settings for any life limiting illness, if relevant education is provided, preferably in a student's undergraduate program (Becker, 2009a; Sheehan & Ferrell, 2010; Yates, 2007) . This approach is predicated on the understanding that an individual's comfort and wellbeing are significantly increased when the principles and practices of a palliative care approach are applied to their care (Becker, 2009a,2009b; PCC4U, 2005; PCA, 2010; Sheehan & Ferrell, 2010).

If models of nursing care embed a palliative care approach into everyday practice, this changed provision of care has and will continue to exert unprecedented demand on all nurses in acute-care hospitals (Calder, 1998; Jodrell, 1998; McWhan, 1991; Paice et al., 2007; Sherman et al., 2005; Thompson, 2005; White, Coyne, & Patel, 2001). To carry out an expanded provision of palliative care necessitates nurses possessing the relevant attitudes, knowledge and skills to provide fundamental palliative care (Becker, 2009b; Ferrell, 2007; Yates, 2007). Alongside this unprecedented demand is the need for all undergraduate health professional programs (Cairns & Yates, 2003) and in particular nursing to include appropriate education experiences on death and dying to support the acquisition of these relevant attitudes, knowledge and skills

(Dixon, 2007; Downe-Wamboldt & Tamlyn, 1997; Ferrell, 2007; Quint, 1967). The literature suggests contemporary nursing practice incorporating a palliative care approach is beneficial to students and new graduates when it addresses issues of general care associated with a dying patient as well as emotional, psychological and spiritual care (Adriaansen & van Achterberg, 2008).

2.3 The nurse's role

With palliative care having expanded to include all life limiting illnesses across a range of clinical settings, an unprecedented demand now exists for all nurses to embed the fundamental aspects of palliative care into their everyday practice (Becker, 2009a, 2009b, 2009c; Boyle & Carter, 1998; Brisley & Wood, 2004; Coyle, 2010; Oermann & Garvin, 2002). Endorsement of this central role has been formally instituted by The International Council of Nurses [ICN, 1997]. The ICN (1997) see nurses as having a unique and primary responsibility to ensure individuals at the end of life experience a peaceful death. Globally, agreement exists that care of the dying patient is different from the care provided by nurses at other times in an individual's life (Becker, 2009b, 2009c; Jakobsson, Bergh, & Öhlén, 2007; Johnson & Bourgeois, 2003). Care of the dying patient is multidimensional involving the existential, physical, psychological, social and spiritual, dimensions of an individual (Becker, 2009b, 2009c; Haley & Daley, 2008; Johnston & Smith, 2006). This type of care requires the nurse to deliver holistic care. Holistic care is based on the nurse's commitment to have a presence, develop meaningful and sustainable relationships, build open and honest communication with the dying individual and their family, to foster trust and hope and provide comfort care (Becker, 2009b, 2009c; Haley & Daley, 2008; Johnston & Smith, 2006; Komaromy, 2008; Pearce & Lugton, 1999; V. Taylor,

2004; Zerwekh, 2006). Such care is underpinned by a sound knowledge and skill base informed by evidence based practice (Chang & Johnson, 2008). The delivery of such care supports, sustains and strengthens the individual in their suffering (Boyle & Carter, 1998; Komaromy, 2008; Pearce & Lugton, 1999; Zerwekh, 2006).

The vast majority of nurses in acute-care hospitals are more familiar and comfortable with curative interventions as compared to palliative care (Davies, 2005; Katz, 2008). For nurses to embed palliative care into their everyday practice, it is necessary to develop core attitudes, knowledge and skills (Becker, 2009b, 2009c; Boyle & Carter, 1998). This is borne out in the study by Jakobsson, et al. (2007) which examined the records of 229 adult patients who died in the Swedish public health care system. The content analysis of the record entries revealed nursing care to be mostly described in biomedical and factual orientated terms. Any reference to end-of-life care was broadly stated and vaguely described (Jakobsson, et al., 2007). The non-participant study by Pincombe et al. (2003) on 20 dying patients in eight medical and surgical wards in two acute-care Australian hospitals revealed that unless family members were present, care was associated with routine and technological care. While the observers reported this care to be of a high standard, they also indicated that the patient's individuality, personal circumstances and spiritual needs were frequently disregarded in favour of these more familiar care practices. Both studies conclude that the principles of palliative care are yet to be incorporated into the practice of nurses in acute-care hospitals. Studies by Jakobsson et al. (2007) and Pincombe et al. (2003) largely attributed this to the minimal education nurses received during their undergraduate program.

Many studies have continued to highlight that nurses in acute-care hospitals feel inadequately prepared by their initial nursing program to care for a dying patient and their family (Burton, 2007; Costello, 2006; Forest, 2004; Paice et al., 2007; Pincombe et al., 2003). These feelings stemmed from being challenged and confronted when they encountered dying patients and their families (Boyle & Carter, 1998; Burton, 2007; Costello, 2006; Forest, 2004; Paice et al., 2007; Pincombe et al., 2003; V. Taylor, 2004). Essentially the challenges and confrontation nurses face come principally from an inability to meet the needs of the dying patient and their family and their own self care (Boyle & Carter, 1998; Burton, 2007; Costello, 2006; Forest, 2004; Paice et al., 2007; Pincombe et al., 2003; V. Taylor, 2004). Many of these studies have continually recommended improvement to the education experiences students receive from their nursing program. Other studies suggest this education in palliative care should be continued once the student qualifies, as a means of sustaining and consolidating the knowledge and skills acquired initially, and as a means of promoting professional development (Jodrell, 1998; Sherman, et al., 2003; Yates, 2007).

2.3.1 Care of the dying is a stressful clinical encounter

Generally nursing is described as an occupation which experiences high levels of stress and anxiety, (see for instance Brisley & Wood, 2004; Bryant, Fairbrother, & Fenton, 2003; Chang et al., 2007; Healy & McKay, 1999; Lambert & Lambert, 2001). In many countries, caring for dying patients and their families continues to be identified by nurses as one of the top sources of stress they encounter in their daily practice (Brisley & Wood, 2004; Chang, et al., 2007; Copp, 1999; Bryant et al., 2003; Healy & McKay, 1999; Hipwell, Tyler & Wilson, 1989; Huntington, et al., 2008; Lambert, et al., 2004; Oermann & Garvin, 2002; Tyler & Cushway, 1992). This is

largely due to nurses having a sustained and intimate relationship with patients and their families; being present with people who are physically, psychologically and or spiritually distressed and being with individuals who are wrestling with questions of meaning (Dunn, et al., 2005; Ellershaw & Ward, 2003; Hurting & Stewin, 1990; Wong & Lee, 2000).

Quint's (1967) seminal study first identified nursing students were emotionally affected and stressed by encounters with dying patients. Her study revealed two key findings. Firstly, nursing students had higher anxiety levels as a consequence to exposure with a dying patient and secondly participation in the delivery of care was one of the most uncomfortable and emotionally disturbing aspects they reported in their work. Nursing students have continued to report caring for dying patients as one of the highest sources of stress they experience when undertaking clinical placement in their program (Clarke & Ruffin, 1992; Lindrop, 1991; Rhead, 1995; Timmins & Kaliszer, 2002). The reason most frequently cited by students and nurses is the inadequate education they received from their nursing program on death and dying (Brisley & Wood, 2004; Boyle and Carter, 1998; Quint, 1967). Nyatanaga and de Vocht (2006) suggest being exposed to professional deaths is a significant trigger to causing death anxiety in nurses and warrants instituting appropriate education and support.

Nyatanga and de Vocht (2006) postulate that for anxiety to arise we must first feel fear which causes feelings of uncertainty and insecurity. In turn these feelings, according to Brisley and Wood (2004), reflect an internalisation of the stress encountered by nurses which impacts upon them physically, psychologically, socially

and spiritually. In western society stress and death anxiety are seen as complex entities that represent the interplay between socio-cultural aspects, individual perception, interaction with the environment and past experiences (Boyle & Carter, 1998). In this thesis the terms anxiety and stress are therefore used interchangeably.

The need to deliver fundamental palliative care in an acute-care hospital setting exposes nurses to multiple sources of stress and personal fears. This includes not only having more frequent exposure to death but providing palliative care in an environment which competes with high acuity care and often lacks suitable staffing numbers to adequately implement. This care may further impede the nurse's capacity to manage all of the competing stressors with the resilience required to maintain their own well-being. As a consequence when an individual's stress exceeds their capacity to cope it interferes with an individual's capacity to learn (Gaberson & Oermann, 1999). Many new graduate nurses may experience additional stress as a consequence to the role transition from student to registered nurse.

The Chang et al. (2007) survey study of Australian ($n=328$) and New Zealand ($n = 190$) nurses demonstrated stress is well known to adversely affect a nurses' physical and in particular mental health. A nurses' expression of stress is varied when caring for a dying patient and may be displayed for example as tiredness, frustration, feeling strained, lack of sleep, dreaming and feelings of helplessness (Wilkes, 1999). If a nurse feels personally inadequate this is also recognised as potentiating the nurse's stress (Aranda, 2008). The presence of other stressors compounds the level of stress nurses experience in attempting to implement a palliative care approach in an acute-care hospital. While holistic care is well understood by many nurses in acute-care

hospitals, it constantly competes with curative care (Aranda, 2008; Becker, 2009c; V. Taylor, 2004; Vachon & Huggard, 2010). Limited palliative care resources and support further impede implementation causing competing priorities and tension to arise in the nurse's everyday practice (Becker, 2009c). Ultimately this leads to a burdensome, chaotic and stressful workplace (Becker, 2009c; Bradley et al., 2001; Imhof, 2005; Kwekkeboom et al., 2005; McWhan, 1991).

Nurse's stress is further magnified when incongruence arises between value systems (Chang & Hancock, 2003). There is a high likelihood of incongruence in caring for the dying because of the interplay between the value systems of the nurse, patient and family. Conflict may arise because an individual's notion of death and the nurse's perception of what constitutes an ideal death may differ (Quint, 1967; Wilkes, 1999). Dissonance may also exist in the workplace when other nurses hold differing values of death are therefore at odds with their colleagues (Aranda, 2008). Furthermore, when a nurse's individual values and coping mechanisms are not congruent with the ward's culture this is likely to result in the nurse being punished in the form of occupational isolation and peer condemnation (Boyle & Carter, 1998). Such behaviour is known to increase the emotional distress the nurse experiences at this time (Quint, 1967).

Nurses stress levels are compounded by the degree of death anxiety they hold. According to Neimeyer (1994) death anxiety stems from multiple components including anticipating one's own death; fear of the dying process and fearing the death of significant others. It is highly probable therefore that these aspects give rise to anticipated and perceived anxiety in nursing students when they encounter

professional patient deaths (Evans & Kelly, 2004; Neimeyer, 1994). Nurses demonstrate the presence of death anxiety by: an attitude of death denial; fear of self and others deaths; avoidance of death, a reluctance to interact with a dying person and repression (Boyle & Carter, 1998; Neimeyer, 1994; Nyatanga & de Vocht, 2006). This in turn affects their performance either overtly or covertly as evidenced by distorted problem-solving and thought patterns and an inability to function effectively (Boyle & Carter, 1998).

Furthermore death anxiety causes negative attitudes and behaviours to be present (Boyle & Carter, 1998). Commonly these are exhibited by: withdrawal from the source of the stress (Boyle & Carter, 1998; Wakefield, 2000); distancing themselves from the dying and their family (Boyle & Carter, 1998; Brisley & Wood, 2004; Payne, Dean & Kalus, 1998; Wakefield, 2000); using avoidance coping strategies (Neimeyer, 1994); ineffective delivery of palliative care (Evans & Kelly, 2004); withholding information (Evans & Kelly, 2004); suppression of feelings (Wakefield, 2000) and focussing only on the physical or biomedical needs of the dying patient (Brisley & Wood, 2004; Payne et al., 1998). Several reasons are given for the heightened presence of death anxiety in nurses: minimal theoretical preparation (Beck, 1997; Quint, 1967); the limited personal exposure to death students experience prior to entering their nursing program (Chambers & Haughey, 1993) and little or no support from ward staff or their clinical facilitators at the time or following a patient's death (Mallory, 2003).

The personal background and experiences an individual enters a nursing program with also influences the nature and degree of stress and death anxiety they experience and

their capacity to cope (G.R. Johnson, 1994). A nurse's personality, life experiences, age, religion (Boyle & Carter, 1998) and previous ways of coping with life events (Vachon & Huggard, 2010) are significant determinants of the nurse's level of stress and death anxiety. The level of stress and death anxiety assigned by the nurse when encountering a dying patient is therefore a direct reflection of the individual nurse's interpretation of this life experience (Ogden, 2000).

Quint's (1967) study was the first to identify that little attention was afforded by undergraduate nursing programs to prepare nurses to cope with this emotionally challenging practice. Burney-Banfield's (1994) study further highlighted the paucity of hours and content dedicated to students' behavioural, cognitive and emotional reactions and development of coping strategies. Boyle and Carter (1998) advocate nurse education has an important role to play in adequately preparing nurses by developing relevant coping mechanisms and instituting appropriate support to ameliorate role stress and death anxiety. Vachon & Huggard (2010) believe without adequate education and supervision nurses have difficulty in functioning and assuming the responsibilities associated with caring for dying patients.

2.4 Educational preparation of the nurse

In this section of the literature review a discussion is presented on the two perspectives investigated when researching the total experience of caring for a dying patient. The first section presents a discussion on the studies which have examined education on death and dying in undergraduate nursing curricula. This is followed by a discussion on studies which have been undertaken to explore student and new graduate nurses' experience of caring for dying patients in acute-care hospitals.

2.4.1 Education on death and dying in nursing curricula

The first study to determine the extent and nature of education on death and dying in undergraduate nursing curricula was conducted by Quint and Strauss (1964) in the USA. This first survey indicated that only a minimal amount of attention was provided to education on death and dying. Since then several more studies have been undertaken in Canada (Coty & Downe-Wamboldt, 1983; Downe-Wamboldt & Tamlyn, 1997), UK (Dickinson, Clark & Sque, 2008; Field & Kitson, 1986; Lloyd-Williams & Field, 2002) and USA (Coolican, Stark, Doka, & Corr, 1994; Dickinson, 2006; Dickinson, 2007; Thrush, Paulus, & Thrush, 1979). The only Australian study conducted was Burney-Banfield's in 1994. The results of these studies suggest there is a paucity of education provided to students in their nursing programs on death and dying. Furthermore these results strongly suggest that what is presented is inconsistent making a graduate's capacity to function in the clinical setting variable. No agreement was identified by these studies as to what constituted the core attitudes, knowledge and skills required of a graduate to deliver optimal care to the dying. Collectively the study results showed nursing curricula used an integrated approach to present teaching content while a few programs offered an elective only; minimal teaching hours were allocated; content was primarily presented in a didactic format; evaluation of learning activities was limited or non-existent; clinical placements were unsystematically allocated; clinical educators and ward staff received negligible preparation to support students; support mechanisms for students had a nominal presence if at all (Burney-Banfield, 1994; Coty & Downe-Wamboldt, 1983; Coolican et al., 1994; Dickinson, 2006; Dickinson et al., 2008; Downe-Wamboldt & Tamlyn, 1997; Field & Kitson, 1986; Lloyd-Williams & Field, 2002; Quint, 1967; Quint & Strauss, 1964; Thrush et al., 1979).

Recent studies have shown evidence of some changes to nursing curricula being initiated to strengthen the education experiences students receive from their initial nursing program (Dickinson, 2006; Dickinson, 2007; Dickinson et al., 2008) but a general reluctance by curriculum designers to incorporate adequate educational experiences on death and dying remains in nursing programs. In the past this has largely been attributed to: curriculum designers failing to develop curricula cognisant of current population need; nurse academics being generally uncomfortable with this topic area; staff not well skilled to teach in this area; an already overcrowded curriculum limiting the opportunity for discussion and self-reflection and a continued orientation on curative care dominating curriculum development (Burney-Banfield, 1994; Quint, 1967).

To date, only two studies (Burney-Banfield, 1994; PCC4U, 2005) have been conducted investigating education on death and dying in Australian undergraduate nursing curricula. The study conducted by Burney-Banfield (1994) investigated whether coping mechanisms were taught and the pedagogy used to teach them. No other aspects of curriculum design were examined. The limited focus of this study does not provide sufficient insights into the relative adequacy of the curricula to prepare Australian nurses for the practice of caring for a dying patient. More recently a scoping survey was conducted on all Australian undergraduate health professionals curricula (PCC4U, 2005). The majority of data reported is in an aggregate form and determining the specifics in relation to undergraduate nursing curricula are limited. In general, this study confirmed little penetration of a palliative care approach across undergraduate health professional's curricula. These two Australian studies report

similar results to those identified in the international literature (Burney-Banfield, 1994; PCC4U, 2005).

No studies were identified by the literature review which specifically investigated education on death and dying in transition program curricula. As a result a determination as to what is offered by hospital new graduate programs on death and dying is unknown.

2.5 The nurses' experience of caring for the dying

The first study to explore nurses' experience of caring for a dying patient and their family was reported by Quint and Strauss (1964). They interviewed newly graduated nurses about their experience as a student and their instructors from five schools of nursing in San Francisco and Oakland in California. Quint and Strauss wanted to understand what customs, beliefs and practices were taught about death in preparing students for these encounters. Apart from reporting the number of nursing schools involved, the study does not report the number of participants or identify how long after completing their program the new graduate participants were interviewed.

Quint and Strauss's (1964) findings provided the first evidence that the educational preparation nurses received from their initial program was insufficient to adequately prepare them for practice. In particular, Quint and Strauss found little evidence of content dedicated specifically to death and dying present in the curricula of the five nursing schools studied. When teaching did occur it was related specifically to terminal care, that is, the care which immediately precedes and follows death. Other contributing aspects highlighted were the minimal attention afforded to this learning as

a planned student experience and almost no acknowledgement of the need for dialogue and skill development to take place to support the nurse's coping in this highly emotional encounter (Quint & Strauss, 1964). Quint and Strauss concluded that a significant problem in nursing curricula design existed which led to the inadequate preparation of nurses to practice caring for a dying patient and their family.

Quint (1967) subsequently undertook further analysis of the data by comparing the curricula and participant interviews from the university school against curricula and interview data from the four hospital schools. The impetus for this comparison stemmed from her speculation about the relationship between what is expected of nurses when they work with dying patients in hospitals and their educational experiences as students (Quint, 1967). Quint found that the university school's curriculum had a heavy emphasis on the interpersonal aspects of nursing, as compared to the hospital nursing schools. From the university school participant interviews, she believed degree educated nurses were more acutely aware of the emotional needs of their dying patients and as a consequence their encounter with the dying had a larger impact on them as compared to the nurses from the hospital based curricula (Quint, 1967). This further analysis reaffirmed the initial conclusion previously reached by Quint and Strauss (1964).

2.5.1 Undergraduate nurses experience

Following the studies by Quint and Strauss (1964) and Quint (1967) a further seven studies have been conducted on the student's experience of caring for a dying patient (Allchin, 2006; Beck, 1997; Cooper & Barnett, 2005; G.R. Johnson, 1994; Kelly, 1999; Loftus, 1998; Van Rooyen et al., 2005). From the time of the seminal work, it has taken over 35 years before further research was conducted signifying the

relatively low importance educators of nurses attribute to this area of curriculum design. Three studies were conducted in the UK (Cooper & Barnett, 2005; G.R. Johnson, 1994; Loftus, 1998), three in USA (Allchin, 2006; Beck, 1997; Kelly, 1999) and one study from South Africa (Van Rooyen et al., 2005). All seven studies used a single paradigm of inquiry, namely qualitative. The transferability of the study findings while having similarities would need to be considered cautiously in light of the lack of transferability from one socio-cultural context to the other. No studies were identified from the Australian context, eastern cultures or developing countries. Of the seven studies conducted, only one study sought to access the nurse's first experience of caring for a dying patient (Kelly, 1999). Kelly (1999) limited the participant's recount to focus on their first encounter with a dying patient. This approach supports Quint's (1967) belief that the nurse's initial encounter with the dying is the most influential in forming future attitudes, behaviours and values displayed in any future encounters. In taking this approach Kelly (1999) also acknowledged the potential gain further exposure to dying patients contributes to the interpretation and understandings of the experience. The mixing of first and subsequent experiences during data collection may have led to findings in other studies where all of the nursing students needs were not captured. It is possible that some needs may have been abated as the nurse encountered subsequent experiences with dying patients. The remaining studies (Allchin, 2006; Beck, 1997; Cooper & Barnett, 2005; G.R. Johnson, 1994; Loftus, 1998; Van Rooyen, 2005) recounted a mixture of initial and subsequent exposures to care of the dying.

Phenomenology was the most common methodology selected by the majority of studies (Allchin, 2006; Beck, 1997; G.R. Johnson, 1994; Kelly, 1999; Loftus, 1998;

Van Rooyen et al., 2005). Of these studies Allchin (2006) specified hermeneutic phenomenology was used to conduct her study. The remaining study by Cooper and Barnett (2005) employed a broad qualitative framework. Irrespective of the particular approach used the qualitative mode of inquiry enabled the study participants to tell their stories by describing in detail their experience of caring for a dying patient in the socio-cultural context in which it occurred. The origin of the participants' experiences, were all generated from caring for an adult dying patient in general wards or units in acute-care hospitals. Experiences in specialised palliative care wards or units were excluded.

Data collection methods consisted of individual interviews (Allchin, 2006; Kelly, 1999; Loftus, 1998; Van Rooyen et al., 2005), writing a narrative (Beck, 1997), focus groups (G.R. Johnson, 1994) or the involvement of more than one method as used by Cooper and Barnett's study where method triangulation was used involving reflective dairies, interviews and focus groups. All studies (Allchin, 2006; Beck, 1997; Cooper & Barnett, 2005; G.R. Johnson, 1994; Kelly, 1999; Loftus, 1998; Van Rooyen et al., 2005) collected the participants' data at a single interval of time. None of the previously conducted studies followed their participants longitudinally either across their education programs or during their transition from student to new graduate nurse. Furthermore the findings of the studies were interpreted in isolation from the curricula documenting the specific education on death and dying the participants received at the time of their interviews.

Data analysis was informed by a number of approaches used across the studies to reveal the underlying meaning of the experience of caring for a dying patient. Three

studies chose the method by Giorgi (Allchin, 2006; Kelly, 1999; G.R. Johnson 1994); two studies selected Collaizzi (Beck 1997; Cooper & Barnett, 2005), Van Rooyen et al. (2005) employed Tesch's method, and Loftus, (1998) employed van Manen's method. Regardless of the data analysis method chosen the seven studies (Allchin, 2006; Beck, 1997; Cooper & Barnett, 2005; G.R. Johnson, 1994; Kelly, 1999; Loftus, 1998; Van Rooyen et al., 2005) generated themes to establish what it means to care for a dying patient. A range of data analysis methods are available in the conduct of phenomenology research that lead to the uncovering of themes to aid interpretation and understanding (O'Brien, 2003).

Most of these studies (Allchin, 2006; Cooper & Barnett, 2005; G.R. Johnson, 1994; Van Rooyen et al., 2005) recruited participants from a single education provider. It is likely these participants were exposed to a single curriculum during the conduct of the study thereby aiding reliability of the findings. The study by Kelly (1999) accessed three schools of nursing and while not stated it may be inferred that potentially not all participants were educated by the same curriculum. Loftus's (1998) study provides insufficient information to draw a conclusion about the number of education providers involved in her study.

Participant numbers ranged from 5-11 consistent with a qualitative approach where small numbers are used until such time as data saturation is achieved (O'Brien, 2003). Larger participant numbers ($n = 38$) were initially reported by Cooper & Barnett (2005) but these figures were pared down to 11 following analysis of the reflective journal in which only 11 out of the 25 participants who used the reflective diary volunteered to take part in the focus group interview.

The stage of the program in which data collection took place varied. Only Cooper and Barnett's (2005) study selected first year students based on the rationale they were more likely to have encountered death as a relatively new experience. With no justification for the selection made other studies collected data in the third year of the student's program (Loftus, 1998), second year (Van Rooyen et al., 2005) while Kelly's (1999) study accessed all years of a four year program. The studies by Allchin, (2006), Beck (1997) and G.R. Johnson (1994) do not report the stage of program in which data was collected.

The majority of studies conducted had only female study participants included (Allchin, 2006; G.R. Johnson, 1994; Kelly, 1999; Loftus, 1998; Van Rooyen et al., 2005). The study by Van Rooyen et al. (2005) does state an attempt was made to recruit male participants however this was unsuccessful. The study by Loftus (1998) is also suggestive of participants being female as the cited exemplars have only female names attached. The gender breakdown of her participant cohort is not specified. Interpretation of the findings therefore were female centric. The studies are potentially limited as they do not acknowledge that bereavement and grief reactions may differ between genders which may have had an impact on the participant's capacity to care for a dying patient. Studies therefore involving male participants have the potential to identify different themes. Beck's (1997) study was the only study to comprise female and male participants.

Both genders are important in researching the experience of caring for a dying patient as they reflect the reality of the nursing profession's workforce (AIHW, 2007). In recognising that male numbers are generally lower in nursing workforces, their

inclusion however gives a more realistic representation of the 'real world' of nursing in developed countries. The findings reported by Beck (1997) can be considered to be more holistic and offer greater insights into the total experience encountered by nursing students caring for the dying. By contrast those studies (Allchin, 2006; G.R. Johnson, 1994; Kelly, 1999; Loftus, 1998; Van Rooyen et al., 2005) using only female participants had the potential for bias as the experience was taken only from female nursing students' perspectives. However it could be argued that as females represent the largest proportion of the nursing workforce that they hold the dominant view in the experience of caring for the dying. For this reason some justification surrounding the lack of recruitment of male participants to their studies or conducting studies with only female participants could be made. The Cooper and Barnett (2005) study did not report the gender split of their participants.

The key finding common to all seven studies was, that caring for a dying patient is both a challenging and emotionally disturbing clinical encounter for students of nursing (Allchin, 2006; Beck, 1997; Cooper & Barnett, 2005; G.R. Johnson, 1994; Kelly, 1999; Loftus, 1998; Van Rooyen et al., 2005). This key finding further validates Quint's (1967) original conclusion. The underlying premise of this central finding continues to be based on participants identifying that their initial nursing program failed to prepare them adequately to carry out the role of caring for an adult dying patient in an acute-care hospital (Allchin, 2006; Beck, 1997; Cooper & Barnett, 2005; G.R. Johnson, 1994; Kelly, 1999; Loftus, 1998; Quint, 1967; Quint & Strauss, 1964; Van Rooyen et al., 2005).

Researchers continue to report this central finding yet evidence exists which shows that the nurse's role in care of the dying has also expanded necessitating additional knowledge and skills to carry out this contemporary practice (Copp, 1994; Oermann & Gavin, 2002). This is despite the increasing expectation that nurses will provide care to the dying patients in acute-care hospitals (Adriaansen & van Achterberg, 2008; Kwekkeboom, et al., 2005; Paice, et al., 2007; Sherman, et al., 2005). However their educational preparation remains unaligned to meet these needs (Adriaansen & van Achterberg, 2008; Glen & Clark, 1999; Mallory, 2003). The level of importance expressed by students and new graduate nurses has not been universally ascribed to by schools of nursing in developing curricula to support care of the dying patient more explicitly (Ferrell, Virani, Grant, Coyne & Uman, 2000), though some reversal to this trend is slowly occurring (Clark & Holmes, 2006; Mallory, 2003).

2.5.2 New graduate nurses' experience

A number of studies have reported that new graduate nurses frequently identify caring for a dying patient to be one of the most common practises they feel least equipped to deal with by their initial education program (Brisley & Wood, 2004; Ferguson & Mabgood, 2007; Hopkinson, 2001; Hopkinson, Hallet & Luker, 2003; Maben & Macleod Clark, 1998; O'Shea & Kelly, 2007). Each of these studies was conducted in western developed countries. Brisley and Wood's (2004) study demonstrated that nurses could not recall clearly the details of how their initial nursing program supported them in this area. An Australian study surveyed both new graduate nurses and registered nurses with three to five years experience (Boxer, Fallon, & Samuelson, 2001) to determine the relative importance of 60 clinical skills using a Likert scale. A 52.7% response rate were returned from new graduates and 67% from registered nurses (Boxer et al., 2001). Supporting a grieving family was rated as a

highly critical skill by 93% of registered nurses and 91% of new graduates (Boxer et al., 2001). Qualification as to why this skill was so highly rated was undertaken by interview with the reason being the need to perform this skill every day (Boxer et al., 2001). The study by Ferrell et al. (2000) showed 89.5% of qualified nurses believed end-of-life content was an important inclusion in nurses' initial education programs. In contrast, a survey study by Tan et al., (2006) of Singaporean nurses shows a different finding. In their study a 73% response rate was achieved. The results found most nurses never or only occasionally felt uncomfortable caring for dying patients while 83% never or only occasionally felt helpless in caring for a dying patient (Tan et al., 2006). These results provide contradictory evidence to previously cited studies. This may be the result of differences in the nature of the education program and the socio-cultural beliefs and practices held about death in Singapore.

It is well documented that new graduates generally feel unprepared to assume the challenges and responsibilities of being a registered nurse (Brisley & Wood, 2004; Chang & Daly, 2008; Clare & van Loon, 2003; Clark & Holmes, 2006; Gerrish, 2000; Hopkinson, 2001; Hopkinson et al., 2003; Johnstone, Kanitskai, & Currie, 2008; Mooney, 2007a, 2007b; Newton & McKenna, 2007; O'Shea & Kelly, 2007; Ross & Clifford, 2002; Zerwekh & Claborn, 2006). Feelings of personal inadequacy stemming from caring for a dying patient compound the nurse's stress in the role transition between student and new graduate (Brisley & Wood, 2004; Chang & Hancock, 2003). Examples of practice issues frequently highlighted by new graduates contributing to their stress were: communicating with dying patients and relatives (Hopkinson, 2001; Maben & Macleod Clark, 1998); difficulties when providing direct care to dying patients (Hopkinson et al., 2003; Maben & Macleod Clark, 1998) and dealing with death

and dying as a traumatic encounter (Hopkinson, 2001; Hopkinson et al., 2005; O'Shea & Kelly, 2007).

A lack of information on new graduate programs impedes knowing how these transition programs can better support new graduates in assuming the roles and responsibilities and warrants further investigation. Specific detail on death and dying content and strategies related to care of the dying patient in new graduate programs was not available.

Ferguson and Mabgood's (2007) study recommended the need for continued professional development in care of the dying subsequent to a nurse's initial education program however no insights from the study's new graduate program into the specific education on death and dying provided were identified.

In their descriptive correlational design study Ferguson and Mabgood (2007) gathered data at four time periods over the course of the participants first year of practice at a large Australian teaching hospital. A revised Casey-Fink Graduate Nurse Experience Survey tool (2004) modified to the Australian context was used to obtain this data. New graduates in this recent Australian hospital transition program reported care of the dying as the most commonly recurring and persistent skill that caused participants concern (Ferguson & Mabgood, 2007). Of greater importance was the finding that at the end of the fourth survey round, participants were about to exit their new graduate program, but continued to report considerable evidence of discomfort when caring for dying patients (Ferguson & Mabgood, 2007).

These studies have shown repeatedly that nurses feel personally inadequate to care for the dying and attribute this to their initial education program. Verification of the need

for curricula to be re-designed incorporating more relevant educational experiences on death and dying is raised in several studies with students (Allchin, 2006; Beck, 1997; Cooper & Barnett, 2005; Kelly, 1999; Kiger, 1994; Loftus, 1998; G.R. Johnson, 1994; Quint, 1967; Van Rooyen et al., 2005) and new graduate nurses (Brisley & Wood, 2004; Ferguson & Mabgood, 2006; Gerrish, 2000; Hopkinson, 2001; Hopkinson, et al, 2003, 2005; Maben & Macleod Clark, 1998; O'Shea & Kelly, 2007). Studies have also demonstrated more experienced nurses hold this perception of being inadequately prepared by their initial nursing program on death and dying several years after graduating from their nursing program or moving into more specialised areas of practice (Costello, 2006; Field, 1984; Dunn et al., 2005; Ferrell, Grant & Virani, 1999; Ferrell, et al., 2000; Pimple, Schmidt, & Tidwell, 2003; Rittman, et al., 1997)

2.6 Gaps in the research

The reviewed literature showed minimal emphasis has been given to education on death and dying in undergraduate nursing curricula to adequately support students' experience of caring for adult dying patients and their families in acute-care hospitals. The findings from the reviewed studies investigating student, new graduate and more experienced nursing staff experiences revealed how inadequately prepared these participants felt by their nursing programs to embed the principles of palliative care into their practise.

The previously conducted international studies have investigated the experience of caring for a dying patient and their family using a single mode of inquiry, namely qualitative. Studies using a mixed method design have not been previously undertaken. Mixed method designs can facilitate a more complete, holistic and therefore comprehensive understanding of the issue. Using a different methodological

approach enhances the possibility of generating new findings to be contributed to the current field of knowledge. Incorporating two-phases, quantitative followed by qualitative, into the study design enabled access to the overall educational context in existence at the time the participant interviews were held. Previously conducted studies had only ever examined curricula and the student's experience as separate entities. A flaw with these single paradigm studies is that they have failed to link the student's experience with the curricula which prepares them for this practice. A mixed method design enabled understanding and insights into the relationship between experience and education to be captured in the one study. Of importance to this study was that while previously conducted international studies had explored undergraduate nursing curricula extensively, only one Australian study with limited outcomes was in existence, at the time this mixed method research was conducted.

The inclusion of a longitudinal element incorporated into the study design offered an innovative approach previously not undertaken. The inclusion of the longitudinal element enabled the same study cohort to be followed up at two time intervals. This element provided the opportunity to examine the same phenomenon at different times in the participant's professional life. The anticipated benefit of this inclusion was to determine if the experience changed over time by gaining insights into whether time or multiple encounters of the experience or both affect the participant's interpretation of the experience. A second interview provided the opportunity to re-examine and probe the participant's reflection on their first experience in light of subsequent experiences in their new graduate role. This approach allowed a deeper understanding to be gained than compared to if the experience was accessed only once. Previous studies had not addressed the experience in this way.

In the absence of any Australian studies, this study sought to understand what it means to Australian students and new graduate nurses to care for an adult dying patient and their family in an acute-care hospital. This study builds on previously published work by contributing the first Australian findings on this topic.

2.7 Conclusion

This chapter has discussed the influences which shape a nurse's perception of caring for a dying patient and their family in an acute-care hospital. As part of this discussion, studies which have examined the provision of education on death and dying in undergraduate nursing curricula were presented. This was followed by a discussion on the international studies, previously conducted, which investigated student and new graduate nurse's experience of caring for adult dying patients. The final section of this literature review highlighted the research gaps on this issue, particularly the paucity of Australian studies and demonstrated the need to use an innovative methodological approach to potentiate the discovery of new findings.

The following chapter presents a description of the two-phase mixed method study design used to conduct this research. An overview and rationale for a selecting mixed method study design is provided. The specific type of mixed method study design is explained and elaborated upon. A brief description of phase one and two of the study is also presented.

CHAPTER 3

METHODOLOGY

This chapter describes the methodological approach and methods used to address the aim of this research study. The chapter gives an overview of mixed method design and its application to this study and includes the rationale for selecting mixed method. The two phases of this study and the data collection methods used are briefly described. Details of the specific methodology and methods used in phase one of the study are located in chapter 4. Chapter 5 presents the specific methodology and methods used in phase two of the study. The final section of this chapter outlines the ethical considerations of the study and how they were addressed.

3.1 Aim

This study aimed to understand what it meant to Australian students and new graduate nurses to care for an adult dying patient and their family in an acute-care hospital. The phenomenon necessitated investigation holistically to achieve a more complete and deeper understanding of this complex and multidimensional experience. No international or Australian studies had been conducted in this manner previously. Understanding the context in which this experience occurred meant an exploration of the current curricula practices undergraduate nursing programs use to provide education on death and dying was necessary. Evidence gained from this study enabled the subsequent investigation of the student and new graduate nurse's experience to be conducted in a more informed and meaningful manner.

The specific aims of this study were to:

(1) describe the current curriculum practices Australian undergraduate nursing programs use to provide education on death and dying.

(2) understand students' and new graduate nurses' experience of caring for an adult dying patient and their family in an acute-care hospital.

3.2. Research Design

A two-phase, sequential explanatory mixed method design incorporating a longitudinal element was chosen to conduct this study. The phenomenon of caring for an adult dying patient and their family is a multilayered, multidimensional experience involving many complexities (Stephenson & Corben, 1997; Whitehead, 2007a). Acknowledgement is also made that the experience of caring for a dying patient comprises both educational and practice perspectives. To ensure both these perspectives are understood as part of the total experience necessitates a holistic investigation of the phenomenon. Understanding this experience more completely allows nursing knowledge to be built in a deeper and more meaningful manner (Greene, 2008; Sosulski & Lawrence, 2008). Investigating this experience required a methodology capable of examining the phenomenon from multiple perspectives by simultaneously asking questions on 'what is happening' and 'how' or 'why' it is happening.

A mixed method design provided the capacity for both the epistemological and ontological questions raised by this study to be addressed in a single study (Kroll & Neri, 2009; Moule & Goodman, 2009). This study offered for the first time an opportunity to gain an expanded understanding of the phenomenon with potential for new insights that provide direction for action and change (Sosulski & Lawrence, 2008). These new insights had potential to 'value add' to the already accumulated knowledge in this field, rather than just re-confirm previous findings (Kroll & Neri,

2009). A mixed method design therefore provided this study with an overall structure to facilitate integration of more than one paradigm and multiple data collection methods into a cohesive and coherent manner in a single study (Kroll & Neri, 2009; Tashakkori & Creswell, 2007).

This mixed method study consisted of two sequentially conducted studies. Each study was named as phase one or two respectively. Phase one of the study was framed by the quantitative paradigm and undertaken prior to the phase two qualitative investigation. Phase one of the study used survey method to gather preliminary data to describe the current curriculum practices undergraduate nursing programs used to provide education on death and dying. This supported the development, implementation and interpretation of the phase two qualitative study. When a quantitative study is conducted first and its purpose is to inform a qualitative investigation it is named sequential explanatory (Kroll & Neri, 2009). The basis for this implementation sequence was made on the need to firstly understand the educational context which prepared students and new graduate nurses to care for dying patients and their families. The phase one study results informed the development of the phase two interview questions and assisted with the interpretation of the key findings. Obtaining results and findings from multiple perspectives in a single study provides stronger evidence for a conclusion through convergence and corroboration of findings which enhance the study's reliability and validity (Johnson & Onwuegbuzie, 2004; Moule & Goodman, 2009).

Phase two of the study was framed by the qualitative paradigm using phenomenological interviews, informed by van Manen (1990). Phenomenological

interviews enabled access to the participant's interpretation of the experience and what this meant to them caring for dying patients and their families in an acute-care hospital. Using interviews helped to overcome the limitations of survey method by obtaining a greater depth of understanding, improving the study's reliability and strengthening the overall conclusions (Whitehead & Elliot, 2007). This phase also included a longitudinal element. Participants were interviewed as final semester nursing students and then followed up approximately 12-18 months later on completion of a hospital new graduate program. The inclusion of the longitudinal element into this study design was intended to determine whether time and further exposure to encounters with dying patients made a difference to the participant's experience. Investigation of the phenomenon in this way enabled the researcher to gain a deeper and more complete understanding of this experience, a dimension not captured by previous studies.

3.3 Data Collection Methods

Two data collection methods were used in this study. Phase one of the study was conducted using survey method. Phase two of the study was undertaken using phenomenological interviews, informed by van Manen (1990). The following section of this chapter presents a brief outline of the data collection methods chosen for this mixed method study.

3.3.1 Phase One: Survey method

The most appropriate data collection method to describe the current curriculum practices Australian undergraduate nursing programs used to provide education on death and dying was survey. The choice of survey method was based on the need to access information from Australian undergraduate nursing programs

geographically spread across six states and two territories. In this context, survey method was considered the most time and cost efficient way to retrieve data in a systematic and consistent manner from a large geographical area. Descriptive statistics were employed to analyse the data. The preliminary data described the characteristics of the research context, assisted in the development of the phase two interview questions, aided in the interpretation of the qualitative data and contributed to the discussion of the study's key findings. A comprehensive discussion of the descriptive survey used in phase one of the study (and detailing aspects of the method and the results) is located in chapter four.

3.3.2 Phase Two: Phenomenological interviews

Phenomenological interviews were held with final semester students and new graduate nurses. This method was used because it allowed access to the student and new graduate nurse's experience of caring for dying patients and their families in an acute-care hospital. Specifically van Manen's (1990) hermeneutic phenomenological approach was used to enable both epistemological and ontological aspects of the experience to be revealed. Van Manen's approach is attentive to both the descriptive and interpretative aspects of the experience and was considered the best means by which to achieve a more complete answer to the research question than could be offered by other methodology. Interviews enabled the contextual characteristics of the research issue to be elicited, thus illuminating meanings behind the survey data, generating deeper understandings and demonstrating relationships inherent between a nurse's educational preparation and maturation of practice over time. The methodology and method used to conduct phase two of the study are presented in more detail in chapter five. The findings generated from this study are located in

chapter six. Chapter seven presents a discussion on the major findings which emerged from this two-phase mixed method study.

3.4 Ethical Considerations

This study was conducted in accordance with the principles of ethical conduct outlined by the National Statement on Ethical Conduct in Research Involving Humans (1999). In Australia, this is legislated by the National Health and Medical Research Council [NHMRC], the statutory body responsible for issuing guidelines on and advising the community on ethical issues relating to health (Coup & Schneider, 2007). Ethical approval was granted by the University of Western Sydney Human Research Ethics Panel prior to the commencement of recruitment and data collection. The approval number for this study was HREC 00.33. The following is a discussion of the ethical principles as they applied to the survey, the interview methods used and an overall statement on how data management was addressed in this study.

3.4.1 Informed Consent

In the phase one descriptive survey study informed consent was implied and gained on two levels. The survey was accompanied by a cover letter which informed potential respondents of the study's aims, the benefits to be gained and an outline of study requirements (Appendix 1). Firstly, if the Deans (or their equivalent) invited to participate in the study referred the survey onto a nominated staff member for completion this implied a willingness to commit the organisation to the study. Secondly, consent was implied if the nominated staff member completed and returned the survey to the researcher. In survey research this practice is the norm as obtaining written consent is not usually possible (Polit & Beck, 2010).

Before the phase two interviews were conducted several strategies were implemented to inform potential participants about the study and to support them making an informed decision about whether to participate or not. An information session for potential participants was conducted by an intermediary. The decision to undertake this approach was based on the researcher's need to be seen to be transparent in the recruitment of participants. This was important because the researcher worked in the school where the study would be conducted and participants were to be recruited from a student cohort known to the researcher. Using an intermediary when researcher and students are known to each other is recognised as being integral to the success of the research process (Clark & McCann, 2005). Employing such a strategy diminishes the student's perception of coercion to participate in the study and attempts to redress the power imbalance (Clark & McCann, 2005; Liamputtong, 2007). A plain English information statement was distributed to potential participants (Appendix 2). This provided participants with the study's purpose, specific aims and benefits and informed participants of the commitment required for involvement in the study. Importantly, the plain English statement indicated that participants would not be harmed or penalised in relation to their grades if they chose not to participate or wanted to withdraw at any point in the study.

Following the information session, interested participants who wanted to volunteer were asked to make direct contact with the researcher. At this point, a consent form was provided (Appendix 3). The consent form reinforced statements made previously in the plain English information sheet. The level of commitment required by the participant was again described. Permission for the researcher to maintain regular contact following the interviews and for the participant to disclose their personal

contact details was also made explicit. Statements relating to how the data would be de-identified and managed were also included. Statements reinforcing that non-participation or withdrawal from the study would not incur harm to the student or a penalty applied to the student's grades, were again reinforced.

Completion and return of the written consent form demonstrated the participant's willingness to volunteer to participate in the study. Consent was gained from all participants before interviews were held. Each participant received a copy of both the Plain English statement and their consent form in accordance with the National Health and Medical Research Committee's national statement on ethical conduct involving humans (1999). After meeting with the researcher, potential participants who did not return a completed consent form, were not followed up. The researcher did not want to be seen to be placing any potential participants under pressure to volunteer. It was considered that the behaviour associated with a non-return of a completed consent form conveyed an unwillingness to participate in the study.

Prior to each interview and on verification of the transcript the researcher sought the participant's willingness to continue in the study. This conveyed explicitly to the participants the researcher's inherent value of their individual well-being over the need to use them as a study participant (Liamputtong, 2007; McIlpatrick, 2006). In this study, because of the highly sensitive topic being explored it was paramount that this was undertaken. Streubert Speziale and Carpenter (2007) name this as 'consensual decision making' or 'process informed consent'. Phenomenological interviews are by their very nature also recognised as being open and emergent (Holloway & Wheeler, 2002; Robley, 1995; O'Brien, 2003; Polit & Beck, 2010). This

type of interview therefore necessitates that at various points along the research journey the researcher reaffirms with participants their ongoing participation in the study (Streubert Speziale & Carpenter, 2007). In reaffirming with participants their consent, two participants withdrew from the second interview and one participant requested the second interview be delayed due to her own father dying at the time. Prior to the second interview, telephone contact was undertaken with all of the original participants to schedule their attendance at the next round of interviews. Failure to return the researcher's telephone call and or non-attendance of participants at the subsequent interview inferred an unwillingness to continue to participate in the study and no further follow up occurred.

3.4.2. Confidentiality and Anonymity

In phase one of the study, statements were included in the cover letter accompanying the survey making clear any information about the participant's university and its geographical location would be removed and known only to the researcher (Appendix 1). Furthermore, results would be reported in an aggregated form thereby diminishing the possibility of individual universities and their locations being identified in any verbal or written dissemination of the study's results.

In the interviews, it was not possible for the researcher to remain anonymous from the data source as it is an interactional process involving one-on-one communication (Streubert Speziale & Carpenter, 2007). Assurance of the participant's confidentiality and anonymity in relation to the data collected and any dissemination of the findings were communicated via the Plain English statement and consent form (Appendix 2 & 3). To promote the privacy of the participant from external sources the researcher used only first names during the conduct of the interviews. These names were

subsequently removed during the transcription process and initially replaced with a numerical code and finally with a pseudonym to personalise the accounts and create resonance with the reader. Furthermore, de-identification of any information that might have revealed a participant's identity or location was removed prior to the researcher's supervisors viewing the transcripts. In the final thesis, at conference presentations and in subsequent published articles, the allocated pseudonyms are used to de-identify the participants. The numerical codes and pseudonyms allocated to the interview tapes are stored separately and known only to the researcher. To further support the confidentiality of the participants, the transcriber was recruited outside of the research setting from a geographically distant location. This decision was based on the potential for a transcriber located in the research setting to know one or more of the participants.

3.4.3 Data Management

In accordance with the researcher's institution, all documentation and records generated from phase one and two of the study will be kept in a locked filing cabinet for 5 years in the research office of the school, where the researcher studied. All data has been de-identified by the removal of any names and geographical locations prior to storage. Information sources related to the survey and interviews will be kept by the researcher in a separate location from the collected surveys, audiotapes and transcriptions to prevent accidental identification. Generated computer files are password protected and known only to the researcher. Backup copies of research data are housed separately to the researcher's office and home.

3.4.4 Support strategies for researching the sensitive topic of death

In this study a heightened vulnerability existed especially for the participants. This was present for two reasons. Firstly the researcher was conducting research on her own students and secondly, the topic of death is considered sensitive and likely to raise emotions (Lee & Renzetti, 1993). It is well recognised that when researchers use their students as study participants the potential for harm is further exacerbated (Clark & McCann, 2005; Lee & Renzetti, 1993; Liamputtong, 2007). This is as a result of the status inequalities already present in the relationship (Elam & Fenton, 2003; Liamputtong, 2007) and the more intimate interactions being different from those normally associated between student and teacher (Dean & McClement, 2002). In addition, students may have thought that disclosure of their experience would lead the researcher to judge them, resulting in a diminished opinion of the student. Such a view may also have led to increased feelings of vulnerability being held by the participants. Heightened vulnerability always exists when the topic of death is researched as it precipitates an intensification of the relationship between researcher and participant and as such, may create a vulnerable position for either or all parties (Cowles, 1988; Liamputtong, 2007). Therefore it was important that a number of strategies were implemented in this study to diminish the participants' feelings of vulnerability as a result of participation in this study.

In phase one of the study, the degree of risk to respondents completing a survey on death and dying was considered minimal. This was based on Polit and Beck's (2010) view that the risk of completion was no greater than that encountered in daily life. The capacity of the survey to evoke issues of distress in the respondents was considered negligible as survey completion was reliant on the response being taken from the

curriculum document and not from the respondent's personal experience. The researcher's contact details were provided in the cover letter accompanying the survey in the event that issues emerged and the respondent wanted to discuss anything further (Appendix 1).

In phase two of the study participants were asked to recount their experience of caring for dying patients and their families in an acute-care hospital. Van Manen (1990) attests that the very nature of phenomenological interviewing will have an emotional effect on the individual producing a range of feelings from discomfort to thoughtfulness. In this study this was further compounded by exploring the topic of death. Recounting experiences of death has the potential to evoke issues of unresolved grief and loss in the participants (Lee & Renzetti, 1993; Liamputtong, 2007; Streubert Speziale & Carpenter, 2007). It must also be acknowledged that this extends also to the transcriber and researcher involved in the research study (Dickson-Swift, 2005; Lalor, Begley & Devane, 2006).

Death as a research topic has long being considered a difficult and sensitive area to research (Campbell, Moore, & Small, 2001). Of all the topics labelled as sensitive, Streubert Speziale and Carpenter (2007) acknowledge death, as the topic as having the most potential to produce an evocative response. The evocative response emerges as a consequence to the intrusion into the participants' private lives or deeply personal experiences (Lee & Renzetti, 1993; Usher & Holmes, 1995). Generally the topic of death is seen as intimate and emotionally laden where feelings are traditionally kept private (Campbell et al., 2001; McIlpatrick, 2006; Wellings, Branigan, & Mitchell, 2000). Consequently, topics labelled as sensitive or perceived as sensitive by the

individual pose a greater risk for harm to all individuals involved in the research process (Elam & Fenton, 2003; Lee & Renzetti, 1993; Sieber & Stanley, 1988).

In acknowledging the impact the recount may have on participants the researcher included the following support mechanisms into the research plan: 1) provision of a Plain English Statement (Appendix 2) outlining the names and contact details of referral agencies for counselling, 2) piloting of interview questions using the researcher's usual interview and communication technique thereby enabling the researcher to predict the level of response the questions may evoke and evaluate the degree of support required, and 3) acknowledgement by the researcher of her role as interviewer and not a counsellor or therapist and knowing at what point to refer the interviewee for further support.

The sensitive nature of the topic being explored and the types of experiences recounted necessitated the appropriate closure of the interviews. Therefore in this study the researcher thanked the participants for their honesty and openness; affirmed the importance of their contribution to making educational changes and improving practice and reinforced the availability of the researcher and trained counsellors post interview, if the need arose. McIlpatrick (2006) suggests when using phenomenological interviews on sensitive topics there is a need to balance the potential harm to the participant against the benefit of gaining a deeper understanding of the issue.

With respect to the transcriber, the researcher undertook debriefing with the transcriber periodically during the transcription process and if required referral to one

of the agencies listed in the plain English statement (Appendix 2) would have been initiated. The researcher undertook a range of self care activities which included debriefing with her supervisors; discussions with her partner; appropriate scheduling of the participant interviews to allow time for reflection and debriefing; and the option to obtain support from the university ethics committee and / or counsellor, if required. Implementation of such strategies to minimise the impact of the topic, by the researcher in a research plan, acknowledges the potential harm that can be caused to all those involved in the research process (Lee & Renzetti,1993;Liamputtong, 2007).

3.5 Conclusion

This chapter has provided a discussion on the mixed method design selected to conduct this study and the rationale for its selection. An outline of the two-phases and the data collection methods used in each study phase are briefly described. The chapter concludes with a discussion on the ethical considerations present in conducting this mixed method study. The following chapter provides a detailed discussion on the conduct of phase one of the study using survey method, the data analysis employed and the results obtained.

CHAPTER 4

PHASE ONE STUDY

This chapter presents the methodology and key results in phase one of the study. A descriptive study design using survey method was undertaken to explore education on death and dying in Australian undergraduate nursing curricula. The first section of this chapter outlines the rationale for selecting the study design and details the study's purpose. Section two discusses an overview of survey method and details the rationale for participant selection, instrument development and issues related to validity and reliability. The third section of this chapter outlines the data collection procedures used in phase one of the study. Section four details the data analysis procedures used. The final section of this chapter reports on the results of the descriptive survey. The chapter concludes with a discussion of the key results and the implications for nurse education drawn from phase one of the study. A detailed and integrated discussion of the major findings from the phase one results and phase two findings can be found in chapter seven.

4.1 Study Design

A descriptive study design was selected to frame the conduct of phase one of the study. The intent of phase one of the study was to answer the following research question: *What are the current curriculum practices used in Australian undergraduate nursing programs to provide education on death and dying?* A descriptive study design was recognised as the most appropriate means to uncover the breadth and extent of education on death and dying in Australian undergraduate nursing programs. Revealing the breadth and extent of education on death and dying in Australian undergraduate nursing programs enabled the current curriculum

practices to be described. The generated description informed the researcher of the context in which the phase two study would be conducted and contributed an added dimension to understanding the nurse's experience of caring for dying patients and their families. Descriptive study designs are well suited to identifying issues with current practice as they explore and describe phenomena in real-life situations (Burns & Grove, 2009). Furthermore, with minimal information available on the Australian experience the knowledge gained from the description informed phase two of the study. Using a descriptive study design to inform a subsequent qualitative investigation is considered a legitimate approach in mixed method research (Kroll & Neri, 2009).

The terms 'descriptive' and 'survey' are often used interchangeably within the literature (Burns & Grove, 2009). In phase one of the study the narrower definition of survey is applied as a data collection method.

4.2 Study Purpose

The purpose of phase one of the study was to generate a comprehensive description of the current curriculum practices used by Australian undergraduate nursing programs to provide education on death and dying. This comprehensive description was used to: 1) inform the researcher of the context in which the phase two interviews were situated; 2) assist in the development of the phase-two interview questions; and 3) aid in the interpretation of the phase two participant experiences.

4.3 Method

4.3.1 Research Context

Phase one of the study was conducted at Australian universities with departments, faculties or schools of nursing or nursing and midwifery who offered an undergraduate nursing program at the time of the study. These universities were geographically dispersed across the six states and two territories of Australia. The student cohorts in each of the departments, faculties or schools of nursing or nursing and midwifery varied in age, culture, educational background, gender and student number.

4.3.2 Population and Sample

The study population was the Australian Council of Deans of Nursing (2000) now known as the Council of Deans of Nursing and Midwifery [CDNM]. Membership of this group comprised all Australian and New Zealand Deans or Heads of Department, Faculty or School of Nursing or Nursing and Midwifery. This group provides a national leadership role to promote quality standards in the university education of nurses and midwives in Australia and New Zealand (CDNM, 2005). Eligibility for inclusion was based on the following criteria: respondents were required to hold membership on the Australian Council of Deans of Nursing (2000); hold the position of Dean (or equivalent position title) of a Department, Faculty or School of Nursing or Nursing and Midwifery in an Australian university and offer a bachelor's degree in nursing. The Deans (or equivalent position title) were crucial in gaining access to curriculum documentation.

The sample was drawn from a pool of academics, one of whom was nominated by their Dean (or equivalent position title) as the most relevant staff member to complete the survey instrument. The Deans (or equivalent position title) were encouraged to nominate an academic staff member most familiar with the death and dying education in their institution's curriculum documentation to complete the survey (Appendix 4). Recruiting the sample in this targeted manner enabled the researcher to potentially gain the 'best responses' to the survey questions, thereby enhancing the accuracy and detail of the description. Using this strategy facilitated access to a more informed and complete picture of the issue than might otherwise have been collected if the Dean (or equivalent position title) had responded.

4.3.3 Survey Instrument

In the absence of a suitable instrument identified for replication in the Australian nurse education context, a survey instrument was specifically developed to conduct phase one of the study (Appendix 4). The survey consisted of 10 closed-ended questions, required respondents to self-report in writing and was mailed to each participant. Given no uniformity exists in curriculum documentation a data collection method capable of retrieving accurate and reliable data was required. Survey method was chosen because it has this capacity to systematically and efficiently retrieve data (Burns & Grove, 2009; Elliot & Thompson, 2007). Furthermore this method facilitated access to undergraduate nursing curricula geographically dispersed across six states and two territories of Australia in an efficient, economical and timely manner (Newell & Burnard, 2006; Polit & Beck, 2010).

4.3.4 Instrument Development

Initial development of the survey instrument was informed by previously conducted studies (Burney-Banfield, 1994; Caty & Downe-Wamboldt, 1983; Coolican et al., 1994; Degnar & Gow, 1988b; Dickinson, 2006, 2007; Dickinson et al., 2008; Dickinson, Sumner, & Frederick, 1992; Downe - Wamboldt & Tamlyn, 1997; Field & Kitson, 1986; Lloyd-Williams & Field, 2002; Thrush et al., 1979). These studies supported identification of the critical elements of curricula design and formed the basis on which the instrument's questions and pre-determined listed responses were developed. Secondly, the researcher's expertise and leadership in curriculum development of undergraduate and new graduate programs in the public, private and tertiary sectors was used to further develop the survey questions and responses. Final development of the instrument was informed by advice from an expert panel. This panel comprised two specialist palliative care nurses with 15 years or more experience in nurse education. Their role was to critique the survey for resonance with Australian nurse academics and provide feedback on aspects of survey content. Instrument development informed in this way most likely ensured the scope of the instrument was sufficiently broad enough to generate a comprehensive description of the curricula practices (Burns & Grove, 2009; Elliot, 2007; Polit & Beck, 2010).

Ten critical elements of curriculum design were identified for inclusion in the survey instrument. These elements formed the focus for developing the survey questions and were: curriculum approach, teaching schedule, teaching hours, theoretical content, teaching strategies, professional discipline of academic, clinical placements and assessment strategies. This approach to question development assisted in constructing

clearly focussed questions and avoided large numbers of questions being included in the instrument. Such an approach has been found to influence survey return rates and compliance of participants to respond to all questions (Burns & Grove, 2009; Polit & Beck, 2010). The pre-determined responses listed for each question were generated from the reviewed literature, the researcher's expertise and feedback from the expert panel. The full survey instrument is located in Appendix 4.

A closed-ended question format was chosen. Closed-ended survey formats are considered easier for respondents to complete compared to open ended question surveys (Burns & Grove, 2009; Polit & Beck, 2010). Due to their ease of completion return rates are likely to be higher than open ended surveys (de Vaus, 2002; Elliot & Schneider, 2007). The respondent reads each question and responds by selecting the most appropriate answer from a list of pre-determined responses. The respondent inserts a symbol against the nominated response. Unanticipated responses were captured by the inclusion of an 'other' category. This allowed the respondent to insert a written comment if the selection from the pre-determined list was unsuitable. It is possible for researchers to omit a response from a pre-determined list. Inclusion of an 'other' category in the instrument's design attempted to compensate for any potential omission (de Vaus, 2002; Elliot & Schneider, 2007; Polit & Beck, 2010).

Defining the term 'death and dying content', in this study, was left to the survey respondent. A prescriptive definition was not provided so that the term could be locally interpreted. Additionally, the terms palliative care or palliative education were avoided to negate confusion with specialist palliative care education offered at a post graduate level.

The following is a discussion on each of the 10 questions included in this survey instrument. The survey instrument is located in Appendix 4.

Question one invited respondents to identify the curriculum approach used to incorporate education on death and dying into their program. The stimulus for including this question came from several reviewed studies (Caty & Downe-Wamboldt, 1983; Coolican et al., 1994; Degnar & Gow, 1988b; Dickinson, 2006, 2007; Dickinson et al., 2008; Downe - Wamboldt & Tamlyn, 1997; Field & Kitson, 1986; Thrush et al., 1979). Other international studies, in the area of death and dying education, also supported the inclusion of this curriculum element as it is known to influence how students learn (Beck, 1997; Copp, 1994).

Question two identified the semester most commonly used by nursing programs to schedule education on death and dying. Few studies made reference to this curriculum design element (Coolican et al., 1994; Thrush et al., 1979). Burney-Banfield's (1994) study, while not addressing this element specifically, highlighted the importance the timing of education sessions on death and dying has on the overall curriculum and what this means to the learner. Mallory's (2001) study also gave emphasis for inclusion of this element. In light of this information a question focussed on scheduling was included.

Question three quantified the number of teaching hours most frequently allocated to education on death and dying in an undergraduate nursing curriculum. Most studies reviewed included a reference to the total number or range of teaching hours allocated to education of death and dying (Burney-Banfield, 1994; Dickinson, 2007; Dickinson

et al., 2008; Downe - Wamboldt & Tamlyn, 1997; Field & Kitson, 1986; Lloyd-Williams & Field, 2002; Thrush et al., 1979). Quantifying the number of curriculum hours allocated served several purposes. Firstly, it enabled the Australian experience to be compared against other international studies; secondly, it assisted in determining the depth of coverage against the number of theoretical topics included and thirdly, it determined a mean national figure on the teaching hours offered by Australian undergraduate nursing programs.

Question four identified the professional discipline of the academic or health professional primarily responsible for teaching death and dying education in their curriculum. An interdisciplinary teaching team would be congruent with the philosophy of palliative care and the researcher wanted confirmation that this value was reflected in Australian undergraduate nursing curricula. Several other international studies have also elicited this information (Coty & Downe-Wamboldt, 1983; Dickinson, 2006, 2007; Dickinson et al., 2008; Dickinson et al., 1992; Downe - Wamboldt & Tamlyn, 1997; Field & Kitson, 1986).

Question five asked the extent to which undergraduate nursing curricula specifically planned clinical placements to align to the theoretical content on death and dying. Several overseas studies indicated this had occurred for some of their students (Coty & Downe-Wamboldt, 1983; Degnar & Gow, 1988b; Dickinson, 2006, 2007; Dickinson et al., 2008; Downe-Wamboldt & Tamlyn, 1997; Thrush et al., 1979). It was also important to determine if this was also the case for Australian undergraduate nursing students. This question was constructed in a binary format to facilitate the

respondent's progression through the survey. A 'yes' response, led respondents to question six. A 'no' response took the respondents directly to question seven.

Question six provided evidence on the range of clinical areas undergraduate nursing programs used to generate exposure to dying patients for their students. The importance of clinical placements as a learning experience was initially highlighted by Quint's (1967) seminal work. Gauging the range of clinical areas used would inform future decisions as to how best clinical experiences could be planned and offered to Australian nursing students.

Question seven and eight elicited the teaching strategies Australian undergraduate nursing curricula used to provide education on death and dying. Question seven identified the most frequent teaching strategies used in undergraduate nursing curriculum. Question eight elicited the primary teaching strategy when a program used more than one strategy. Both questions were informed by several other international studies which had included this question in their studies (Coty & Downe-Wamboldt, 1983; Dickinson, 2006, 2007; Dickinson et al., 2008; Dickinson et al., 1992; Downe-Wamboldt & Tamlyn, 1997; Field & Kitson, 1986; Lloyd-Williams & Field, 2002). Frequently these studies reported a didactic approach as being commonly used. In 1994, Copp identified that it still remained unclear as to how teaching methods were selected to provide death and dying sessions. The results from Burney-Banfield's (1994) study also highlighted the mismatch between the ideal and reality. This however is in contrast to most palliative care education which predominantly employs experiential learning (Johnson & Jackson, 2005; Sheehan &

Ferrell, 2010; Spruyt et al., 2007). It was therefore necessary to confirm the current practice in Australian undergraduate nursing programs.

Question nine established the range of death and dying topics covered by Australian undergraduate nursing curricula. Confirmation of the range of theoretical topics delivered would enable the researcher to make some determination as to the relative level of preparedness Australian undergraduate nurses acquire in terms of attitude, knowledge and skill development. Furthermore, identifying the number of topics delivered against the allocated teaching hours was also important to establish the relative breadth and depth of coverage. The predetermined response options were drawn from several previously conducted studies (Burney-Banfield, 1994; Coolican et al., 1994; Dickinson, 2007; Dickinson et al., 2008; Downe-Wamboldt & Tamlyn, 1997; Field & Kitson, 1986) in conjunction with the researcher's knowledge and input from the expert panel.

Question ten determined the most frequent means student learning on death and dying was evaluated. Relatively few survey studies conducted on this topic included this element (Downe-Wamboldt & Tamlyn, 1997; Field & Kitson, 1986; Lloyd-Williams & Field, 2002). Assessment of learning however, is an important educational principle but in education on death and dying it is not always incorporated into curricula design (Lloyd-Williams & Field, 2002).

The instrument design included the option for the respondent to insert additional written comments. This option provided the researcher with an opportunity to capture any additional thoughts the respondent may have had while completing the survey or

reflecting on the topic or both. These comments may have further informed the study and assisted with data interpretation. The majority of respondents were likely to have progressed through the questions in a linear fashion. For this reason, the option to include additional written comments was scheduled after the last question, question 10. This ensured survey respondents had the maximum time for reflection. The option for respondents to provide their contact details was also incorporated into the instrument's design to allow follow up by the researcher, if required.

All survey questions, except question five, provided respondents with the opportunity to provide multiple responses. This feature was deliberately included in the question development to facilitate maximum scoping of all curriculum practices used in an undergraduate nursing program. Offering respondents a single response only had the potential to limit the researcher's understanding and not be aligned to the reality of current practice. The inclusion of this design feature took account of the need to generate a comprehensive description of the current curricula practices used in Australian undergraduate nursing programs. The questions in which multiple responses could be elicited a statement was included informing respondents of this option. In questions reporting multiple responses this is acknowledged in the graphical presentation of the results presented later in this chapter.

Several strategies were incorporated into the instrument's design to facilitate a higher than normal survey return rate. These features included: the use of plain English statements; the avoidance of jargon; a user friendly format; the use of bolded key words in the question stem to support comprehension; the use of size 12 font, single focussed questions and sufficient white space to facilitate readability; the sequencing

of questions in a logical manner to facilitate the respondent's thinking and limiting the number of questions asked to reduce non-completion and return of the survey (Burns & Grove, 2009; Elliot & Schneider, 2007; Newell & Burnard, 2006; Polit & Beck, 2010). Two other strategies used were an expert panel and pilot study. The following section of the discussion describes these two strategies and how they were applied in this study.

4.3.4.1 Expert Panel

An expert panel was convened to evaluate the suitability of the instrument to the intended audience and the retrieval of accurate data. The panel members were two specialist palliative care nurses with 15 years or more experience in nurse education. Both members had extensive experience in the development of curriculum and were invited to critique the draft survey instrument. They were asked to critique the draft survey instrument by ensuring the questions posed captured all critical elements of curriculum design; that the questions retrieved suitable data from the curriculum documentation to generate a description and the instrument's design encouraged the respondent's commitment to complete and return the survey. The panel members were also responsible for critiquing the language and expression used in the instrument to ensure the instrument's resonance and suitability for Australian nurse academics. Surveys lacking resonance are less likely to have respondents complete them which leads to lower return rates (Burns & Grove, 2009; Elliot & Schneider, 2007; Polit & Beck, 2010).

4.3.4.2 Pilot Study

A pilot study was conducted to identify issues with the instrument's reliability and validity. The pilot study aimed to evaluate the ability of the instrument to

consistently and systematically retrieve the data required to answer the research question. The pilot study was conducted with four nurse academics from one Australian nursing school which offered an undergraduate nursing program. They were selected on the basis of their expertise in students nursing curriculum development and familiarity with their program's curriculum documentation. As participants they were representative of the intended main study sample (Burns & Grove, 2009; Elliot, 2007). Conducting a pilot study on a new instrument, prior to undertaking the main study, is considered best practice to determine and resolve issues of reliability and validity (Burns & Grove, 2009; Elliot, 2007; Newell & Burnard, 2006; Polit & Beck, 2010). Furthermore, a pilot study offers an opportunity to pre-test the research plan and the collation and analysis of retrieved data (Polit & Beck, 2010).

The pilot study involved the researcher comparing participants' responses among the group and against the curriculum documentation. This strategy determined the degree of consistency present among the four participants' responses which confirmed the clarity of the questions asked and the level of accuracy present in the data retrieved in relation to the curriculum document. Participants were also invited to make verbal comment to the researcher on all aspects of the survey instrument including presentation, readability, ease of completion and degree of clarity of the instrument (Burns & Grove, 2009; Elliot & Schneider, 2007; Polit & Beck, 2010). The researcher timed the participant's completion of the survey instrument. It was important to acknowledge this aspect as the main study sample had known time constraints and the researcher wanted to achieve a higher survey response rate than normally anticipated. Response rates are generally low between 25-30%, as compared to other forms of

self-reporting but are lowered further when the survey is mailed out (Burns & Grove, 2009; Elliot & Schneider, 2007).

The other significant benefit to the researcher in piloting the instrument is the experience it provides in implementation of the proposed instrument and the research plan (Elliot, 2007; Newell & Burnard, 2006). Piloting ensures the instrument is implemented in an effective and efficient manner. Pre evaluating the effectiveness of the research plan in terms of conducting the survey, data collection and analysis alerts the researcher to any unanticipated issues. For example the method and or research plan may not fulfil their intended purpose or may fail to retrieve the required data thus inhibiting data analysis (Burns & Grove, 2009; Polit & Beck, 2010).

Following receipt of the expert panel's critique and feedback from the pilot study several adjustments were made to the survey instrument. The following changes were made and the instrument re-drafted:

- replacing the term 'death education' with 'death and dying education' as this was consistent with the language used in the Australian nurse education context;
- bolding key words in the question stem to give emphasis and assist with readability;
- reordering the questions to promote a more logical flow so as to more closely reflect the principles of curriculum design to further stimulate the respondent's thinking;
- increasing the categories of health professionals listed to better reflect current practice; and

- expanding the clinical areas listed to better reflect those currently used by nursing schools to allocate students.

The final survey instrument incorporating these changes is located as Appendix 4.

4.3.5 Validity and Reliability

The following section discusses how validity and reliability were achieved in phase one of the study.

4.3.5.1 Validity

The two aspects of validity relevant to the phase one study are content and face validity. Content validity in this study was confirmed in two ways. Firstly, an expert panel critiqued the survey instrument's questions to determine if they had the scope to elicit and describe the current curriculum practices of undergraduate nursing programs. An instrument's quality is determined by its capability to retrieve consistent, accurate and valid data (Burns & Grove, 2009; Elliot, 2007; Polit & Beck, 2010). Secondly, a pilot study was undertaken using the proposed instrument to examine the responses obtained to confirm content validity. The measure being tested was the capacity of the instrument to provide an accurate and comprehensive description of the curriculum practices used in undergraduate nursing programs to provide education on death and dying. The principle of validity seeks to confirm that the instrument measures what it claims to measure (Burns & Grove, 2009; Elliot, 2007; Newell & Burnard, 2006; Polit & Beck, 2010).

Face validity or more recently re-labelled as 'content experts approach' (Elliot, 2007) was also present. This aspect of validity relies on an individual's subjective judgement as to the relative capacity of the instrument to measure the appropriate

construct (Burns & Grove, 2009; Elliot, 2007; Polit & Beck, 2010). Both the opinions of the expert panel and the pilot study respondents were sought to give their impression as to the relative merit of the survey to measure the intended construct. This measure is considered the weakest form of validity as the opinions sought are fallible; there is potential for inherent bias by those giving their opinion and a potential lack of awareness of the technical elements of a measure by the respondents may exist (Burns & Grove, 2009; Elliot, 2007; Newell & Burnard, 2006). In other studies criterion-related and construct validity, as described by Polit & Beck (2010), may apply but were not present in this study.

4.3.5.2 Reliability

The reliability of the survey instrument was evaluated by undertaking a pilot study, as previously described, prior to conducting the main study. The researcher was able to make a determination as to the degree of consistency achieved among the respondent's responses by comparing the pilot group's responses against the curriculum document. This allowed the researcher to determine if the questions were ambiguous and open to multiple interpretations by the respondents. The results revealed that the survey questions retrieved accurate information from all four respondents and were accurately matched against the curriculum document. The principle of reliability comprises two concepts: consistency and repeatability (Burns & Grove, 2009; Newell & Burnard, 2006; Polit & Beck, 2010). Reliability testing determines if the same results on repeated testing are achievable if all variables remain the same (Burns & Grove, 2009; Elliot, 2007). This involves such elements as: consistency, precision, stability, equivalence and homogeneity (Polit & Beck, 2010).

The inclusion of a cover letter accompanying the survey instrument was another strategy used to enhance this study's reliability (Appendix 1). The cover letter invited the Deans of Nursing (or their equivalent position title) to refer completion of the survey to the most relevant nurse academic in their department, faculty or school. Respondents with a more intimate understanding of the survey issue usually respond with greater accuracy and this request was therefore made of the Deans. Seeking the retrieval of data in this way was more likely to be reliable and therefore generate a more accurate description of the current curriculum practices.

4.4 Data Collection Procedures

All Australian Deans of Nursing (or equivalent position title) recorded on the Council of Deans of Nursing mailing list were sent a survey. The mail-out consisted of a cover letter, survey instrument and stamped self addressed envelope for return. The initial section of the cover letter invited the potential respondent's participation. This was followed by a series of statements informing potential respondent's of: the study's scope, the institution's and respondent's commitment, benefits in participating, the voluntary nature of their participation; that responses would be de-identified and results reported in an aggregate form in any publications arising from this study. A statement advising the researcher's institution had granted ethics approval was also included.

The information supplied in the study's cover letter enabled potential respondents to make an informed decision as to their participation in the study (Coup & Schneider, 2007). Furthermore the use of a cover letter may also serve to attract potential respondents to the study (Burns & Grove, 2009; Polit & Beck, 2010). Statements

included in a cover letter also demonstrate the researcher's respect for the respondent by taking account of the ethical considerations of anonymity, confidentiality and privacy (Coup & Schneider, 2007).

The cover letter requested the Deans (or equivalent position title) to forward the survey on for completion by an academic most familiar with their institution's curriculum documentation. Targeting survey completion in this way assists in retrieving more reliable data as the respondent's knowledge and skills of curriculum documentation is usually higher than the original contact person. By forwarding on the survey the Dean's implied their consent on behalf of the institution to participate in this study. On receipt of the cover letter and survey the nominated academic could decide whether to participate or not in the survey. The mailed return of the completed survey to the researcher implied the respondent's consent to participate. The cover letter informed respondents that the mailed return of the completed survey instrument would imply their consent. This approach is a common practice in survey research where formal, written consent is not able to be obtained and implied consent is gained via return of the completed survey (Burns & Grove, 2009; Polit & Beck, 2010). On receipt of the completed survey the researcher de-identified the survey and allocated a numerical code known only to the researcher.

Six weeks after the initial mail-out respondents who failed to return a survey were followed up by re-sending the cover letter, survey and stamped return enveloped. If, after the two mail-outs, no response was received no further reminders were sent as this may have implied an unwillingness to participate. This strategy is an acceptable means through which to promote a higher response rate without coercing potential

respondents to participate (Burns & Grove, 2009; Newell & Burnard, 2006; Polit & Beck, 2010).

Several strengths exist in using mailed surveys as a data collection method over other methods such as face-to-face interviews. The principal strengths of survey method are: 1) generally less costly to conduct than interviews; 2) require less time and energy to administer; 3) retrieve data in a relatively short time frame; 4) enable ready access to geographically dispersed study samples; 5) offer the possibility of complete anonymity; and 6) minimise potential for bias due to the absence of human interaction in the construction of the response (Burns & Grove, 2009; Newell & Burnard, 2006; Polit & Beck, 2010).

Mailed surveys also have limitations which need to be recognised and compensated for in the instrument design and research plan. Response rates for mailed surveys are frequently low and the results therefore may not be a true reflection of the study sample (Burns & Grove, 2009; Newell & Burnard, 2006; Polit & Beck, 2010).

Furthermore, surveys usually seek one word or short phrase responses with little depth and for this reason are often considered superficial and lacking in-depth (Burns & Grove, 2009; Polit & Beck, 2010). Finally, survey instruments depend on self-reporting and as a result have a higher potential for respondent bias caused by a natural tendency to present a positive image related to the research issue (Burns & Grove, 2009). These limitations and how they were addressed in this study are outlined in the following section of the discussion.

A number of strategies, informed by the literature, were incorporated into the instrument's design and research plan to minimise the impact of these identified limitations. Response rates are known to be enhanced when the following strategies are used: use of official letterhead including a date for the cover letter, a different colour handwritten signature to the body of the letter and the personal position title of the researcher and enclosing a self addressed, stamped envelope with the survey (Burns & Grove, 2009; Gillis & Jackson, 2002; Polit & Beck, 2010); the inclusion of a cover letter to accompany the survey which outlined the aim, benefits and outcomes of the study plus statements reassuring anonymity and confidentiality. Additionally, the cover letter offered a willingness to make the results available and to answer any questions that may arise (Burns & Grove, 2009; Gillis & Jackson, 2002; Polit & Beck, 2010). To overcome potential for bias due to self reporting the instrument asked clearly worded questions in a consistent manner to lessen the opportunity for respondent bias to occur (Burns & Grove, 2009; Polit & Beck, 2010). The option for the respondent to provide a qualitative written comment was also included as part of the instrument design. Inclusion of this design feature had the potential to minimise the impact of survey research to collect superficial data with little depth (Burns & Grove, 2009). Respondents were encouraged to provide any additional comments which arose in response to reflecting on the questions asked by this survey. The final strategy implemented to promote a higher response rate was the use of a reminder letter mailed several weeks after the original mail out to non-respondents to prompt completion.

4.5 Data Analysis

Descriptive statistics involving frequency counts with conversion to percentages were the data analysis procedures used in this study. Frequency count and percentages have the capacity to elicit the characteristics, patterns and trends within the data sample and are commonly applied to closed-ended questions (Burns & Grove, 2009; Fisher & Schneider, 2007; Polit & Beck, 2010). Using frequency counts and percentages to analyse this study's data enabled a description of the current curriculum practices to be generated.

Data was coded and entered into a personal computer for analysis. Interpretation and presentation of the results was enhanced by generating a series of graphs using STATISTICA software package. Presentation of data in a graphical form is often a more meaningful representation of quantitative results (Fisher & Schneider, 2007; O'Leary, 2004). Graphical presentation aids interpretation of the data by visually identifying the characteristics, patterns and general trends within a data set (Fisher & Schneider, 2007; Polit & Beck, 2010).

4.6 Results

The survey results are presented in three parts: firstly, the demographic profile of the study sample followed by the survey return rate and the final section details the results for each of the 10 closed-ended questions.

4.6.1 Demographic Profile of the Study Sample

Thirty nine potential respondents were sent the survey instrument following identification from the Australian Council of Deans of Nursing mailing list. Following the initial mail out three potential respondents were removed from the study sample as they did not meet the inclusion criteria. Two were excluded as they were Deans of Nursing from New Zealand universities and a further one removed after they self identified as a Dean of a Continuing Education unit in which no undergraduate nursing programs were offered. A reminder letter was mailed six weeks after the initial mail out to the remaining 36 potential respondents. Following the second mail-out a further two respondents were removed as the Deans advised their university did not offer an undergraduate nursing program. A further eight potential respondents did not respond to the reminder letter. A total of ten potential respondents did not participate in this survey. Twenty six completed surveys were returned.

4.6.2 Survey Response Rate

This descriptive survey study achieved a 72% ($n = 26$) response rate. This response rate was higher than normally anticipated. Typically response rates of between 25-30% in survey studies are the norm (Burns & Grove, 2009; Polit & Beck, 2010). According to Newell and Burnard (2006) a response rate of around 70% implies a well-conducted survey. Polit and Beck (2010) believe for the sample to be considered representative of the population being studied, response rates of greater than 60% are required. This survey fulfilled both these parameters.

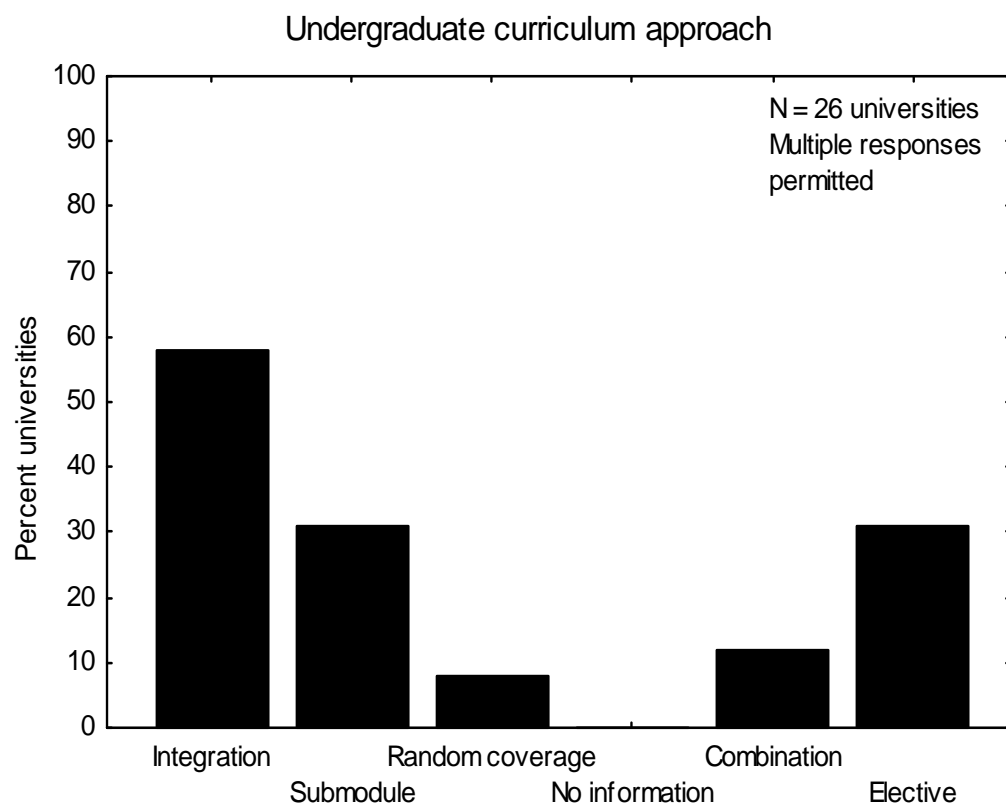
4.6.3 Survey Results

The results for each question are presented in the following section. The questions are presented in the order of sequence as they appeared in the survey

instrument (see Appendix 4). For each question, the total number of respondents who answered the question is stated. In some cases respondents did not answer all survey questions. Possible explanations for why respondents did not complete a survey questions were time constraints, limited access to the information in the curriculum document, minimal knowledge of the curriculum or an unwillingness to disclose a response to the question asked. No respondent supplied reasons for non-completion of questions. In the graphical presentation of the results where respondents provided multiple responses a statement is included on the graph.

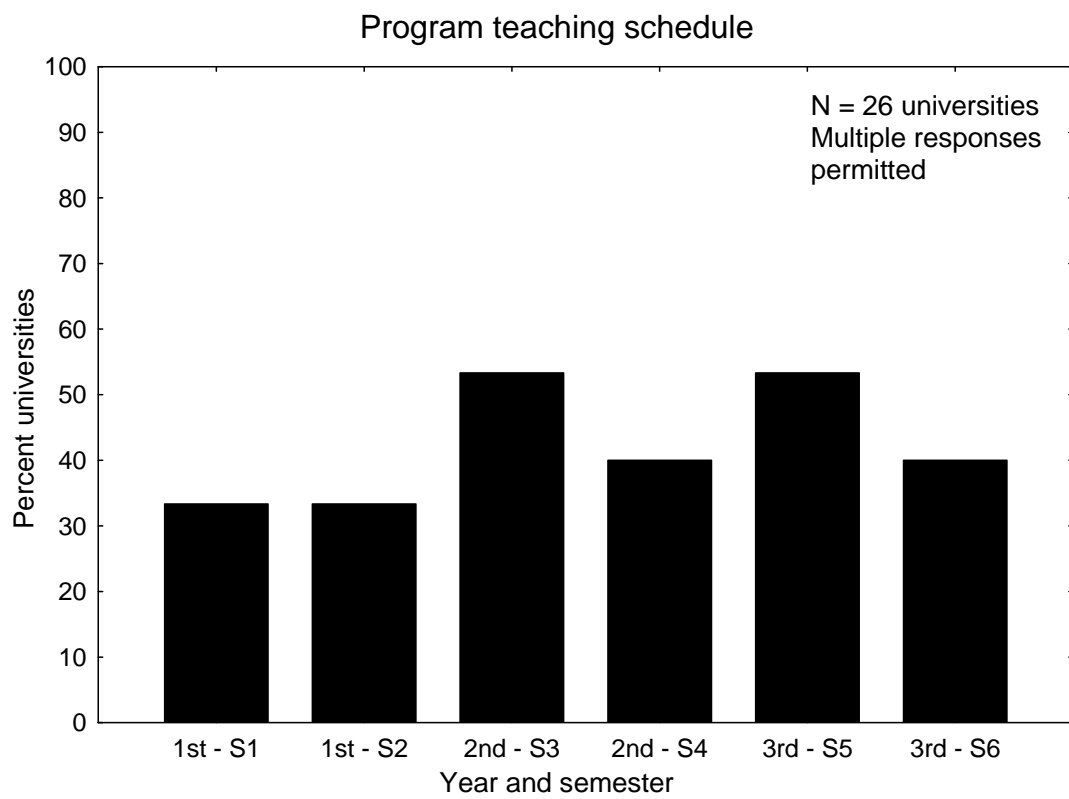
In question one a response rate of 57% ($n = 15$) was achieved in identifying the curriculum approach used in Australian undergraduate nursing programs. Of those who responded, just over half 53% ($n = 8$) reported using an integrated approach as the most frequently used approach in undergraduate nursing curricula. The remainder reported using a sub-modular approach within another teaching unit 33% ($n = 5$). A very limited number of curricula 13% ($n = 2$) offered education on death and dying as an elective option. The results for question one are shown in Figure 1.

Figure 1



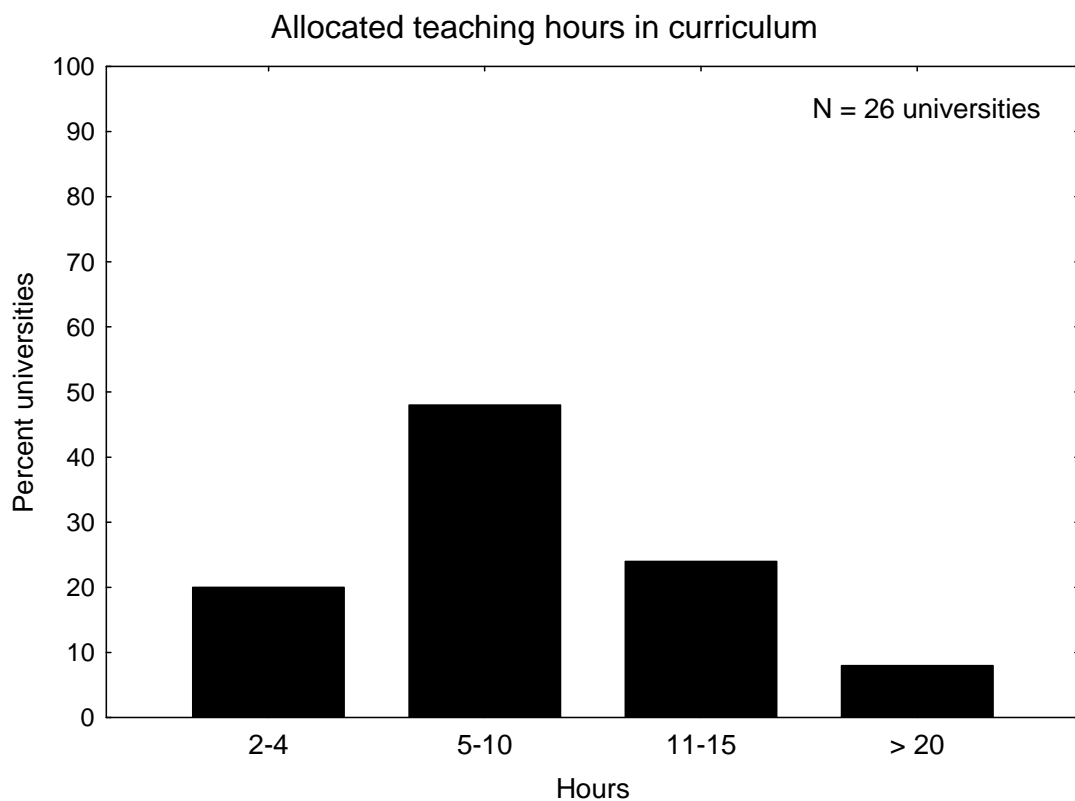
A response rate of 57% ($n = 15$) was achieved in question two. No clear scheduling pattern emerged for the delivery of education on death and dying in the surveyed Australian programs. The results for question two are shown in Figure 2.

Figure 2



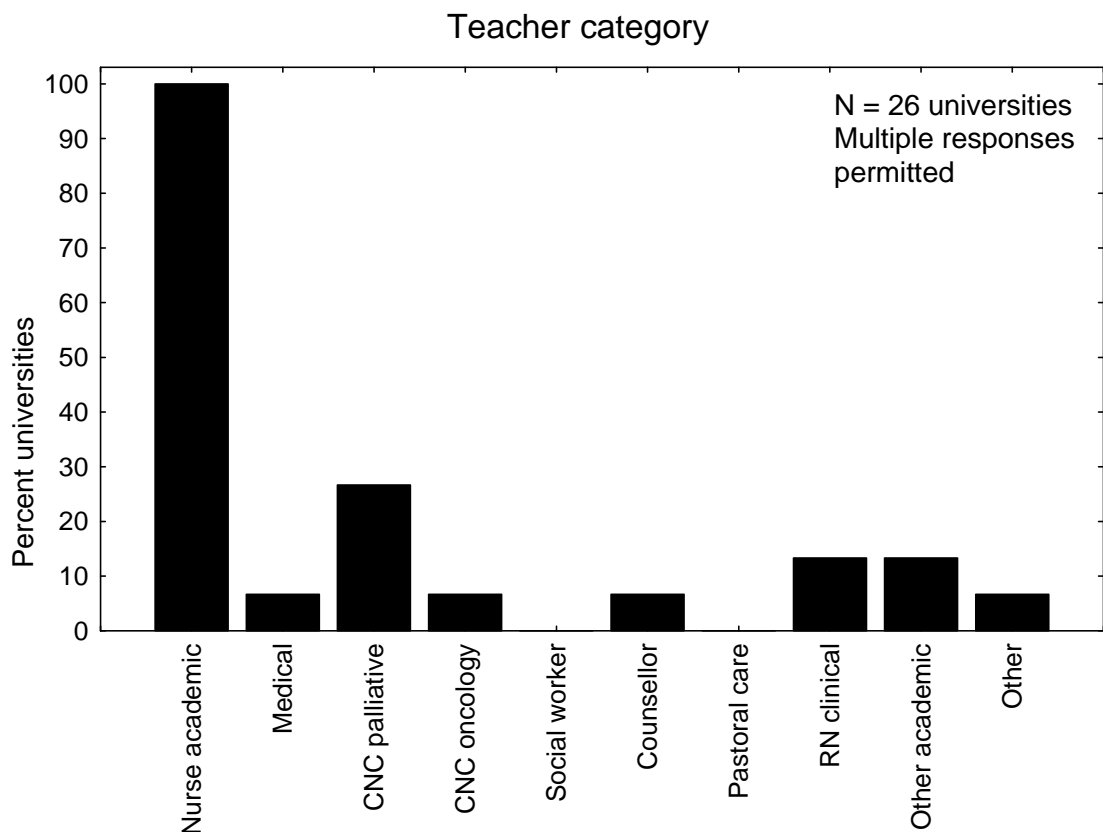
In question three a response rate of 96% ($n = 25$) was achieved. Of those who responded, almost half 48% ($n = 12$) allocated between 5-10 hours across the six semesters of their program to content related to death and dying. In 8% ($n = 2$) of curricula, when 20 hours or more were allocated, these hours were directly attributable to the inclusion of an elective option on palliative care in the program. While the inclusion of an elective option increased the overall teaching hours, the content was not accessible to the entire student cohort of the nursing program. Results for this question are shown in Figure 3.

Figure 3



A 100% ($n = 26$) response rate was achieved in question four. All respondents reported a nurse academic as the category of teacher primarily responsible for delivery of death and dying education in Australian undergraduate nursing programs. When additional health professionals were used they were also drawn from nursing and consisted of clinical nurse consultants in palliative care (27%) followed by registered nurses from the palliative care clinical setting (13%). The use of other disciplines to provide education sessions in Australian undergraduate nursing programs was negligible. Figure 4 shows the results for this question.

Figure 4

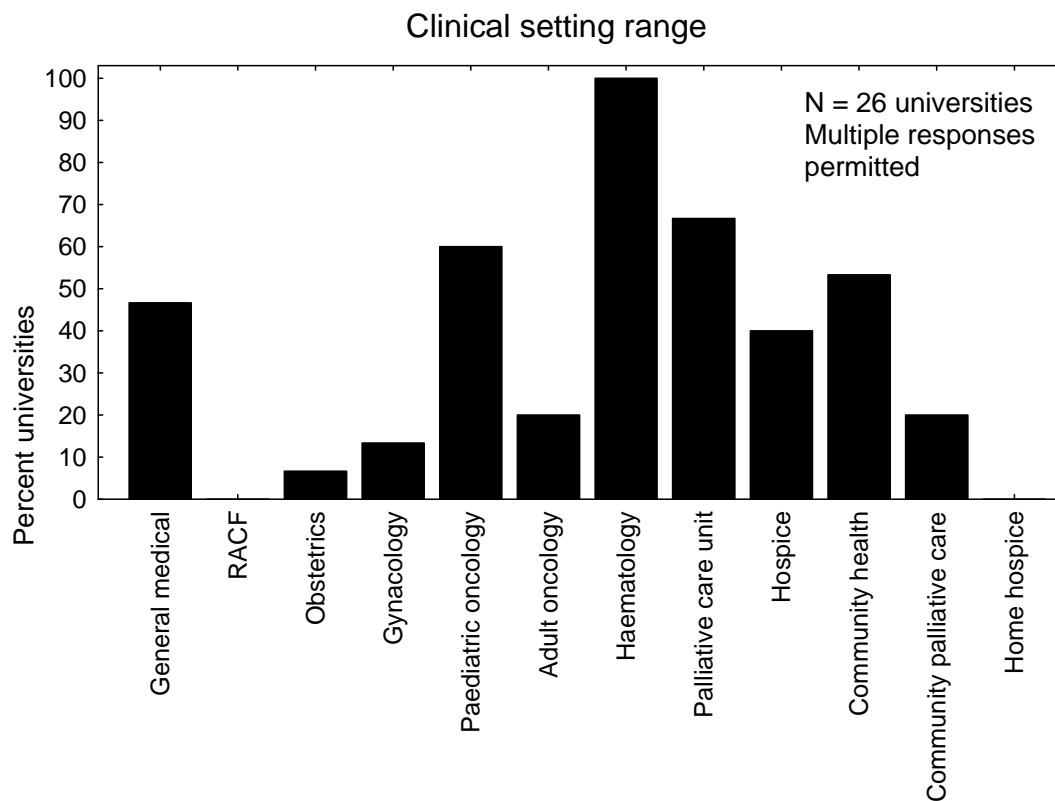


In question five a 96% ($n = 25$) response rate was achieved. A high proportion of surveyed programs 72% ($n = 18$) reported no attempt was made to have a specific death and dying clinical placement aligned to the student's theoretical learning. By contrast, respondents who offered an elective option ($n = 2$) reported their intention for students to engage in a planned palliative care clinical placement.

A response rate of 58% ($n = 15$) was achieved in question six. All reported using haematology units (100% $n = 15$) as the most frequently used clinical area followed by palliative care units 67% ($n = 10$) to provide exposure to dying patients.

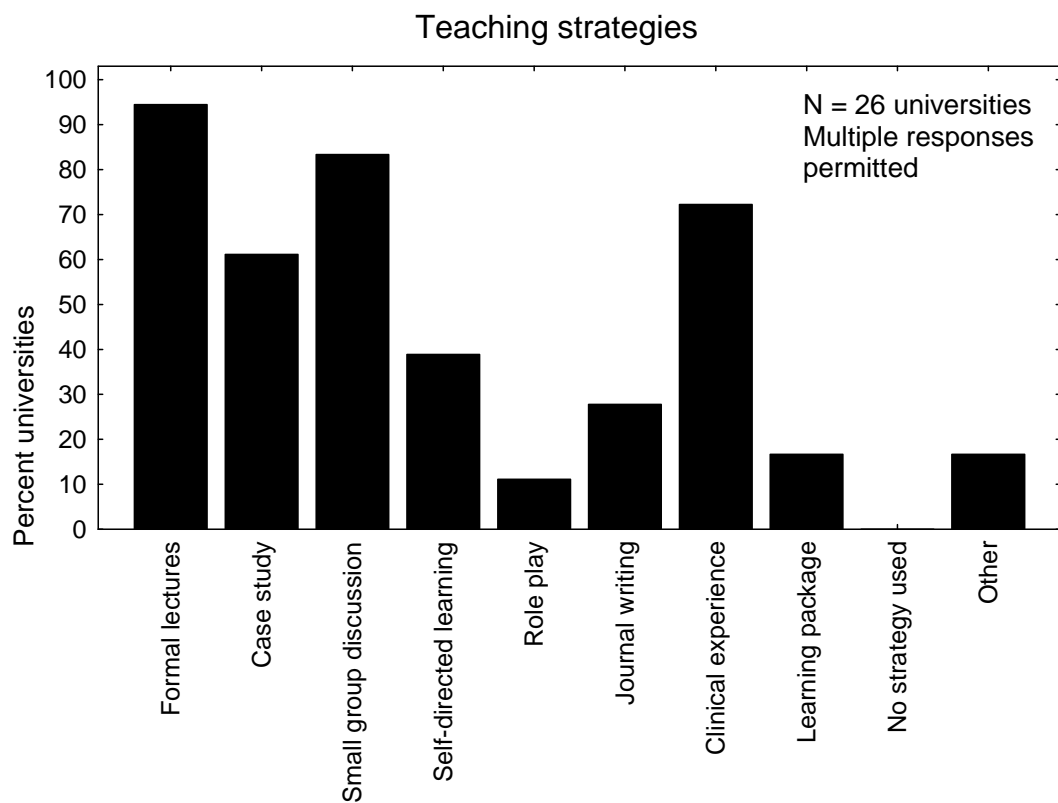
Widespread use of other clinical areas was found and these are illustrated in Figure 5.

Figure 5



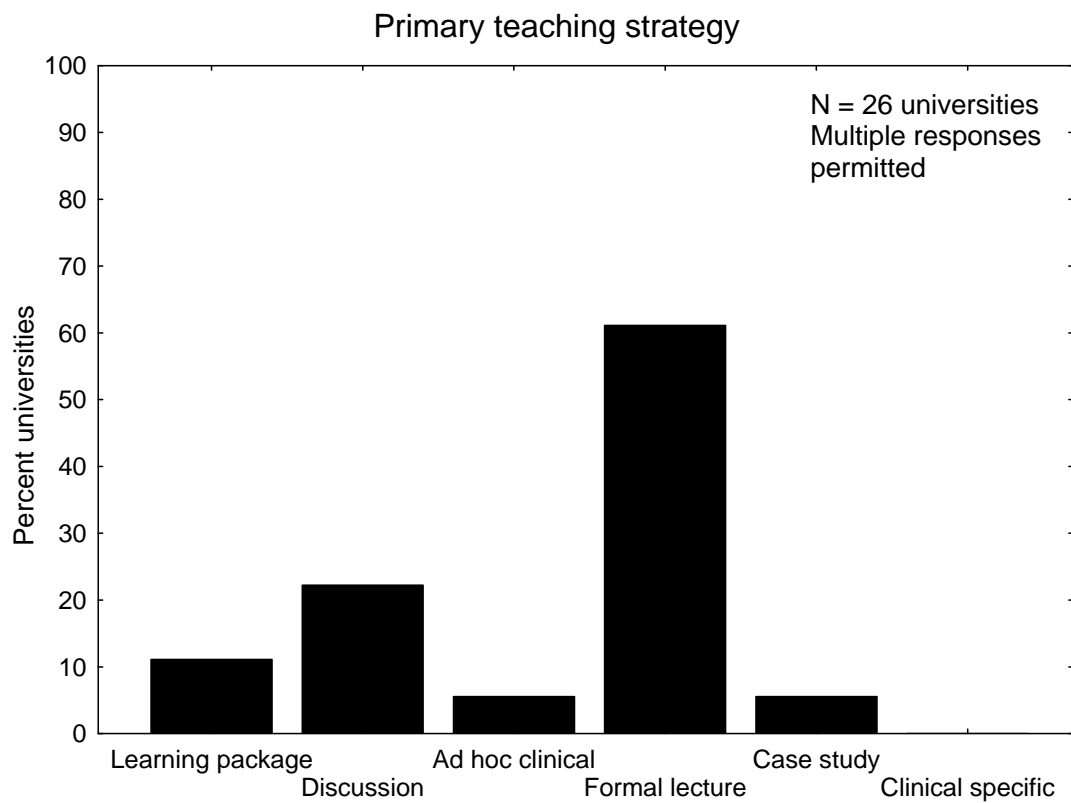
In question seven a response rate of 69% ($n = 18$) was achieved. The most frequently reported teaching strategies were formal lectures 94% ($n = 17$) followed by small group discussion 83% ($n = 15$), as shown in Figure 6. The least used teaching strategy identified was role play in only 8% ($n = 2$) of undergraduate nursing programs.

Figure 6



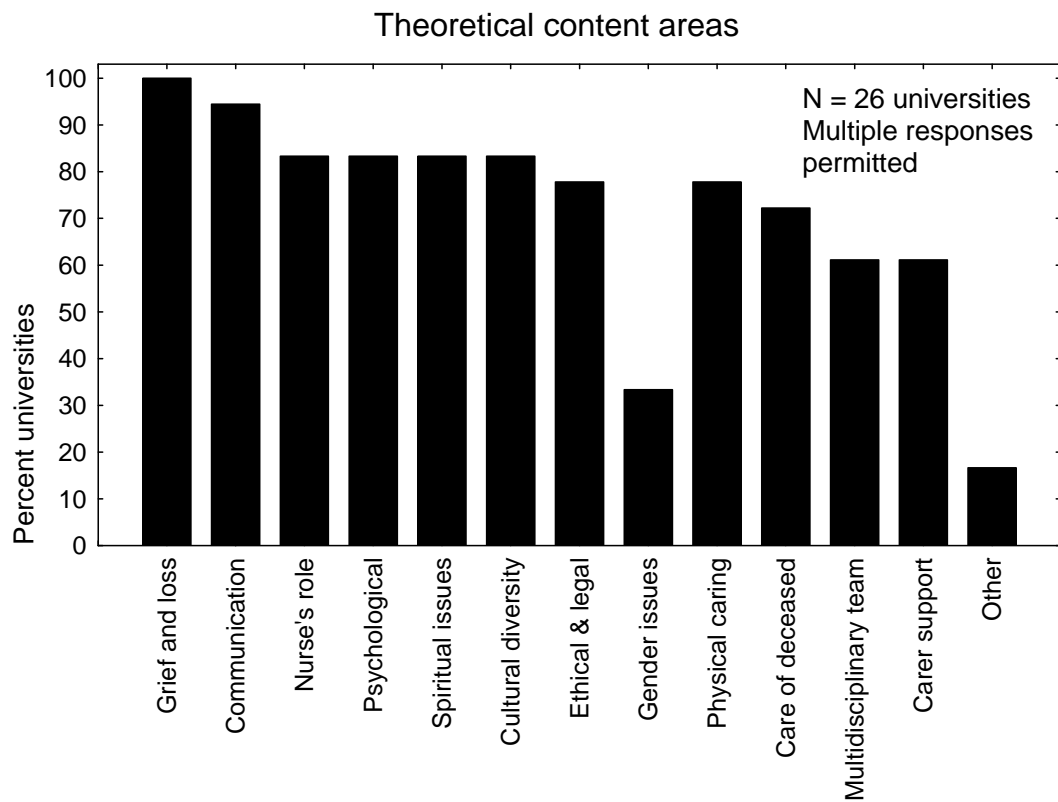
A response rate of 61% ($n = 11$) was achieved in question eight. All respondents indicated the primary teaching strategy used was formal lecture as illustrated in Figure 7.

Figure 7



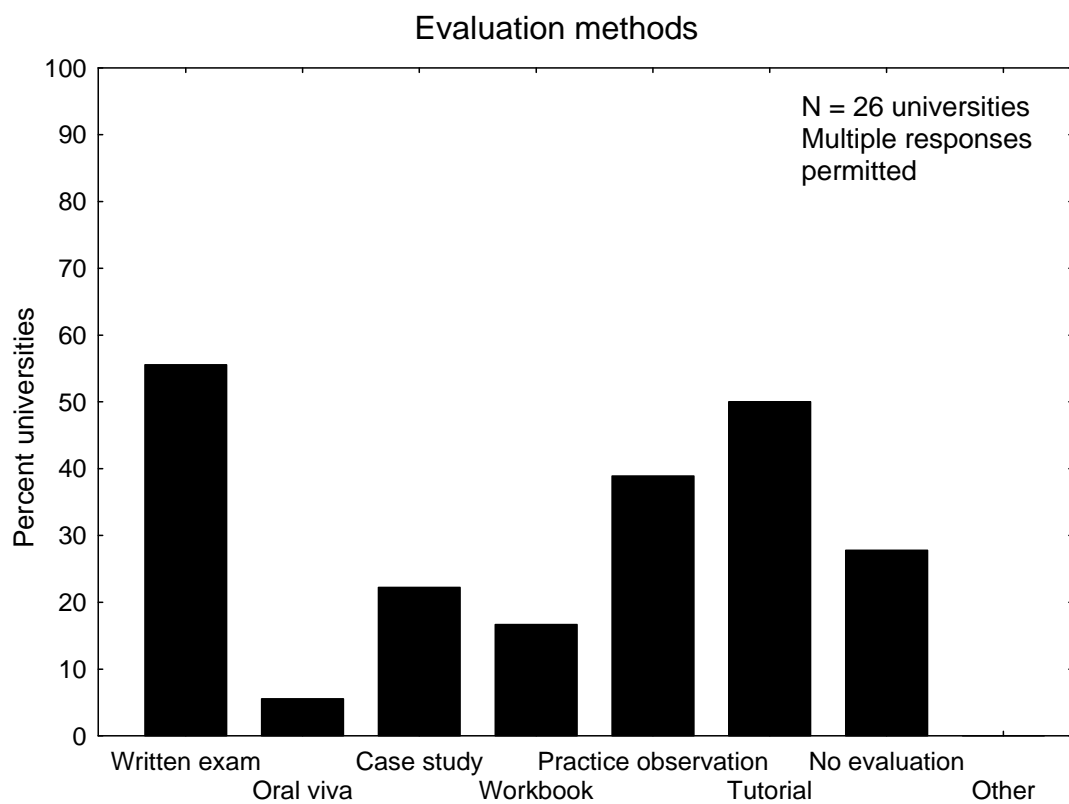
In question nine a response rate of 69% ($n = 18$) was achieved. Figure 8 reports the results for this question. All respondents (100%) reported the inclusion of grief and loss as a theoretical topic in their program. This was followed by communication in more than 90% of programs. The least included content area (33% $n = 6$) was gender issues.

Figure 8



The response rate in question 10 was 69% ($n = 18$). The results for this question are displayed in Figure 9. Respondents reported student learning was most frequently assessed by formal written examination 55.5% ($n = 10$). Oral viva 6 % ($n = 1$) was the least preferred method for assessing student learning. Figure 9 shows the range of methods employed by Australian undergraduate nursing programs.

Figure 9



Respondent comments included on the survey instrument conveyed a high level of commitment to provide accurate information to the researcher so that this topic could be further improved in nurse education.

4.7 Discussion

This descriptive study using survey method aimed to access data from curriculum documentation with the purpose of generating a comprehensive description of the current curriculum practices used to provide education on death and dying. All respondents ($n = 26$) reported the presence of education on death and dying, to some degree, in their undergraduate nursing program. However, the key results suggest education on death and dying is inconsistently presented, has minimal penetration into the overall curriculum, and is pedagogically under developed. These key results are commensurate with other studies conducted in this field (Burney-Banfield, 1994; Caty & Downe-Wamboldt, 1983; Coolican et al; Degnar & Gow, 1988(a); Dickinson et al., 1992; Dickinson, 2006; Dickinson, 2007; Dickinson et al., 2008; Downe-Wamboldt & Tamlyn, 1997; Field & Kitson, 1986; Lloyd-Williams & Field, 2002; Thrush et al., 1979; Quint & Strauss, 1964; Quint, 1967). In the following section of this chapter, the key results are discussed in relation to preparing students and new graduate nurses to perform in the role of caring for a dying patient and their family in an acute-care hospital.

The first key result suggests education on death and dying among Australian undergraduate nursing programs is inconsistently presented. This means undergraduate programs offer a myriad of education on death and dying. The outcome leads to students graduating with varying levels of capabilities, knowledge and skills in the fundamental principles of palliative care. This variance arises because no agreement exists on the minimal or core capabilities graduate nurses need to provide quality care to dying patients and their families. As a consequence dying patients and their families are most likely to be recipients of care that differs widely in quality. The

Australian community's expectation is that they will receive high quality palliative care across a range of health care settings (PCA, 2008). Mallory (2001) suggests this situation reflects the reality that the provision of education on death and dying in undergraduate nursing curriculum has not kept pace with the needs of their students or the wider community.

The inconsistent presentation of education on death and dying also highlights the lack of recognition Australian curriculum designers have ascribed to accessing previously conducted research in this field. Accessing this information would show that internationally, student and new graduate nurses have identified the specific educational needs they require of their program to adequately prepare them for this practice. In addition, this lack of recognition demonstrates the failure by curriculum designers to use educational research as evidence to inform curriculum development (Quint, 1967).

The second key result identified education on death and dying in undergraduate curricula has a minimal presence in Australian nursing programs. A minimal presence assumes curriculum designers assign education on death and dying a low priority status relative to other curriculum content. The finding of a minimal presence and assigning a low priority status are also reported in other studies conducted in this field (Burney-Banfield, 1994; Dickinson et al., 2008; Field & Kitson, 1986; Lloyd-Williams & Field, 2002; Quint, 1967; Thrush et al., 1979). Several curriculum design elements contribute to a minimal presence and assignment of a low status.

This survey reported the majority of programs frequently use integration as the approach for incorporating education on death and dying into their program. These findings are synonymous with the majority of international studies reviewed (Coty & Downe-Wamboldt, 1983; Coolican et al., 1994; Degnar & Gow, 1988b; Dickinson, 2006, 2007; Downe-Wamboldt & Tamlyn, 1997; Field & Kitson, 1986; Thrush et al., 1979). An integrated approach, as compared to a discrete module, is more likely to lead to education on death and dying being invisible to the student (Degnar & Gow, 1988b; Dickinson, et al., 1992). Several reasons lead to this invisibility. In using an integrated approach the content is subsumed into other topics, or modules or both. Structuring learning experiences in this way may act as a barrier to students being able to discern what content relates specifically to the principles of palliative care. By comparison, structuring education on death and dying into a discrete and cohesive learning experience is supportive of students making these links to the overall concept. Enhanced visibility is also gained when it is named as such (Degnar & Gow, 1988b). Mallory (2003) argues that an integrated approach may therefore be an ineffective and inefficient way to structure learning experiences on death and dying. She believes without a more explicit structure educators out of necessity may be inclined to either miss completely or give little emphasis in their teaching to the principles of palliative care (Mallory, 2003). This has the potential for students to fail to recognise the teaching as palliative care.

In this survey, education on death and dying were reported as being scheduled across the six semesters of the program without a preferred semester for teaching identified. This scattered approach further dilutes the presence of specific palliative care content to the student. A further consequence of this approach sees death and dying concepts

unable to be spiralled to support the student acquiring palliative care knowledge and skills as they mature as a learner and into their professional role. Mallory (2003) suggests the timing of death and dying sessions may be important to how students receive, assimilate and transform attitudes. Furthermore she advocates research is needed to investigate if education should be provided in regular intervals across the curriculum or if a discrete module once has a long lasting effect (Mallory, 2001). If student's needs were taken into account in the planning of relevant education, then a by-product of this understanding would be the appropriate scheduling to meet the student's learning. Given the importance to the student's needs being the determinant in planning relevant educational experiences, limited reference to this element is found in other studies (Coolican et al., 1994; Thrush et al., 1979). Coolican and colleagues (1994) identified the inclusion of planning in their survey but failed in their article to report their results. The study by Thrush et al., (1979) did not include this element as a survey question but highlighted that future research should address this area.

The basis of a minimal presence is also argued on the low teaching hours allocated to education on death and dying. On average between 5-10 hours were allocated. This result infers education on death and dying competes with curative care topics which traditionally have received a higher percentage of the total curriculum hours (Mallory, 2001). Receiving a higher percentage of teaching hours in itself offers more visibility than when low hours are allocated. Many of the international studies reviewed report similar findings (Burney-Banfield, 1994; Dickinson, 2007; Downe-Wamboldt & Tamlyn, 1997; Field & Kitson, 1986; Lloyd-Williams & Field, 2002; Thrush et al., 1979) with only a slight increase noted over time. However, the exception is found in

the Dickinson et al. (2008), study in which UK pre registration nursing programs have on average 44.5 hours dedicated to this area. The reason attributed to this dramatic increase is associated with various reports which recommended such an increase in hours was necessary in order to support health professionals acquiring palliative care principles and practices (Dickinson et al., 2008). Furthermore, low hours in tandem with a widespread number of topics, suggests these topics are insufficiently covered in the depth required for nurses to practice confidently and competently.

Generally care for the dying was not seen as an educational priority until recently (Dickinson et al., 2008; Field & Cassell, 1997). Specifically, Quint and Strauss's (1964) study first highlighted this need to nurses. Several reasons are put forward for the continued low priority ascribed to education on death and dying by designers of undergraduate curriculum. The reasons proposed are: an overly crowded curriculum already exists due to rapid increase in knowledge and technology (Mallory, 2003), time constraints (Dickinson et al., 1992; Quint & Strauss, 1964), curriculum development designs which are content laden and highly structured (Moyer & Wittmann, 2008), lack of effective teaching skills and resources (Mallory, 2003), a scarcity of suitably educated academic staff in generic palliative care, confident to teach in this area (Dickinson et al., 1992; Lloyd-Williams & Field, 2002; Quint & Strauss, 1964; Thrush et al., 1979), existential fear of death by designers of undergraduate nursing programs and those who teach (Mallory, 2003), academics continuing to develop curriculum unresponsive to the current societal and healthcare trends (Moyer & Wittmann, 2008) and a prevailing attitude by curriculum designers who devalue this topic area against acute care topics within the overall curriculum (Dickinson et al., 1992). All these reasons play a contributory role to the invisibility

of this area in undergraduate nursing curriculum overall. While some change has recently been reported in the UK (Dickinson et al., 2008), Canada and the U.S.A show smaller improvements by comparison.

The third key result concerns the pedagogical underdevelopment of the learning and teaching strategies reported by this study. This survey identified an absence of experiential learning experiences among the vast majority of programs. Several aspects of the learning and teaching process provide the evidence for underdeveloped pedagogy and are outlined below.

The use of formal, didactic lectures as the primary teaching method in Australian undergraduate nursing curricula are synonymous with their international counterparts (Caty & Downe-Wamboldt, 1983; Dickinson et al., 1992; Dickinson, 2006, 2007; Dickinson et al., 2008; Downe-Wamboldt & Tamlyn, 1997; Field & Kitson, 1986; Lloyd-Williams & Field, 2002; Quint & Strauss, 1964). A lack of resources and educator knowledge have continued to see the lecture format as the prevalent teaching method (Caty & Downe-Wamboldt, 1983; Dickinson, 2006, 2007; Dickinson et al., 2008; Dickinson et al., 1992; Downe-Wamboldt & Tamlyn, 1997; Field & Kitson, 1986; Lloyd-Williams & Field, 2002; Quint & Strauss, 1964). This view is further reinforced by the low teaching hours and priority in the overall curriculum. This teaching method however is antithetical to research which advocates that palliative care education is best delivered by experiential strategies (Durlak, 1978; Johnson & Jackson, 2005; Sheehan & Ferrell, 2010; Spruyt et al., 2007; Yates, Clinton & Hart, 1996). The numerous benefits in using experiential teaching methods in the education

of death and dying are known (Johnson & Jackson, 2005; Sheehan & Ferrell, 2010; Spruyt et al., 2007; Wee & Forbes, 2007; Yates et al., 1996).

Several international studies also surveyed to identify the teaching strategies used by undergraduate nursing programs (Coty & Downe-Wamboldt, 1983; Dickinson et al., 1992; Dickinson, 2007; Dickinson et al., 2008; Downe-Wamboldt & Tamlyn, 1997; Field & Kitson, 1986; Lloyd-Williams & Field, 2002). Lecture followed by small group discussion was also reported by these studies to be the most frequently used teaching strategy. However, small group discussion and other means of teaching and resources are reported in some USA programs to slowly replace formal lectures (Dickinson, 2006). The most likely reason for this change is the support provided to educators through a formal training program for all nursing faculty responsible for teaching end-of-life issues, which commenced in 2001 (Ferrell, 2007; Paice et al., 2007; Sherman et al., 2003). A recent Australian initiative has also attempted to support educators in the education of death and dying (PCC4U, 2005) but its impact in penetrating undergraduate curriculum, in particular nursing curricula, remains unreported to date.

In tandem with formal lectures used as the primary teaching strategy, a written, formal examination most frequently evaluates students' learning on death and dying. Assessment of learning is infrequently surveyed by other studies. Lloyd-Williams & Field (2002) believe that this topic is rarely assessed and therefore this may in part explain why not many studies considered surveying for it. When this element is surveyed the results confirm the main approach used is written examination (Downe-Wamboldt & Tamlyn, 1997; Field & Kitson, 1986). However, Wee & Forbes (2007)

advocate the need for the inclusion of a variety of assessment tasks to mimic the holistic approach embedded in palliative care that requires reflection in the education provided. Inclusion of a variety of tasks would result in the students' attitudes, knowledge and skills, as applied to the whole person, being assessed rather than the current emphasis on regurgitation of knowledge (Wee & Forbes, 2007). Such an approach also reflects the value held in palliative education that it is a combination of attitudes, knowledge and skills which enables the student to adequately support the 'whole person experience' when caring for someone who is dying (Becker & Gamlin, 2004; Yates et al., 1996).

A further aspect which confirmed poor pedagogy was the sole reliance on nurses to teach education on death and dying. This reliance reflects a 'nurse-centric' approach which is antithetical to palliative care philosophy which advocates a multidisciplinary approach to care. This pedagogical feature is also reported elsewhere (Adriaansen & van Achterberg, 2008; Caty & Downe-Wamboldt, 1983; Dickinson et al., 1992; Dickinson, 2006, 2007; Dickinson et al., 2008; Downe-Wamboldt & Tamlyn, 1997; Field & Kitson, 1986). Possible explanations as to why this occurs are presented in several of the reviewed international studies. The majority of academics teaching nursing are from the nursing discipline and schools tend to draw on their own academic discipline to teach (Field & Kitson, 1986). In some USA nursing schools an attitude is present that nurse educators do not feel the need to bring in 'outsiders' to teach their own because they are comfortable to do so (Dickinson, 2007). This is possibly due to the education of faculty which has been going on for some time (Ferrell, 2007; Sherman et al., 2003).

In the UK study conducted by Lloyd-Williams and Field (2002) they reported two thirds of their program co-ordinators had difficulty in finding appropriate people to teach this area. Furthermore, accessing other health related professions to teach outside of their discipline or recruitment from the clinical areas was also identified as problematic (Lloyd-Williams & Field, 2002). Dickinson's (2006) comparison study on end-of-life issues from 1984-2006 in nursing curricula identified a greater presence of multidisciplinary teaching in 1984 than was found in 2006. A possible explanation given for this finding was the opportunity for USA faculty staff to access specific, formal training in end-of-life issues as compared to staff in other countries (Dickinson, 2006).

Of significance to learning about caring for dying patients is the need for well planned and supported clinical placements to consolidate the student's knowledge and skills acquired in the classroom (Degnar & Gow, 1988a, 1988b; A. Johnson, 2007; Quint, 1967). In particular, Mallory's (2003) study showed exposure to dying patients while learning about how to care enhances students' attitudes towards the dying. Seventy two percent ($n = 18$) of the surveyed Australian nursing curricula reported no intent to assign a planned and specific clinical placement during the student's undergraduate program. When exposure to a dying patient did occur it was either ad hoc or as a result of being a participant in a palliative care elective. Palliative care is about being with and having a presence with the dying patients and their families (Sherman et al., 2003) and learning experientially underpinned by a sound theoretical foundation that is well facilitated by clinical teachers. Full immersion of the learner into a planned clinical experience exposes the student to dying patients, their families and expert role models. Planned clinical placements offer a greater opportunity to bridge the theory-

practice gap when combined with classroom learning (Mallory, 2003). They also further enhance skill development not achievable in classroom or simulated learning environments. Internationally, nursing programs acknowledge that the clinical area is central to students' learning (Conway & McMillan, 2006).

Few international studies reviewed specifically included this element in their survey questions (Coty & Downe-Wamboldt, 1983; Degnar & Gow, 1988b; Dickinson, 2007; Downe-Wamboldt & Tamlyn, 1997; Thrush et al., 1979). When it was reported, Dickinson et al. (2008) identified 62% of students in UK pre registration programs attempt to provide a hospice experience while Coty & Downe-Wamboldt's (1983) Canadian study showed only one out of thirty three programs systematically assigned students to a dying patient. More recently a study by Downe-Wamboldt & Tamlyn of Canadian and UK nursing and medical programs revealed the majority of Canadian (66%) and UK (57%) nursing programs provide most students with an opportunity to work with dying patients while the Lloyd-Williams & Field (2002) study showed that 51% of their respondents indicated the need for more clinical placements related to death and dying be provided.

Australian universities have repeatedly faced difficulties in organising planned clinical placements overall for their nursing students (Chang & Daly, 2008), let alone attempting to provide a specific placement in caring for dying patients and their families. However Cooper & Barnett (2005) recommend learning about caring for dying patients be an integrated experience which consists of exposure in clinical practice as well as classroom learning. They consider it is highly beneficial for the student's anxiety levels but must be well supported using reflection to promote

learning otherwise the experience acts as a stressor. Between 48 – 62% of students in UK and USA programs, receive a limited assignment to specific clinical placements which appear linked to the availability and access to hospices and palliative care units (Dickinson, 2007; Dickinson et al., 2008). There are still many barriers in Australia to be overcome to facilitate the ‘best’ placement opportunities for nursing students (Chang & Daly, 2008).

4.7.1 Implications for education

These key results provide future direction for Australian nurse education and in particular the curriculum development of education on death and dying in undergraduate nursing programs. Yates (2007) suggests the focus has to be on undergraduate students curriculum because many people dying may have uncomplicated needs easily addressed by a palliative care approach being implemented by all health care professionals. This suggestion is equally applicable to nurses who if adequately prepared with the fundamental knowledge and skills in a palliative care approach by their undergraduate program would be able to undertake such care (Becker, 2009a, 2009b, 2009c; Yates, 2007). Further verification of this need comes from nurses in practice who see that their practice is deficient because of little input from their initial nursing program (Cooper & Barnett, 2005; Dunn, et al., 2005; Pimple, et al., 2003). Moyer and Wittmann (2008) argue therefore that changes to nursing practice demand new approaches to and the transformation of nursing education. Ferrell, and colleagues (1999) strongly advocate that changing curricula is the first step toward changing practice.

Giddens and Brady (2007) suggest there is significant need for curriculum reform globally to better meet the health needs of communities, to be research-based and

apply pedagogical innovation. Similarly, van Manen (2002) has called for educators to be much more cognisant of the current agendas which exist in students' everyday practice so that teaching (and hence curriculum development) is a responsive representation of this comprehensive understanding. In Australia this call for reform has most recently been led by Walker (2009). With respect to education on death and dying however, Quint (1967) first called for curriculum reform in this field. Quint showed that students who receive systematic education and planned clinical experiences were more likely to develop positive attitudes and less likely to withdraw from care. A curriculum framework which is evidence-based will support program development better able to produce graduates capable of fulfilling their roles and responsibilities and providing improved clinical practice (Conway & McMillan, 2006; Moyer & Wittmann-Price 2008; Walker, 2009).

Based on the survey results it is highly questionable that the educational experiences provided in Australian undergraduate nursing programs are sufficiently adequate to prepare nurses with the relevant attitudes and values, knowledge and skills in a palliative care approach. International studies identify students believe they are inadequately prepared by their nursing program (Allchin, 2006; Beck, 1997; Ferrell et al., 2000; Hopkinson et al., 2005; Kelly, 1999; Loftus, 1998; Van Rooyen et al., 2005). A lack of consensus exists on how to best design nursing curricula and the educational experiences to adequately prepare Australian nurse graduates for this role. Also of concern is the lack of evidence to suggest students and new graduate nurses well being for future death and dying encounters are supported. Yet, increasingly they are called upon to care for more and more dying patients and their families in acute-care hospitals.

Seeking feedback from students and new graduate nurses would be useful in future curriculum planning. Following students during their transition year may provide additional insights regarding the effectiveness of undergraduate curriculum to their newly acquired role (Barrere, Durkin, & La Coursiere, 2008). This information would elicit an assessment of the nurse's level of preparedness to engage with dying patients and their families. Furthermore, a curriculum design which promotes a culture of self reflection on death, the learner's own mortality and their practice will have a significant impact on a student's growth both personally and professionally. Such insights could then be used to guide the development of relevant education experiences on death and dying to better meet the needs of students and new graduate nurses. Planning education experiences aligned to the projected needs of the Australian population will also serve to ensure the delivery of contemporary practice.

Informing undergraduate nursing curricula through these means provides an evidence base. It is from this evidence base which leads to curricula constructed with a capacity to turn out a product for its intended purpose. The intended purpose in this instance is for Australian nurses to deliver a palliative care approach to dying patients, regardless of their end-stage disease, in any setting of an Australian acute-care hospital. Recent research suggests that with the incorporation of relevant palliative care principles and practices into undergraduate nursing curricula it is possible to increase the clinical effectiveness and competence of nurses (Loftus & Thompson, 2002).

Finally these Australian results make a further contribution to improving the global delivery of palliative care provision in undergraduate nursing programs. They have recently been published (Johnson, Chang & O'Brien, 2009).

4.7.2 Limitations

Four limitations were identified in this descriptive survey study. Firstly, the use of descriptive statistics only for analysis, limits the description generated to that of the study sample. The description is not able to be generalised to other contexts. However, the description generated was comprehensive enough to give insights into the current curriculum practices used by Australian undergraduate nursing programs to provide education on death and dying.

Secondly, the survey was dependent on the respondents' self reporting. Self reporting may have influenced the results reported in the following ways. Respondents with a specialist palliative care background may have inflated their responses in their desire to provide a more positive account. Lloyd-Williams and Field (2002) also suggest respondents who complete surveys on death and dying, do so because they are interested in this area. As a result, they are more likely to overestimate rather than under-estimate the nature of their program's experience. Respondents lacking expertise in curriculum design and or lack familiarity with their program's curriculum documentation may also have influenced the results. Self-reported survey data tends to be limiting because closed-ended questions constrain respondents without opportunities to expand on responses.

Thirdly, the term death and dying was open to interpretation. The respondents' interpretation was shaped by their personal and professional experiences on death and dying and the differing terms used in the literature and nurse education.

Finally, the data was insufficiently detailed to enable a determination as to why certain core elements of curriculum design had been included or excluded in each of the individual nursing programs.

4.8 Conclusion

This chapter has provided a discussion on the descriptive survey study conducted as phase one of the study. Discussion on the development of the survey instrument used, the key results obtained and implications for nurse education are presented.

The following chapter presents a discussion on the methodology used to conduct phase two of the study. The following chapter outlines how hermeneutic phenomenology, informed by van Manen (1990) was applied, followed by a detailed discussion on the method and quality strategies used for data analysis in phase two of the study. The phase two findings are presented in chapter six.

CHAPTER 5

PHASE TWO STUDY

5.1 Introduction

This chapter is presented in three sections and outlines the methodology, method and quality strategies used to conduct phase two of the study. The first section provides the rationale for selecting hermeneutic phenomenology, informed by van Manen (1990), as the methodological framework to guide the conduct of phase two of the study. Section two details the method employed, and outlines the procedures used for participant recruitment, data collection, management and analysis in this study. The final section outlines the strategies used to ensure the quality of this study in relation to trustworthiness and transferability. The findings generated from phase two of the study are presented in chapter six.

5.2 Methodology

5.2.1. Qualitative Paradigm

The purpose of phase two of the study was to understand the Australian nurse's experience of caring for adult dying patients and their families in an acute-care hospital. The qualitative paradigm was selected to frame the overall conduct of phase two of the study. When a study's purpose seeks to examine subjective human experiences a qualitative mode of inquiry is considered the most suitable (Jackson & Bobasi, 2008). Congruence existed therefore between the purpose of the study and selecting the qualitative paradigm to frame this study. Both explore human life experiences from the participant's perspective in their natural setting (Burns & Grove, 2009; Jackson & Bobasi, 2008; Polit & Beck, 2010; Whitehead, 2007a). The

decision to use a qualitative paradigm to guide the conduct of this phase two study was therefore based on the study purpose.

Irrespective of the specific approach adopted, the goal of qualitative research is to gather information from those who possess knowledge of the subjective experience so that their feelings, perceptions and thoughts are made accessible (Burns & Grove, 2009; Jackson & Bobasi, 2008; Polit & Beck, 2010; Whitehead, 2007a). Viewed through the qualitative lens, life experiences are seen as multifaceted phenomenon and not as a single, fixed, objective reality (Jackson & Borbasi, 2008; van Manen, 1990). Thus undertaking a qualitative investigation of complex phenomena, such as death and dying from the perspective of Australian students and new graduate nurses, are highly amenable to this form of enquiry (Jackson & Borbasi, 2008; Polit & Beck, 2010).

Further justification in selecting the qualitative paradigm was based on the compatibility of this inquiry mode to investigate nursing issues, problems and research questions (Jackson & Borbasi, 2008; O'Brien, 2003; Streubert, Speziale & Carpenter, 2007; Whitehead, 2007a). Nurses through their everyday practice are committed to participating in the human experiences associated with living and dying (Jackson & Borbasi, 2008; O'Brien, 2003). As such nurses are also interested in developing holistic understandings of people and their experiences (Jackson & Borbasi, 2008). Therefore studies seeking to understand the nurse's experience of their practice in specific patient situations are ideally suited to qualitative investigation (Jackson & Borbsai, 2008; Van der Zalm, 2000; Whitehead, 2007a). Furthermore qualitative inquiry provides researchers with methodical and rigorous

ways of exploring and explicating meaning from life experiences (Jackson & Borbasi, 2008). Inductive reasoning processes are used to understand the whole phenomenon being studied in the context in which it is situated (Jackson & Borbasi, 2008). The outcome qualitative researchers seek is a holistic and comprehensive understanding of the phenomena (Jackson & Borbasi, 2008; Whitehead, 2007a). Knowledge produced in this way provides an evidence base which serves to highlight the need for change and improve future nurses' practice (Whitehead, 2007a).

By contrast the quantitative paradigm is a form of inquiry concerned with the frequency, effectiveness and timing of interventions and treatments instituted (Burns & Grove, 2009; Polit & Beck, 2010; Whitehead, 2007a). Explanation of human behaviour, in quantitative inquiry, is through detached observation, controlled experiment or numerical measurement (Burns & Grove, 2009; Polit & Beck, 2010; Whitehead, 2007a). The quantitative mode of inquiry was considered unsuitable for conducting phase two of the study as it was unable to explicate meaning of human phenomena (B. Taylor, 1993; Van der Zalm, 2000; van Manen, 1990; Whitehead, 2007a). Use of the quantitative paradigm to conduct phase two of the study would have denied the human dimension of this phenomenon and failed to access the multiple truths and perceptions held by individual nurse's about their experience (Newell & Burnard, 2006; Van der Zalm, 2000). The result would have meant that the purpose of phase two of the study would not have been achieved denying access to insights and knowledge which had the potential to inform nurse education.

The following terms: constructivist, interpretive, interpretative or naturalistic are often used in the literature interchangeably with qualitative paradigm (Burns & Grove,

2009; Polit & Beck, 2010; Whitehead, 2007b). However, Jackson and Borbasi (2008) suggest these terms reflect how different theoretical perspectives in qualitative research can be classified. In phase two of the study, the term qualitative is used to reflect the broader paradigmatic position used to guide the conduct of this study overall.

5.2.2 Phenomenology

Phenomenology was chosen, over other inductive approaches, as it has the capacity to investigate highly complex human phenomenon from those who have experience of the phenomena (Jackson & Bobasi, 2008; O'Brien, 2003). For this reason phenomenology was chosen to conduct phase two of the study. Phase two of the study aimed to investigate the Australian nurse's experience of caring for adult dying patients. The study required a methodology capable of seeking this understanding of a highly complex multidimensional and multi layered phenomena. As such investigating the phenomena of death and dying studies from the nurse's perspective was well suited to phenomenological investigation (Stephenson & Corben, 1997; Whitehead, 2007a). The qualitative paradigm offers several approaches capable of exploring the complexity, depth and richness present in most lived experiences (Burns & Grove, 2007; Jackson & Borbasi, 2008; Polit & Beck, 2010). After due consideration, and based on the purpose of phase two, other inductive approaches were discarded and phenomenology selected.

The goal of phenomenological research is to describe the entirety of an experience as it is lived and to understand what this means to those who live the experience (Jackson & Borbasi, 2008; Newell & Burnard, 2006). This description is accessed by gaining entry to the participants' world so that the essence or meaningful structures of

the lived experience are uncovered revealing the multiple truths which co-exist in an individual's reality (Polit & Beck, 2010). Phenomenology is underpinned by the premise that the way individual's *know* is through their perceptions (Jackson & Borbasi, 2008; Newell & Burnard, 2006; Polit & Beck, 2010). The best means to elicit perceptions of phenomenon is from those who live the experience (O'Brien, 2003; Whitehead, 2007a). Exploration in this way offered an opportunity to explicate understanding and meaning which had potential to generate findings that were holistic and comprehensive. From these rich and detailed descriptions of the phenomenon, exemplars are chosen to illuminate the embedded meanings in the experience to promote a deeper understanding and resonance in 'others' (O'Brien, 2003; Whitehead, 2007a).

Phenomenology acknowledges each individual's lived experience is uniquely situated and shaped by culture, history, language, purpose and values (Newell & Burnard, 2006; Polit & Beck, 2010). As a consequence phenomenology frequently uncovers previously hidden and complex meanings embedded in human life experiences (Polit & Beck, 2010; Stephenson & Corben, 1997; Whitehead, 2007a). Importantly, researching using a phenomenological approach demonstrates that all lived experiences are unique but also they are not totally different (Newell & Burnard, 2006).

In terms of understanding what the experience of caring for dying patients and their families meant to Australian students and new graduate nurses, phenomenology as a research approach has much to offer. By accessing individual perceptions of phenomena enables the experience to be shared so we can learn what it is like to be

this student and new graduate nurse, living the experience of caring for dying patients and their families. Gaining these insights, from those who live the experience, offers the best opportunity to inform others, instigate change based on evidence that has most relevance and likely to meet the needs of those who live the experience (Burns & Grove, 2009; Jones & Borbasi, 2003; van Manen, 1990; Whitehead, 2007a). Further justification in selecting phenomenology was accorded because of the synergies which exist between phenomenology and nursing. Both share the same beliefs and values about human beings, everyday human life events and the meanings this holds for those individuals who experience this phenomena (Burns & Grove, 2009; O'Brien, 2003; Polit & Beck, 2010; Whitehead, 2007a). As a methodological approach, phenomenology has the capacity to enable the understanding and meaning of events and experiences, as lived in our everyday, ordinary life to be explicated from a variety of contexts (Burns & Grove, 2009; O'Brien, 2003; Polit & Beck, 2010). Sharing these common beliefs provides the ideal synergies to produce a deeper understanding of what it means to nurses in their everyday practice to provide care to dying patients and their families in an acute-care hospital.

A final consideration in selecting phenomenology related to the need to examine this everyday practice issue in a rich and meaningful manner (O'Brien, 2003; Polit & Beck, 2010; Whitehead, 2007a). In the absence of any Australian studies conducted on this experience, phenomenology is highly suited to illuminating previously invisible issues through revealing meaning embedded in the phenomena (O'Brien, 2003; Whitehead, 2007a). The phenomenology findings generate 'pathic' understanding useful to nurses in the development of empathetic care and guiding nursing actions concerned with emotions and feelings (Mackey, 2005; van Manen,

1990; Whitehead, 2007a). These findings offer a critical examination of nurses' experience and provide evidence of potential need for change thus enhancing disciplinary understanding (Dowling, 2007; O'Brien, 2003; Polit & Beck, 2010; Whitehead, 2007a).

For these reasons, the other inductive approaches available in the qualitative paradigm, for example ethnography and grounded theory, were rejected on the basis of their unsuitability to achieve the purpose of phase two of the study (Burns & Grove, 2007; Polit & Beck, 2010; Whitehead, 2007a).

5.2.3 Hermeneutic Phenomenology

In phenomenology several different approaches to conducting research exist. The approach adopted to guide the conduct of phase two of the study, was van Manen's (1990) interpretation of hermeneutic phenomenology. In general, the aim of hermeneutic phenomenology is to gain entry into another individual's world to discover their interpretation and meaning of phenomenon in context (Burns & Grove, 2007; Polit & Beck, 2010). Hermeneutic phenomenology is attentive to both how things appear (descriptive phenomenology) and how things speak for themselves (interpretive phenomenology). Van Manen's (1990) approach to hermeneutic phenomenology addresses both the epistemological and ontological aspects of phenomenon (Jones & Borbosoi, 2003; van Manen, 1990). Addressing both the epistemological and ontological aspects of the experience of caring for dying patients and their families, allows multiple perspectives to be obtained. Using van Manen's (1990) hermeneutic phenomenology to access these multiple perspectives was considered the best phenomenological approach to generate the most complete and holistic understanding of the phenomena.

In striving to access the epistemological and ontological perspectives of an experience, van Manen's (1990) hermeneutic phenomenology draws on elements informed by the Husserlian (descriptive) and Heideggerian (interpretive) schools of phenomenology. Additionally, van Manen incorporates aspects of Merleau-Ponty's existentialism and Gadamer's work in relation to hermeneutics (Jones & Bobasi, 2003; van Manen, 1990). This eclectic mix, according to van Manen, allows him the means by which to elicit a more comprehensive and holistic understanding of the phenomenon than is offered by a single perspective (Jones & Bobasi, 2003; Polit & Beck, 2010). His interpretation of hermeneutic phenomenology places a significant emphasis on understanding the lived experience in relation to the cultural, historical, political and social context in which the phenomenon is situated (Polit & Beck, 2010; van Manen, 1990). The focus for van Manen is on how individuals interpret their world in any given context and the meaning this generates of the phenomenon being studied (Polit & Beck, 2010; van Manen, 1990).

Van Manen (1990) argues that the hermeneutic element of his approach assists the researcher to illustrate to others the shared experience through "borrowing the words of another since this other person is able, or has been able, to describe an experience in a manner [with a directness, a sensitivity, or authenticity] that is beyond our ability" (van Manen, 1990, p.113). He considers the research-writing involved in the investigation of phenomenon to be a creative process that requires "a high level of reflectivity, an attunement to lived experience and a certain patience or time commitment" (van Manen, 1990, p.114). For example, the co-creation of the interpretative text between participant and researcher is a powerful means of influencing others to initiate change in education and practice. He sees this as an

important source of new knowledge from which others can gain understanding. By making visible and sharing this new knowledge van Manen asserts that change to practice is possible.

A further consideration for using van Manen's (1990) hermeneutic phenomenology is that the approach is reliant on language in the form of a conversational interview. Through this conversational interview a participant's personal life story on living the experience is revealed (van Manen). Holding conversational interviews has synergies with nurses in particular, as they conduct a large percentage of their work based on oral communication. Hence, the use of a conversational interview style provided a more comfortable and easier means to promote the participant's recall of their story as compared to a written recount. It is from this conversational interview that a written text is created that allows for meaning to be explicated through a process of reflection and re-writing that leads to interpretation (Jones & Borbasi, 2003; van Manen). Van Manen does not advocate a set of procedures to undertake phenomenological research but rather argues interpretation stems from the deliberate act of describing aspects of an experience in textual form.

The final consideration in selecting this method is van Manen's (1990) pedagogical relationship between research method and educational research. His method was aligned to my own pedagogical understandings and allowed me to have a voice in this experience. This further contributed to gaining a complete understanding of this phenomenon by presenting sensitive insights into the processes of teaching and nursing from an educator's perspective. Van Manen asserts that for educationalists to understand their students' experiences, they too must live the experience and study it

in a way which allows them to also be immersed with the phenomena studied. Van Manen believes that this engagement between researcher and participant, afforded by this research inquiry, makes for more sensitive and competent teachers and practitioners who thus understand experiences in practice.

5.3 Method

5.3.1 Overview

Van Manen (1990) does not believe in a predetermined set of fixed procedures, techniques or concepts to investigate phenomenon but rather offers the practical means by which the researcher can be a sensitive observer of the subtleties of everyday life (van Manen). This practical means is afforded through the interplay between six research activities that provide the elemental methodical structure to guiding research informed by van Manen. These six research activities are:

- turning to a phenomenon which seriously interests us and commits us to the world;
- investigating experience as we live it rather than as we conceptualize it;
- reflecting on the essential themes which characterise the phenomenon;
- describing the phenomenon through the art of writing and rewriting;
- maintaining a strong and oriented pedagogical relation to the phenomenon;
- balancing the research context by considering the parts and whole.

(van Manen, 1990, pp. 30-31)

The following discussion outlines how each of these methodological themes was applied in guiding the conduct of phase two of the study.

5.3.2 The Setting

Phase two of the study was conducted in two settings. The first setting was in a tertiary nursing school located in an Australian university offering an undergraduate nursing program. The university was located in a semi rural setting. The second setting consisted of several hospitals which offered hospital new graduate programs of 12 months duration. These hospitals were in proximity to the university's nursing school.

5.3.3 The Participants

5.3.3.1 Researcher as participant

My strong interest in the phenomena of caring for dying patients in an acute-care hospital spans more than 20 years and is the culmination of being involved in a number of different roles that have given me some insight into the need for the improved preparation of nurses' practice in this area. These roles include: student nurse, graduate nurse in a surgical ward and an educator of nurses in both clinical and classroom settings in the hospital and tertiary sectors. Prior to undertaking the phase two study interviews, I engaged in a period of introspection using the overall study question to guide my reflection. This allowed me to describe what the experience of caring for a dying patient and their family in an acute-care hospital was like for me, to recall any feelings I had at this time and to express any feelings which emerged at the time of writing the recount. Engaging with the phenomenon in this way allowed me to make some sense of this experience from my professional life in a more meaningful way. Achieving this meaning translated into gaining insights into what the participants might describe and the emotions and feelings they might express.

Participating in this self reflection assisted in maintaining my orientation to the phenomenon under study, in conducting clearly focussed participant interviews and supported the on-going interpretation of the data (van Manen, 1990). Furthermore as a result of this writing-reflective process, I brought my unique perspective to the experience being explored. Van Manen believes both participant and researcher therefore offer an individual perspective of the experience which contributes to the ongoing interpretation and meaning that is made. Engaging with the lived experience in this way extends the researcher's role beyond that of a researcher to be re-defined as that of a co-participant (van Manen). This redefinition recognises the researcher's experience as possibly the experience of others and the dialogical iteration engaged in, when interviewing their study participants, promotes further reflection and interpretation. The interpretation co-created between borrowing from others experiences and adding the researcher's reflections, promotes a more complete and deeper understanding (Gillis & Jackson, 2002; Stephenson & Corben, 1997; van Manen, 1990).

5.3.3.2 Interview participants

Fourteen participants with the experience of caring for adult dying patients and their families in an acute-care hospital agreed to share their experience during a face-to-face interview with the researcher at two time intervals during the conduct of the phase two study. A fifteenth student volunteered for the phase two study but while conducting the interview it became apparent that the student did not have experience of the phenomenon being studied. The student expressed a desire to talk to someone about fears at work and saw this as her only opportunity. This data was therefore not included in the study. According to van Manen (1990) the primary criteria in selecting participants is that they should have direct, personal knowledge about the

phenomenon being studied and be ready to share their experience. Of importance to achieving quality findings the participants recruited must have the capacity to engage in reflection and an ability to verbally describe and express their feelings in a detailed manner on the phenomenon being studied (O'Brien, 2003; Streubert Speziale & Carpenter, 2007). Failure to recruit in this manner leaves the findings vulnerable and at risk of being compromised (Whitehead, 2007a).

Several recruitment cycles were instigated in this study as participant numbers were low. The low participant numbers initially gained in this study had the potential to impede the opportunity to access rich and detailed experiences required for the interpretive processes used in this study. The researcher therefore had a responsibility to ensure that the sample size was sufficient to achieve data saturation. In qualitative studies sample size is largely unpredictable and dependent upon the data being adequate enough to generate rich and comprehensive descriptions of the phenomenon (Gillies & Jackson, 2002; Whitehead & Annells, 2007). Data saturation occurs when no new material is revealed or the data emerging becomes repetitive (Burns & Grove, 2009; Polit & Beck, 2010; Whitehead & Annells, 2007). Typically sample size ranges between 5 – 15 participants but can vary on either side of this range and are still considered credible (Gillies & Jackson, 2002; Jackson & Borbasi, 2008; Whitehead & Annells, 2007). This is in contrast to quantitative methodologies which seek large numbers of participants for statistical significance (Gillis & Jackson, 2002; Whitehead & Annells, 2007).

When the first interviews were held all participants were in the final semester of their undergraduate nursing program. All participants reported being Australian born, with

no participants self identifying as an indigenous Australian. English was the main language spoken. Eighty six percent of the participants were female ($n = 12$) and 14% were male ($n = 2$). The participants ranged in age from 18 - 44 years of age. The majority of participants (71%, $n = 10$) were under 34 years of age with the remaining 29% ($n = 4$) in the 35 - 44 year age bracket. Nine (64%) participants reported an affiliation with a formal western religion, most notably Catholic ($n = 5$) followed by Anglican ($n = 4$). The remaining participants reported no formal religious affiliation.

Six of the original study cohort agreed to be re-interviewed on completion of their hospital new graduate program. Eight participants were lost from the study between the first and second interviews. Reasons given for non-participation in the second interviews were: entered directly into a midwifery program and therefore no longer met the inclusion criteria of completing a hospital new graduate program (2); and not eligible for registration due to illness (1). The remaining participants ($n = 5$) failed to re-contact the researcher after several requests to schedule a second interview had been made.

To understand the context in which the participant entered their undergraduate program in relation to personal and professional experiences with death and dying a series of questions were asked prior to the commencement of the first interview. Overall the majority of participants reported receiving no additional education on death and dying either in the context of their undergraduate program or as a result of being employed in a paid nursing role. Typically, these roles were either as an Enrolled Nurse or Assistant in Nursing. Two participants reported attending the palliative care elective offered by their undergraduate program. A further two

participants attended a single day seminar program, as part of their employed nursing role. Only one participant reported receiving formal education in grief and bereavement while in an employed nursing role prior to entering their undergraduate program. The vast majority of participants on entering the undergraduate program had not been exposed to a personal death. Six participants reported that through their employed nursing role they had been exposed to at least one patient death prior to entering the undergraduate program. During the course of their undergraduate program, nine out of the 14 participants gained employment in a nursing role concurrent to their studies. These participants, on average, were exposed to 5.2 deaths while in these 'other' nursing roles.

5.3.3.3 Recruitment process

Participant recruitment involved an initial approach to the Dean of Nursing for permission to commence the recruitment process. Approval was granted with the following caveat: that an intermediary academic colleague, namely the Bachelor of Nursing Course Coordinator, initiate the preliminary recruitment so as to diminish any perceived coercion. This requirement was necessary due to the dual role held by the study's investigator as an academic and researcher in the nursing school, where participant recruitment was planned. Using an intermediary is a widely accepted strategy when researching one's own students that helps to diminish the impact of any threat to the potential participant cohort (Clark & McCann, 2005; Liamputtong, 2007). Recruitment occurred across several program intake cycles. All study participants were the recipients of the same curriculum version of the undergraduate program with delivery by the same academic staff across all program intakes.

Information sessions inviting students to consider volunteering for this study were advertised via flyers posted on the nursing laboratory notice boards and in class announcements. Potential volunteers were advised that attendance at this information session did not imply their participation in this study. The intermediary colleague held a number of information sessions across a one week period. At the commencement of the information session The Plain English participant information sheet was distributed to those who attended (Appendix 2). The intermediary colleague then outlined the study aims, participant commitment and benefits from a brief prepared by the researcher. Further emphasis was accorded to the commitment required by the volunteer as it necessitated them being re-invited to undertake a second interview on completion of their hospital new graduate program. Furthermore the intermediary colleague advised the potential participants that given the dual role held by the study investigator she would not be involved in any aspect of their final semester education including finalisation of grades. This strategy sought to diminish any pressure the students may have perceived to participate in the study or that repercussions would occur if they withdrew. Any questions or concerns potential participants had at this time were addressed in the group setting. Due to the sensitivity of the topic being studied, the option of speaking outside of the group setting with the intermediary colleague was also offered. Students who expressed interest in volunteering for this study were provided with a consent form (refer to Appendix 3) and asked to arrange an individual meeting with the researcher.

Arranging an individual meeting with each potential participant served two purposes. Firstly it enabled the potential participant to discuss with the researcher any issues they did not feel comfortable raising in the larger information session or which

occurred as a result of reflection post session. Secondly, it supported the establishment of rapport that led to development of a trusting relationship between the researcher and participant prior to the interview being conducted. As the quality of this study's findings was reliant on the participants verbally disclosing their innermost feelings on their patient death experience, it necessitated that a comfort level sufficiently appropriate to each individual was achieved. These strategies were considered important in achieving the establishment of this comfort level. Due to the time lapse between the information session and individual meeting, the researcher provided a further explanation of the study and interview process. Once this had taken place the volunteer was sufficiently informed to make a decision as to whether they wished to participate or not. If the participant indicated a willingness to participate they were asked to complete the consent form (Appendix 3). Interviews were not conducted without the participants' consent being obtained. On completion of the consent form the final part of the meeting involved an interview schedule being negotiated between the participant and researcher.

5.3.4 Data Collection and Management

Data collection in phase two of the study was undertaken using an unstructured, conversational style of interview involving a broad, open question that started with *Tell me about ...?*. This form of interview style was chosen to facilitate story telling by the participants of their experience of caring for adult dying patients and their families. The use of a conversational style of interviewing encouraged an open, interactive, reflective and engaged discussion (Jackson & Borbasi, 2008; O'Brien, 2003; Polit & Beck, 2010; van Manen, 1990). Furthermore this style is more likely to promote a relaxed environment precipitating a deeper disclosure by participants on this sensitive topic.

5.3.4.1 Pilot Interview

Prior to conducting the first interview, the interview questions, process and schedule were piloted. The rationale for conducting a pilot study was two-fold. Firstly, undertaking interviews is a complex process which requires the researcher to have well developed interviewing skills (Burns & Grove, 2009; O'Brien, 2003; Polit & Beck, 2010; Whitehead & Annells, 2007). Secondly, exploring the sensitive topic of death with a vulnerable population adds another level of complexity to the interview process (Campbell, et al., 2001; Elam & Fenton, 2003; Liamputtong, 2007). Topics commonly investigated by phenomenological research are frequently intensely personal and often involve participants recalling a traumatic life event (Jackson & Borbasi, 2008). This necessitates the researcher formulating a well thought out research plan, anticipating potential distress and possessing the skills to support the participants' disclosure (Liamputtong, 2007; O'Brien, 2003).

To seek volunteers for the pilot study an advertisement was posted at another university nursing school. Three final semester students agreed to participate. Piloting of the first interview questions served to ensure that the questions supported the retrieval of sufficient depth and detail from the participants recount to support analysis and interpretation. Furthermore the researcher needed to ensure the questions were asked in a non judgemental and non threatening manner in order to promote the participant sharing their inner most thoughts (Burns & Grove, 2009; Polit & Beck, 2010; Whitehead & Annells, 2007). A pilot also provides the additional outcome of providing the researcher with an opportunity to anticipate potential distress and institute planned strategies to diminish their impact (Liamputtong, 2007; Zurbriggen, 2002).

The researcher's skills as an empathetic listener and an effective communicator were piloted to ensure the presence of a sensitive attitude which encouraged participants to share their story. The use of verbal and non-verbal expression, tone of voice, body language and the use of silence are examples of the interview techniques that were piloted. Other aspects of the pilot interview process included: the transcription skills of the researcher; preliminary immersion with the data to anticipate possible themes; an awareness of the level of distress and uncomfortableness the research question may pose for the participant and researcher and an evaluation of the research plan.

Adjustments to the interviewing process and the researcher's skills were made on the feedback gained from the pilot. These consisted of: decreasing the amount of talk the researcher engaged in with participants; increasing the use of silence to create the space for more reflective thought by the participant and the explicit use of a question to guide the participant back to the experience by recounting a concrete example. In addition, other aspects of the research plan piloted included quantifying the time required for interviewing, creating a comfortable environment, ensuring privacy, confirming that all items required to conduct the interview were available and able to be worked by the researcher. Instituting these measures facilitated the best possible interview process being created for the participant (Burns & Grove, 2009; Polit & Beck, 2010; Whitehead & Annells, 2007).

5.3.4.2 The Interviews

The researcher invited the participants to describe in their own words their experience of caring for adult dying patients and their families in an acute-care hospital. To encourage this description the researcher asked participants' an open, non directive question, to invite the participants to tell their story. Each participant was asked the following question: *"Tell me about your experience of caring for an adult dying*

patient and their family in your role as a student and how you felt at this time?” The basis for this opening interview question was informed by the phase one study results, literature review and researcher’s experience.

At the time of undertaking these face to face interviews, the researcher observed that all participants appeared willing to talk about their experience. At some point in the interview the majority of participants became teary and or uncomfortable, while recalling their feelings and issues that had confronted and challenged them while caring for a dying patient. Many of the participants indicated that this was the first opportunity they had to talk about their experience, while several stated having someone to just listen made them feel better.

Van Manen (1990) sees the researcher’s responsibility in a hermeneutic interview lies in keeping the question open and oriented to the phenomenon being studied.

According to O’Brien (2003) the researcher needs to engage with the participant in such a way so that the narrative contains sufficient material and examples to provide an understanding of the experience. The outcome, therefore, of a phenomenological interview is a descriptive and interpretative text that serves to illuminate understanding and meaning of the experience as it is lived (O’Brien, 2003; van Manen, 1990). For van Manen, hermeneutic phenomenological interviews serve two specific purposes:

“(1) it may be used as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and a deeper understanding of a human phenomenon, and (2) the interview

may be used as a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of the experience”

(1990, p.66).

Van Manen believes that all interviews are bound by a particular philosophical orientation resulting in agreed rules of conduct (van Manen). Interviews informed by van Manen’s philosophical orientation require the researcher to “ask what an experience is like ... by eliciting a concrete example by asking the person to think of a specific instance, situation, person or event” (van Manen, 1990, p.67). Following on from this, van Manen encourages the researcher to explore the whole experience to the fullest with the participant. Commencement of this exploration with the participant is undertaken by the researcher initially leading the participant to the phenomena in order to promote an optimal level of comfortableness. Van Manen discourages the use of multiple prompting questions when the participant falters with their story. He believes that the use of silence is a powerful way to facilitate the participant’s recollection of the experience that allows the participant to proceed (van Manen). When a block is evident van Manen encourages the researcher to “repeat the last sentence or thought in a questioning sort of tone” (1990, p.68). Additionally, whenever the participant starts to become general in the way in which they describe their experience van Manen suggests that the researcher “insert a question that turns the discourse back to the level of concrete experience” (1990, p.68). However it must also be acknowledged that no two interviews within phenomenological research are identical due to the unique encounter with each participant interviewed (Burns & Grove, 2009; O’Brien, 2003; Polit & Beck, 2010).

Each interview conducted in this phase two study lasted approximately 1-1 ½ hours duration. Generally interviews exploring the life experiences of others do not exceed a two hour time frame as the participant is most likely to become fatigued (Whitehead & Annells, 2007). Participants nominated the location for the interviews. On all but one occasion these were held on the university premises away from the school of nursing as it was a convenient location for participants. Demographic information was collected from the participants prior to the first interview commencing to support interpretation of the data.

All interviews were audio-taped. Use of this technology enables the researcher to focus on the participants' story and responses at the time of interview rather than concentrating on the recording of their words in a written format (Farley & McLafferty, 2003; Polit & Beck, 2010). Furthermore audio-taping facilitates the participant's language being captured (O'Brien, 2003). Having this ability to re-listen to the interview supports ongoing immersion with the participant's experience facilitating recall and on going reflection and interpretation by the researcher. At the completion of each interview the researcher wrote down any reflective thoughts which arose as a consequence to the interview. This activity of ongoing immersion and reflection with the data also assisted in the researcher's interpretation (Whitehead & Annells, 2007).

After the interview, the audio tape was transcribed verbatim into a written text. These transcriptions were circulated to the participants for verification of authenticity, which is referred to as *member checking* (Annells & Whitehead, 2007; O'Brien, 2003; Polit & Beck, 2010). Participants were asked to confirm the authenticity of the transcription

as a truthful written account of the audio-taped interview. They were also encouraged to make any additional contributions which were the result of ongoing reflection post interview. Participants were advised they could contact the researcher at any time if any further ideas, thoughts or feelings came to mind after the first interview. These additional reflections also contributed to the ongoing interpretation of the text. Owing to the longitudinal nature of this phase two study the researcher attempted to maintain participant contact via telephone and email as a means of promoting participant retention and maintaining the relationship established.

At the second interview participants were again invited to re-read their first transcript as a means of re-immersing themselves with the phenomenon and as a starting point for the second interview. From both perspectives, meeting for a second time afforded the researcher and participant an opportunity to clarify global or specific issues arising from or since the first interview. In their role as a new graduate nurse, these participants were invited by the researcher to recount their experience of caring for an adult dying patient and their family in an acute-care hospital. The opening question used to explore this phenomenon was: *Tell me about your experience and how you felt caring for an adult dying patient and their family in your role as a registered nurse?* The second interviews were transcribed and circulated as per the previously described process for interview one.

The rationale for incorporating a second interview at the completion of the participant's hospital new-graduate program was to determine whether they showed evidence of maturation in their experience of caring for an adult dying patient and their family in an acute-care hospital. At the start of the second interview, the

significance of the preliminary themes was confirmed by the researcher with the participant by the researcher asking: *Is this what the experience is really like?* Thus the second interview adopted a more interpretive conversational tone as the transcription of the first interview formed the starting point for sharing the phenomenon being studied. Including a second interview in the phase two study is consistent with van Manen's (1990) method. He believes an interview series promotes further reflection on the textual representation that leads to a deeper understanding and explication of meaning being attained (van Manen).

The use of a non-directive, interviewing style incorporating an open question in this study was more likely to encourage the participant to talk about the phenomenon than if a more structured, scripted interview schedule was used (Whitehead & Annells, 2007). Van Manen (1990) sees the conversational interview as the best means to gather experience. When participants moved away from the phenomenon, the researcher employed facilitative techniques to re-orient the participant. These included: asking the participant to provide a concrete example of what they were describing; the insertion of a question by the researcher that turned the conversation back to the phenomena, for example: *"You said before"* or *"What happened then?"*; and *"What is the significance of... for you?"* The emergent nature of phenomenological interviews requires that the participant speak freely and uninterrupted by the researcher (Polit & Beck, 2010; Whitehead & Annells, 2007; van Manen, 1990).

Phenomenological interviews enable the researcher to enter the participant's world to uncover and convey the true essence of their experience. Through the interview

process and the dialogical conversation that occurs as a consequence, detailed and rich experiential descriptions are elicited from the participant's verbal account of their experience. When human life experiences need to be accessed, phenomenological interviewing is considered the best means by which to gather these data (Clark, 1997; O'Brien, 2003). This is because phenomenological interviewing has the capacity to reveal meanings or the 'essence' of human life experiences that allows accessibility by others to create a shared understanding (Jones & Borbasi, 2003; Whitehead, 2007a).

Interviews as a data collection method have many benefits but also limitations. They are often considered time consuming and present challenges in gaining access to a participant's inner thoughts, exploring sensitive topics and in managing power relationships (Liamputtong, 2007; Whitehead & Annells, 2007). Furthermore O'Brien (2003) advocates that the researcher in phenomenological research requires effective interviewing skills to support exploring and eliciting the meaning of the experience and in asking for concrete examples to illustrate this meaning. In this study to overcome these perceived limitations piloting of the research questions, process and schedule assisted in ameliorating any potential impact the limitations may have had on the study.

5.3.4.3 Transcription

At the commencement of the transcription process a pseudonym was allocated by the researcher to de-identify the participant prior to the researcher's supervisors receiving copies of the transcripts for review. Because the researcher had previous experience transcribing the pilot interviews, and due to the number of interviews involved, a decision was made to employ a professional transcriber who transcribed

verbatim the audiotape of each participant's interview. To ensure the authenticity of the transcripts, the researcher re-listened to each of the audio tapes against the transcription generated for accuracy. This process also meant that the researcher was re-immersing herself with the data by re-listening to the taped interview and the reading of the transcript. The transcription represented the textual or written representation of the conversation between participant and researcher of the experience studied (van Manen, 1990). Conversion into a textual form makes the participant's language accessible to thematic analysis (O'Brien, 2003; van Manen, 1990).

5.3.5 Data Analysis

In phase two of the study van Manen's (1990) thematic analysis was used with the texts created from the transcription of the first and second interviews. The decision to use his approach to thematic analysis was based on the study's purpose of wanting to *know* what the experience of caring for dying adult patients and their families in an acute-care hospital means to students and new graduate nurses. Meaning, according to van Manen, is multi-dimensional and multilayered, accessible only through textual representation. His process of reflectively appropriating, of clarifying and of making explicit the structure of meaning of the lived experience was used (van Manen). Construction of phenomenological themes provides control and order to participants' experiential descriptions that makes meaning visible (van Manen). The researcher was attempting to grasp the essence of the experience so she could more fully live the experience in her role as an educator of nurses. These enriched understandings give permission for the researcher as an educator to be practically responsive to this everyday life experience by suggesting changes to education based on evidence (van Manen, 1997).

5.3.5.1 Van Manen's thematic analysis

Van Manen's (1990) thematic analysis consists of three approaches the: "wholistic or sententious approach; selective or highlighting approach and the detailed or line-by-line approach" (van Manen, 1990, pp. 92-93). Van Manen argues that applying one or more of these approaches to the written text will isolate or uncover thematic aspects of the phenomenon studied. The rationale for using all three approaches simultaneously was based on the presence of multiple realities and layers embedded in this complex experience. This multiplicity necessitated a procedure of analysis capable of revealing and making visible all these realities and layers to elicit a holistic understanding. Using one procedural approach only had the potential for meaning to remain hidden. Van Manen's procedure strives to capture the essence of the phenomena by describing an aspect of the structure of the lived experience. This is achieved through constructing themes that make visible the meaning of lived experience. In turn, this will resonate with others, initiating for them reflection of the phenomenon that leads to a shared understanding. In this phase two study, all three approaches were applied to the textual representations of the participant's interviews.

The wholistic reading approach involved the researcher re-reading all transcripts and asking a central question of the text: *What sententious phrase may capture the fundamental meaning or main significance of the text as a whole?* (van Manen, 1990, p. 93). By engaging in this process the researcher was attempting to formulate a sententious phrase or statement which expresses the meaning of the phenomenon being studied. In this phase two study, the overarching statement generated was: ***caring for dying adult patients and their families in an acute-care hospital for students and new graduate nurses was a traumatic and transforming experience.***

This thematic statement was the foci around which the phrases and sentences from the two other procedures were fastened so as to facilitate the construction of a phenomenological description (van Manen).

Following the crafting of this overarching statement the researcher moved to applying the next approach. Van Manen names this analytical procedure as selective reading. The selective reading approach involves the researcher re-listening to the audio-tapes and re reading each text several times and engaging in reflection as part of these processes. The researcher asks the question of the text: *What statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described?* (van Manen, 1990, p. 93). Following reflection on the thematic statement and comparisons across the participant texts, themes began to emerge. During re-reading recurring phrases and statements were selected and highlighted by the researcher as being thematic of the experience.

For example, it was clear that for all students and some new graduate nurses, a major aspect of their either being with or caring for a dying patient, was they felt confronted enough on several levels to cause significant distress. This reflection led to the theme of **‘Confronting death’** being crafted. Using key words, phrases, or sentences describing the theme were cut and pasted from each of the texts, gathered together and inserted under the theme. In consideration of the second interview being a part of the whole experience, the same process was undertaken and similar perceptions clustered under this theme. In composing the linguistic transformation of this phenomenological description three distinct sub-themes emerged to support this theme illustrating the different facets of confrontation felt by these participants. They

were: *Being repulsed at the physicality of death; Being intimate with the dying and Being lost*. A further two themes evolved from the participants' recall of their experience: **'Being transformed by death'** and **'Grieving the loss of a patient'**. Both themes had a presence in the participants first and second interviews. The final theme to emerge was: **'The buck stops with you: Being responsible for the care of the dying'** which came exclusively from the participants' second interview. This theme illustrated the process of taking on the mantle of the registered nurse role underpinned by the awareness of professional responsibility in this specific context.

The final approach consisted of the detailed reading approach. In this approach the researcher reviewed every sentence or cluster of sentences of the text, line by line asking the question: *What does this sentence or sentence cluster reveal about the phenomenon or experience being described?* (van Manen, 1990, p. 93). Individual sentences or clusters of sentences which revealed something about the nature of the experience being studied were also selected by highlighting, cutting and pasting and then linking to a phrase that best described their meaning. As further reading and reflection was undertaken over the course of this process, phrases and individual sentences were re-organised in an attempt to construct the best phenomenological description. Also sought were the differing perceptions on the nurses' experience. Importantly each participant's experience in being considered as a part of the whole was a uniquely individual experience that warranted understanding on its own. These differing perceptions were highlighted, set aside and are presented in chapter six.

Authenticity of the textual extracts was achieved by individually coding each transcript with a number that then allowed each of the sub-parts to be numerically

linked back to the original transcript. The researcher's supervisors confirmed and could trace the source of the textual extracts back to their original transcript. The supervisors read over the transcripts and engaged in ongoing dialogue with the researcher to ensure that the themes created were a true reflection of the participants' recounts and not those superimposed by the researcher's biases.

During the thematic analysis of the text the researcher needed to take a stance at several points throughout the process to look at the whole in relation to the parts to identify links and sub-themes emerging from the experience. This stance was necessary in terms of viewing the first and second interviews as parts, and then as a whole experience of the phenomenon. This process meant the researcher was continually immersed in the data. Data interpretation was further guided by van Manen's approach in the following ways: re-immersion, coupled with the researcher's on going reflections on text and being engaged in other literary and artistic sources related to the phenomenon being studied.

The findings generated from this thematic analysis are a synthesis of these three analytical approaches and are presented in chapter six.

5.3.5.3 Hermeneutic phenomenology writing.

Important to van Manen's (1990) method is writing. It is through the research-writing phase that for van Manen, interpretation and therefore meaning of the phenomenon being studied are generated. Typically analysis commences first but analysis and interpretation for van Manen are occurring at the same and are not easily discerned. Once the thematic statements were identified and the extracted text clustered under each theme, the researcher commenced writing a story. The use of

story is common for presenting hermeneutic phenomenology (van Manen). *Story*, in this sense, can illuminate previously hidden or inaccessible knowledge by evoking in the reader the need to also reflect on the experience (van Manen). The selected exemplar is the best means by which to illustrate the shared understanding of the phenomenon. Understanding therefore comes from the description of the phenomena by using the practice of phenomenological reflection and writing to promote interpretation (Van der Zalm, 2000). The place of writing in research is significant for van Manen, and he uses Merleau-Ponty's existential phenomenology to guide the researcher in terms of their phenomenological writing. Lived space, time, temporality and relationality contribute to understanding the whole experience in the total socio-historical context in which the phenomena are experienced.

Writing in this method is crucial to tie together the informal story by selecting the best exemplars to illustrate the participants' voices in a formal discourse (van Manen, 1990). These exemplars are borrowed from other people's words because they are more able to describe an experience in a manner more readily accessible to others than we ourselves can express (van Manen). Van Manen refers to this as re-thinking, re-reflecting and re-cognising that aims to create depth that lays bare the truths and meanings of the experience. It is an artistic endeavour of writing and re-writing by going back and forth between the parts and the whole that crafts a sensitive grasp of meaning and understanding of the experience (van Manen).

In borrowing from van Manen's work on the pedagogy of teaching (1988), the researcher (by adopting van Manen's method in phase two of this study) hoped to be more knowledgeable and therefore more responsive to the student and new graduate

nurse's experience of caring for adult dying patients. According to van Manen (1990) writing in this way is a powerful way to elicit change in practice through the directness, sensitivity or authenticity of the exemplars provided. The power lies in the way the researcher gains the reader's attention, leads them to reflect, engages them personally and transforms their thinking. Through this engagement, the reader makes interpretive sense of the phenomenon that creates a shared understanding that informs future decision making. Thus, shared understanding on what it means to nurses to care for an adult dying patient and their family in an acute-care hospital promotes the development of nursing knowledge by bridging the theory-practice gap (Stephenson & Corben, 1997; Whitehead, 2007a).

5.4 Quality Strategies

The criteria for establishing the quality of this study was achieved through use of a variety of strategies (Burns & Grove, 2009; Polit & Beck, 2010). Previously proving a qualitative study's quality was referred to as *trustworthiness* (Annells & Whitehead, 2007). The parallel term in quantitative research is *rigour* (Annells & Whitehead, 2007; Burns & Grove, 2009; Polit & Beck, 2010). In qualitative research strategies promoting the quality (or rigour) of a study have expanded (Polit & Beck, 2010). Selection of the strategies should be determined by the most appropriate criteria for that study (Annells & Whitehead, 2007; Polit & Beck, 2010). Similarly they should also fit with the inherent values underpinning the study's methodology. With respect to van Manen (1990), he is more focused on other forms of accountability, for example, disciplinary relevance, contextual awareness, moral defensibility in preference to applying a set of prescriptive standards as a means of

evaluating the study's quality. The following section outlines the quality strategies used and discusses how they were applied in this phase two study.

Achieving credibility in phase two of the study involved a variety of strategies. The research process and generation of the findings were overseen by the researcher's supervisors. The supervisors expertise in conducting research studies and in the specific methodology chosen for this phase two study supported achieving a credible study and findings (Annells & Whitehead, 2007; Burns & Grove, 2009; Polit & Beck, 2010). Both supervisors were involved at all decision points along the research journey and witnessed how the findings were developed. In qualitative studies verification by others of the effectiveness of the data collection procedures, the comprehensibility of descriptions, the inclusiveness of samples and the logic of arguments is an acceptable practice (Burns & Grove, 2009; Gillis & Jackson, 2002; Polit & Beck, 2010).

Credible findings in phenomenological research are further strengthened by providing a narrative illustrated by concrete examples drawn from the participants' experience (O'Brien, 2003; Polit & Beck, 2010). The exemplars, in phase two of the study, were drawn directly from the transcriptions of the interviews and were chosen as the best examples of the phenomenological description offered by the participants to promote resonance and understanding with others (O'Brien, 2003; Polit & Beck, 2010). The supervisors confirmed that the exemplars selected by the researcher were the best available from the study's data to illustrate the meaning of the phenomenon, and were derived from the data.

A further strategy to promoting quality and attaining credibility was provided by disseminating the phase two study findings at three international and three national conferences (refer to Appendix 5). This prompted readers of the research to also reflect on the phenomenon being studied causing resonance with their own experience, to have dialogue with the researcher and thereby contribute to creating a shared understanding of this experience. Other strategies included: evidence of congruence shown between similar studies and the findings of this study, with this study extending some of the previously identified findings and commencement and dissemination of aspects of the study through publication in peer-reviewed journals. This latter strategy is an acceptable means of strengthening the study through peer review of the findings and the research process that continues post study (Annells & Whitehead, 2007).

The integrity of the study was evaluated in terms of its relative cohesiveness and internal consistency from the research question through to interpretation of the data and findings. This process necessitated that key decisions made throughout the research process were sufficiently described and appropriately justified so that they were transparent and accessible to others. The decisions were made on the basis of congruence with the purpose of the phase two study and the methodology.

Furthermore, during the conduct of this phase two study the interview transcriptions were also viewed by the supervisors, and evaluation of the emerging analysis and interpretation was documented. The supervisors discussed and challenged the researcher regarding the data collection steps, analysis process and researcher's reflections. This strategy had the benefit of detecting bias or inappropriate claims that had emerged in attempting to fit interpretations and explanations not substantiated by

the data. This trail of decision making is often referred to as an audit trail and constitutes the criterion of audibility (Annells & Whitehead, 2007; Burns & Grove, 2009; O'Brien, 2003; Polit & Beck, 2010). Making explicit the decision trail within the study offers the accountability and evidence base upon which a reader can discern the merit of a study and the outcomes produced (Annells & Whitehead, 2007; Burns & Grove, 2009; Polit & Beck, 2010; van Manen, 1990).

Detailing not only the decisions taken but describing in detail the sample, context and research processes further informs other researchers and thereby provides an opportunity to replicate the study with other participants in similar contexts. The criterion of fittingness is also characterised by readers of the study's research process being able to discern the level of importance of this study to their own practice and research. The criterion of fittingness may also be referred to in some literature as *transferability* (Annells & Whitehead, 2007; Burns & Grove, 2009; Polit & Beck, 2010; van Manen, 1990). Finally, the criterion of confirmability, as identified by Annells and Whitehead (2007), is demonstrated by the presence of all three standards: credibility, audibility and fittingness being present in phase two of the study.

This chapter has described the phenomenological research process used to conduct the second study of this two-phase mixed method study. In particular, the discussion details the specific methodology, hermeneutic phenomenology informed by van Manen (1990) and method used to conduct this study. The findings generated from this phase two study are presented in chapter six. Interpretation of the findings and their implications for education, practice and research are presented in chapter seven.

CHAPTER 6

PHASE TWO FINDINGS

6.1 Introduction

This chapter presents the qualitative findings generated from the thematic analysis of undertaken on the phenomenological interviews conducted in phase two of the study.

An overarching thematic statement was created to facilitate construction of the phenomenological description (van Manen, 1990). In essence it attempts to capture the meaning of the phenomenon studied. The thematic statement for this study was: *caring for dying patients and their families in an acute-care hospital for students and new graduate nurses was a traumatic and transforming experience*. Four themes were formulated following the participant interviews.

The first three themes emerged from the participants' recount of their experience as a student in the final semester of their undergraduate nursing program. The first theme to emerge was: **'Confronting death'**. In composing the linguistic transformation of this phenomenological description three distinct sub-themes emerged to support this theme illustrating the different facets of confrontation felt by these participants. The three sub-themes were: *Being repulsed at the physicality of death; Being intimate with the dying and Being lost*. A further two themes evolved from the participants' recall of their experience: **'Being transformed by death'** and **'Grieving the loss of a patient'**. All three themes had a presence in the participants first and second interviews.

A fourth theme emerged from six participants who agreed to be re-interviewed a second time, on completion of their hospital new graduate program. The fourth theme was named: **‘The buck stops with you: Being responsible for the care of the dying’**.

The remainder of the chapter presents each theme that evolved from this study illustrated by exemplars drawn from the participants’ stories. The exemplars provide a concrete example of the phenomenon and are representative of the study participants’ experience. Exemplars were selected on the basis that they were the best source by which to convey the meaning or essence of the experience. As such, they offer the best opportunity to create resonance in others and therefore create shared understanding of the phenomenon.

6.2 Findings

6.2.1 Theme 1: Confronting death

Witnessing and being a part of care to a dying patient gave participants exposure to a form of human suffering and deeper, more intimate relationships, previously not encountered. Encountering a dying patient caused all participants to feel overwhelmed by what they were seeing, feeling and smelling. It seemed they had not anticipated the feelings most likely to be provoked or the intensity in which they would feel them.

Francis says:

"I felt so helpless that there was nothing that could be done..."

Often the participants, particularly in the student role, were likely to be an observer or on the periphery of the events taking place. This is probably due to the student’s

entering the clinical setting for a brief period of time with little opportunity to develop a relationship with clinical staff and or a more intimate relationship with dying patients and their families. The student role seemed to heighten the participants' vulnerability because of the way in which they were exposed to dying patients. When participants indicated they were unsupported in the clinical setting feelings of vulnerability were intensified.

Generally participants expressed feelings of helplessness stemming from a lack of knowledge and skill and control in how to care and behave when encountering a dying patient and their family. This feeling of helplessness intensified also their feeling of vulnerability. The confrontation which emerged as a result of the participants' helplessness suggests they were unprepared, by their education program, to anticipate this impact as they carried out their student and new graduate nurse roles. The origin of the participants' confrontation stemmed from what they saw, smelt and felt in the experience. Three sub themes emerged which took account of each aspect under the overall theme of being confronted by death. The three sub themes were: *Being repulsed at the physicality of death, Being intimate with the dying and Being lost*. The following section presents the findings under each of these subthemes.

6.2.1.1 Being repulsed at the physicality of death

In the initial experience of caring for a dying patient, witnessing the physical decline provoked a strong sense of repulsion and shock in all but one of the participants. Francis recalls how vividly she felt this repulsion:

"The woman was just a skeleton with skin on and she had that death smell. At first that kind of revolted me and then when I got used to the situation and everything it didn't bother me, but at first it was like, "Oh my God," I kept saying to myself "Be professional, be professional 'cause it's not her fault".

Seeing the physical suffering a dying patient experienced challenged all but one of the participants. The physicality of death triggered unanticipated emotional, and to a lesser degree cognitive and physical responses in the participants. They had no expectation of what they would see or how to integrate comfort care in this clinical context. Frequently the participants were guided by registered nurses to perform physical care activities with little support provided as they engaged in this new experience.

The majority of participants were unfamiliar with the dying process for several reasons. Many entered their nursing program with little or no personal experiences of death, giving them no personal reference to draw on. On entering their nursing program students received little education on how to care for, and how they would feel, when caring for dying patients. During clinical placements students were often left unsupported in the provision of care to the dying and were therefore unable to reflect on this as a learning opportunity. For these reasons the confrontation experienced in response to seeing a dying patient had a significant impact on the participants.

In contrast, the only participant not challenged by the physicality of dying had previously been exposed to a number of deaths in her role as an assistant in nursing. In this role she had received ongoing education and support when a death occurred. Several other participants who held nursing roles concurrently with their studies had not experienced the same level of educational intervention as this participant. The learning she gained from these previous encounters enabled her to engage with a dying patient without the adverse impact experienced by the other participants.

Several forms of coping were used by participants to protect themselves from the confrontation they experienced as an observer to the physical decline of a dying patient. The phrase *'being professional'* was typically used by several participants, as a means of distancing themselves from the reality confronting them. Retreating into *'being professional'* enabled them to avoid revealing their revulsion to the patient and colleagues. The depth of confrontation and the degree to which many participants initiated self-protect is shown by Abbey's reflection:

"I knew this lady before she died and I was not interested at all [in seeing her after death]. There was just no way was I was going into that room and I didn't. I basically ran and hid. I don't know why, I mean, the thought of seeing someone die at that stage was scary to me. I just didn't want anything to do with her. I was so scared and actually going and having to deal with a dead body, I couldn't face it."

Several participants like Ellie, displayed disengagement in one form or another:

"I was very detached I could not think of him as a real person".

The degree of disengagement displayed by Ellie exemplified the participants' lack of understanding in prioritising a dying patient's needs beyond meeting their needs first. Engaging in this behaviour would have impacted on the student's capacity to establish and maintain an intimate relationship with a dying patient. This failure limited Ellie's ability to identify the needs of her patient thereby acting as a barrier in providing quality care.

Along with Kate, who said *"I thought people would be much older"*, several other participants also implied losing a patient who was older was more acceptable. It seemed participants entered into their nursing program with this prevailing attitude.

As Donna said:

"I still to this day don't know how I'll ever deal with seeing a young man or a child die. That always scares me. I don't know how I'd deal with that but for now seeing an elderly person who's lived their life die I can cope with that, I can get through [it]".

6.2.1.2 Being intimate with the dying

The needs expressed by dying patients require nurses to enter an individual's personal space with a higher level of intimacy than is expected with patients in an acute-care hospital. This requirement occurs because of a dying patient's increased dependency on the nurse as they move through the dying trajectory. The care of someone dying is focussed on promoting comfort and alleviating suffering holistically. However, these participants had been primarily exposed to curative care practices due to the emphasis given in their undergraduate program and the reinforcement which occurred during scheduled clinical placements. The changed orientation to care added to the participants' feelings of confrontation. They frequently implied they lacked fundamental knowledge and skills in palliative care necessary to participate fully and safely in this paradigm shift. All of the participants' stories frequently implied they lacked fundamental knowledge and skills in palliative care necessary to participate fully and safely in this paradigm shift. This is best captured by Maddie who says:

"There was nothing in my training ... that geared me up for someone who was dying a slow death".

The feeling that this lack of knowledge and skill generated in the participant is conveyed by Nicholas's comment:

"It was tough enough, yeah it was tough enough as it was, I wasn't prepared, it was confronting..."

The lack of knowledge and skill for the majority of participants was focussed on communication as Francis says:

“sometimes I just didn’t know what to say to the poor woman. I just thought I don’t know what to say to you. You know being so inexperienced in nursing, what can you say.”

Jack also reinforced this view:

“I was like a novice and my biggest fear was that I would say or do something inappropriate. They would say something, I don’t think they even probably wanted a response I just acknowledged that I didn’t feel comfortable in the situation [be]cause I didn’t think I had the expertise to give them what they wanted or needed”.

The paradigm shift culminated in the participants being required to form more intimate relationships in order to meet the expectations of their dying patients. This was not something the participants had anticipated. This requirement is best summarised by Francis who said:

“spending time with the patient meant not just [meeting the] physical needs but the emotional and spiritual needs. I find it’s not just the physical when the person is dying you have to look after the whole person and their family and that is hard”.

However for the majority of participants being required to form more intimate relationships was not something they had anticipated. Nicholas said:

“it was the association that was the hardest thing so I really disassociated myself from this particular person and almost treated him not like a person in that I went in there, fed him when I was told to feed him, did the other basic nursing duties, didn’t really talk to him much other than hello, his name, how are you?”

This lack of anticipation further contributed to the confrontation felt by the participants.

The intimacy required in the provision of palliative care, competes against the dominant curative care interventions found in acute-care hospitals. This competition creates tension which adds complexity to the participants' capacity to contend with the competing demands of caring for dying patients in an acute-care hospital. These tensions magnified the participants' emotional responses. This claim is illustrated by Kate who said:

"I think everyone should have experience with a dying client in that kind of environment where you can spend the time with them and you can care for them holistically. Not in a surgical ward where everything is rushed and you don't have any time to spend with them and you at the end of the day you feel that you've failed them because of your circumstance".

The feeling of difference was demonstrated in the simple act of washing a dying patient, as recounted by Cathy:

"I was so nervous. She was so frail and old, with old peoples' frail skin. I was so worried that I would hurt her. It was nerve-racking and so different. I'd washed people before but this was so different. I was so worried about everything. By the end it was a calming thing for her and me. You could see she was more relaxed. It was nerve-racking at first because it was different washing someone who was old and dying. I don't know washing someone when they're just old is just like a part of your tasks. This could be the last time and you want to make sure you do a really good job. You want to make sure that they're so comfortable. I mean it's the same but it just feels different".

Participants seemed unprepared by their nursing program to transfer previously acquired skills to the context of providing care to a dying patient. In addition support

from more experienced staff in acute-care hospitals was not forthcoming. The majority of participants told of frequently having to carry out these activities alone to dying patients. Olivia's comments conveyed how the majority of participants felt

“it was just very confronting. I really didn't know what to do. I did not feel properly prepared for it at all through my education, nobody actually sat you down and said well this is what you're supposed to do and I also felt that there wasn't enough support from the staff. They were all quite desensitised from it and I was um only young so I hadn't had much to do [with] nursing [the] dying”.

All participants had previously engaged in basic, personal care activities. They expressed feeling comfortable and confident in carrying out these care activities with people who were not dying. However, when the task was undertaken with a dying patient, it took on new meaning and accentuated the participants' feelings of inadequacy and vulnerability. The intimacy associated with acts of caring further exposed the vulnerability that participants felt in their student role. This intimacy potentially opened the participant to being more emotionally connected - which they found confronting.

Cathy and the other participants had a frame of reference in which to perform care related to bathing a person, but the feelings of inadequacy and vulnerability they experienced may have acted as barriers to transferring this knowledge and skill to the context of caring for a dying patient. When other nurses directed participants to perform these acts of care, participants were often left alone or received minimal guidance, leading them to feel uncomfortable, nervous and vulnerable. This emotional discomfort became another form of confrontation that the participant had to negotiate when they encountered a dying patient.

Many participants experienced a depth of intimacy not previously encountered or contemplated when they engaged in care activities with a dying patient. They did not seem to appreciate the dependency and vulnerability dying patients expressed, and the associated interventions this creates for the nurse. The participants did not seem to appreciate the dependency and vulnerability dying patients expressed and the associated interventions this creates for the nurse. This lack of appreciation is best illustrated by the following two participants. Isabelle said:

“there was mixed feelings, one for the patient who kept saying to me just let me die and I felt mixed [up] that I couldn’t let him die. The fact that I was nursing and I didn’t want him to die, it was totally mixed because I was thinking Oh no, [I] don’t want a patient to die on my shift. As much as I wanted the experience I didn’t want to accept that we could lose [him], I felt that I would really have liked to sit there with him, while he died but then he just dragged on and on and I was thinking I haven’t got the time to sit there and listen.”

Kate also learnt:

“you had to care for someone’s emotions and their spiritual side. I was so shocked that I would have to do this. Like I knew it would be upsetting to be there but I was shocked that I was that upset and that just shocked me, I could not believe it.”

These comments by Isabelle and Kate illustrate the lack of appreciation generally held by the participants on the dependency and vulnerability dying creates in the patient.

As part of these interventions the dying patient will often forge a deeper relationship with the nurse so that their emotional and spiritual needs are met in conjunction with their physical. The deeper relationship is primarily made through interpersonal communication between patient and nurse. All participants expressed concern at

having to communicate at a deeper level and were fearful of what they said. This often caused participants to feel intimidated when faced with the prospect of providing care activities knowing it could lead to a more intimate connection with the patient. At times it also impeded verbal communication between the nurse and patient.

Providing care to a dying patient created a heightened sensitivity to causing potential physical harm in many participants. This sensitivity seemed to stem from the participants' lack of knowledge on the dying process and how this manifests in a dying patient. Cathy conveyed that the care activities she undertook assumed new meaning when they were connected to a dying patient. Frequently it was the dying patient who intuitively sensed the participants' difficulties, and through their relationship supported them to finding meaning in what was happening to both of them. Involved in a relationship, necessitating a deeper level of connection affirmed that participants frequently failed to grasp the meaning of this relationship in caring for a dying patient and their family. It also reinforced that their nursing program unsuccessfully addressed the nature of this relationship with students in preparing them for this role.

6.2.1.3 Being lost

All participants felt they were on a roller-coaster of emotions when encountering dying patients and their families, which left them with a sense of being lost in the experience. Participants seemed not to have either anticipated, and/or been prepared by their education program, for the range and intensity of emotion they would experience. As Kate said:

"At the beginning of my placement, I was so shocked that I would feel this way. I knew it would be upsetting but I was shocked that I was that upset, I could not believe [I would feel this way]".

The experience of caring for a dying patient acted as a catalyst, unlocking emotions, raising them to the surface and intensifying their feelings in a manner not previously encountered when the participants were on other clinical placements.

Many participants felt their inadequacy in communicating with a dying patient, and their family exacerbated the magnitude of the emotion they felt. They often spoke about not knowing what, when and how to speak to a dying patient or their family, further revealing their vulnerability as students, because they were the ones most often allocated to provide the direct and more intimate care. Being involved in direct care rendered interacting with the patient and family unavoidable. Olivia summed this up best:

"It was very confronting. There was family and you are never too sure of what to say or if you are supposed to talk to the family. I was very overwhelmed with the experience because I had gotten (sic) quite attached to the patient and I wasn't sure whether or not I was allowed to feel the way I was feeling. It was very confronting. I really didn't know what to do".

Kate and Olivia's stories reveal the depth of the participants' emotional responses as a consequence of caring for the dying. Their stories illustrate the lack of awareness and control most participants experienced over their feelings when they encountered a dying patient. Lack of anticipation and control significantly contributed to the

participants' level of discomfort when interacting with dying patients and their families.

While most participants experienced discomfoting emotions Gayle was an exception:

"I felt a lot more confident in what was happening and why things were happening. I felt calm I wasn't nervous about seeing a dead body just the difference of being a student made you sort of lose a bit of confidence".

Gayle's contrasting view was most likely attributed to the amount of time she had spent as an enrolled nurse prior to entering her program. She had undertaken several workshops in palliative care during that time. Her enrolled nursing had exposed her to several patient deaths giving her the opportunity to experience the emotions the other participants were only now beginning to feel. She also had a frame of reference that allowed her to process the encounter cognitively and emotionally. However, Gayle continues to reinforce the vulnerability the participants experienced collectively as students in this encounter. Although Gayle had past experiences to draw on, her role as a student led to a similar lack of confidence.

6.2.2 Theme 2: Being Transformed by Death

This theme described the experience of caring for dying patients and their families and its effect on how participants understood and valued their future practice. The effect was expressed as a transformation manifested by their valuing of 'humanness', suffering and the relationship to nursing. It reflected how many of the participants saw nursing and the manner in which they wanted to deliver care. For three participants, the effect was so great it created a desire to practice in palliative care as a new graduate nurse. As such, the experience influenced the participants to

clarify and reform their values and beliefs, leading them to create new beginnings in their practice. Donna's comment captured the transformation experienced by many of the participants:

"It set up the way I am [in my practice], for the rest of my career".

While Ellie showed how powerful an influence this experience held in defining future career options:

"It was from that experience that made me feel I wanted to work in the area of palliative care".

When undertaking their scheduled clinical placements participants were exposed to numerous patient experiences, yet they did not attribute the same level of significance to these experiences compared to their encounter with a dying patient and their family. This encounter caused the majority of participants to rethink their vision of nursing. Participants conveyed in the absence of this experience they may not have had cause to rethink and therefore recognise the value in adopting the principles of palliative care. This experience prompted Lisa's reflection, typical of many participants:

"You never forget it, probably because of the smell of his skin and seeing him so swollen. Knowing that he was going to die, maybe that's why I remembered him so well".

Part of reflecting on their practice gave students a new awareness of holistic practice, and with that, confidence to interact with the patient more meaningfully, as Olivia explained:

"I'm more aware that they are a person now, not just a body, so I tell them about my day and what I've been up to".

Olivia's comment illustrates the shift many participants had undergone in no longer separating 'the person' from 'the physical deterioration'. In recognising the person as a whole, participants could make their interaction with the patient more meaningful for themselves. This experience gave some participants exposure to role models who implemented care which addressed more than the physical dimension of the dying patient. The worthiness of observing these role models was best summed up by Kate:

"To me, real nursing is caring for a person holistically and that's what palliative care is about. If you learn to care for someone's emotions and their spiritual side, that is nursing. Having this experience and know[ing] they can take this with them into other areas of nursing and adapt it appropriately. I think everyone should have this experience with a dying client, in this kind of environment, where you can spend the time with them and you can care for them holistically".

On reflection, Kate recognised that the knowledge and skills acquired through this experience were transferable to other settings. However, this insight was not articulated by any of the other participants.

All participants entered their nursing program with an understanding of death and dying shaped by their beliefs, culture, education, personal life history, religion and values. These understandings provided a frame of reference through which participants' filtered their experiences of death and dying. As a consequence this influenced their perception and interpretation of the human experience of dying in their role as a student and new graduate nurse. Of significance however, is that the

majority of participants found their initial encounters with a dying patient to be one which critically influenced how they shaped their future professional practice.

While the effect of this experience contributed to how these participants would engage in future professional practice, it also revealed the impact participants suffered as a consequence to being exposed to dying patients. They experienced high levels of anxiety and stress attributed to the sights, sounds and smells embedded in the experience of caring for a dying patient. Their presence led to some participants triggering a stress response. While the majority of responses were emotional, Barbara described in detail the physiological response she felt during her first experience. She said:

"I think my heart stopped. I think it did. It was just like 'it's happened'. It's hard to describe. It was like I was there but I wasn't there. I was like having an out of body experience, like I was watching it but it didn't feel real.... I got goose bumps. It was, I was anxious because you were just waiting for him to take that extra breath and I remember my heart was beating really fast and you were just waiting and then it didn't happen, all this confusion, so what do I do now?"

Barbara's story illustrates how the experience of caring for a dying patient critically defines for her the confrontation she felt being a part of this phenomenon. Barbara thought her anxieties and fears were not externally visible to others but her body responded with a physiological response that she could not control nor hide.

The experience of caring for a dying patient and their family provided a context for these participants to see care practiced from a holistic framework. The impression conveyed by many participants was that this was, for some, the first time they had

observed or recognised holistic nursing being practised while undertaking clinical placements. Ellie explained:

"...all of a sudden everything changed and we were to care for him in a different way, instead of being aggressive and looking after him to keep him alive, the focus shifted to the family, caring for the family.... I think this made me think of nursing as more than just doing procedures on people and getting them better and out of hospital.... It helped me to see things from a wider picture, caring for someone in a very holistic way with the whole family and looking at things in different ways. Not just the patient in the bed.... it made it more real to me, the holistic aspect of caring for people and listening to not just the patient, but the family. A lot of nurses hate having families around".

The relationship between a dying patient, their family and the participant caused many of the participants to review their practice. This relationship forged a deeper level of connection than they had experienced earlier with patients in other settings. For many participants, the connectedness caused them to reflect on and attempt to make meaning of the human suffering they were witnessing. The participants' involvement caused them to understand their practice differently. As Ellie said:

"I'm allowed to enter a very personal place, which is a privilege. When I think about that [She starts to cry]"

Even when participants were involved in clinical situations where poor practice was demonstrated, the experience nevertheless was sufficiently powerful to cause participants to alter their future practice. Nicholas's story illustrates this point:

"There was one situation where the gentleman's behind had to be wiped and I was with four nurses who had stripped him down, turned him over

into a foetal position, wiped him, left him there, discussed one lady that was getting engaged and her wedding, and left him exposed. They basically left the gentleman for 10 to 15 minutes exposed and cold. That sort of thing happens quite a lot, even saying things like, "Don't worry about cleaning there. He won't even know the difference." I felt angry towards these nurses".

At the time, Nicholas was a first year student with limited nursing experience and no personal life experiences with death. He expressed guilt at the care being delivered, and anger towards those so-called *more experienced nurses* delivering care.

Importantly, Nicholas was able to initiate reflection on this experience that enabled him to make meaning of something he found distasteful and did not fit with his vision of nursing:

"I said my goodbyes and said, "Look after yourself." He [the patient] raised his thumb, mumbled something, which I'm sure was thanks, and gave me a thumbs-up salute which throughout the whole week he barely had the energy to open his mouth to eat, and it took a lot out of him. Every time I've come across a person in a dying situation, I try and remember that it was proof enough for me that yes, they do know, they do realise, and he appreciated that I was trying to treat him as a human being. I took that with me into my second and third year placements".

Despite the indifference of the staff towards Nicholas and the dying patient, Nicholas gained an understanding of how he wanted his practice to meet patient need.

6.2.3 Theme 3: Grieving the Loss of a Patient

This theme illustrates how all participants described one or more grief reactions on the death of their patient. The origin of these reactions stemmed from the relationship between participant and patient. All participants spoke of the emotional pain and sadness they felt when their patient died. They equated their feelings to

something similar to those they would experience if a family member or friend died. Although participants acknowledged they were in a professional role this did not shield them from experiencing this pain and sadness. Of significance, was that several participants still felt the emotional pain and sadness when they recounted their story. For others, the interview was the first opportunity to release their feelings. While exploring their grief, this theme also showed the limited resilience participants had towards future encounters with dying patients as a consequence of absent or underdeveloped coping mechanisms.

Abbey explained:

"She was there a little while ago, I was talking to her a little while ago, now she's gone. I didn't know how to deal with it at the time because I hadn't come across it before and it was sad, because I had taken the time to get to know this lady. It was over, and I couldn't go in and say "Hello, how was your dinner, How are you feeling? Is there anything I can do for you?" because she wasn't there any more".

The duration over which these students provided care to a dying patient was inconsequential to the degree of emotional pain and sadness they felt. The degree of connectedness that developed in response to the relationship between the dying patient and the participant determined the amount of hurt they experienced. The depth of pain felt by the participants is best reflected in Olivia's comment:

"It's just too sad for me. I don't think I'm cut out for dying people. It's very, very sad".

These stories revealed how participants' employed a number of behaviours to protect themselves from this pain and sadness. Abbey's description was typical:

"My thinking was, "I knew this lady." I knew her while she was alive. I couldn't cope with that. No, I just went and got on with my job. Everyone was saying well, if you haven't seen a dead body, you know, you should go in, do it, and I've gone, "No, I can't deal with that at the moment." I just couldn't do it. I just got on with my job and just went over where I was supposed to be and just got on with my job".

As it was for Abbey, participants retreated into normal routines as a means of protecting and shielding themselves from further exposure and therefore emotional pain. The participants also conveyed that a dying patient's situation required a higher than normal emotional commitment compared to providing care focused on curative interventions. The act of the patient-nurse-family relationship ceasing often intensified the participants' emotional reaction. Their stories again illustrated that they were unprepared cognitively and emotionally for this commitment and a relationship of this nature.

Donna spoke about a tactic a few participants employed as a deflection to feeling grief. At the time of her patient's death, Donna replaced her feelings of grief with the excitement of being involved in a cardiac arrest, and pushed away or blocked out that her patient had just died.

"It was my first cardiac arrest [and the patient died]. After a while I cut that out [the patient's death] and started to think about the whole excitement of the arrest. I pushed [the awareness that the person had just died] away".

Several participants dealt with their grief by rationalising a patient's death according to their age. They indicated they felt less grief when an older patient died, as they felt

that the individual was more likely to have lived a full life as compared to a younger person. Cathy illustrates the typical response given by most participants:

"I just felt a little bit sad, but I didn't feel like it was when a younger person dies. You feel guilty that you can't do anything".

The majority of participants spoke of the need to repress their emotional responses to their patients' death, as this was seen as being professional. The need to be professional arose from participants' contact with other nurses while on clinical placement. The other nurses sanctioned what was considered appropriate behaviour for the participants to express. Participants' spoke of often needing to conceal their feelings or engage in behaviours aligned to the culture of their clinical placement, so that attention was not drawn to them.

Kate's story tells of how she was encouraged to show her emotions. Yet other participants had spoken about the tension that surrounds the behaviour Kate describes, as other nursing staff conveyed either indirectly or directly this was not professional behaviour. For this reason Kate and the other participants protected themselves from disclosing their inner feelings to the staff.

"They said to me, "It doesn't matter if you cry in front of the relatives", I didn't want to; you've got to be strong but you're not, no one can be strong in that situation".

The participants had not anticipated the range of grief reactions nor their intensity likely to be evoked through the experience of patient death. Kate conveyed the lack of preparedness felt by all participants:

"See, someone can never have preconceived ideas. I guess I did as a student nurse of what I would go through, completely different from what I have experienced because no one said to me you're going to feel upset and you're going to cry and you're going to struggle with the emotionality of this work and you're going to be inconsolable sometimes because you can't comprehend how upsetting these situations are. Like some things have really upset me and I can't justify to myself why this has happened".

The participants' grief seemed proportional to the degree of support they were offered, could seek for themselves, or both. It was evident from the participants' stories, that overall, minimal support was given or made accessible to them at the time of their patients' death. These participants reported being largely left on their own when their patient died. For the majority of participants, guidance and support were not forthcoming from the nursing staff on clinical placements. Many of the nursing staff failed to assess the participants for grief reactions and evidence of suitable coping mechanisms. Similarly, participants spoke of the failure by nursing staff to intervene with appropriate support systems when participants displayed grief. Donna captured the limited support all participants felt they received:

"We [the students] were all left to work it out on our own. I mean, the Uni sort of gave us a little bit but it was really hard because what we were told about caring for the body and then going into the hospital and what to do with the deceased body and what to do with the family, were not always the same. The nurses could never work through or talk to us about our emotions and how we as students deal with the dying. It was left up to us; I think we had to wait for the experience to come.... I had to go through it and access any help I could get. I had the chance to talk about it in professional practice later on and even then all they could

really say was, "How did you feel about that? What happened?" or "Walk us through what it was like.""

While some participants received better support, this essentially depended on the time of day the patient died, the availability of resources and the characteristics and personality of other nursing staff who, on an ad-hoc basis, offered support. This is borne out by Francis, who noted that if a "good educator" was available and it was during the day, you may get some support. However, her experience, as it was for the majority of participants, was, "*I never got any help*".

It was also not only about the timing of when support was offered but also how the staff themselves modeled their grief reactions and displayed their capacity to cope with participants. The prevalence of detachment and disengagement displayed by the nursing staff was high by the participants' accounts. Ellie and other participants faced coming to terms with what was happening around them unsupported:

"I can't cope with this. Everyone has just left him and pulled everything off him. They left him to be wrapped up, taken away and walked out. I hated the whole thing".

Ellie, in her second interview as a new graduate nurse, described how, as a result of being unsupported in this experience, an unpleasant memory still resonates within her. Recalling unpleasant memories associated with a participant's initial experiences was a common feature from the second interviews. Ellie was able to illustrate how powerful these experiences were, the length of time they remained with you as a memory and the deleterious effect it can produce long term. Ellie told me:

"I couldn't cope with it and I've found since then, over the last 2 years I find that when I come onto a shift and someone has died in that room and I've got to either wash them or take them to the morgue or put them in a bag, I just hate it. I can't cope with it and I've just got to shut my eyes and pretend I'm not doing this job; whereas if I've cared for the patient and I've been involved in the dying process and the family, I feel really privileged. It's a bit weird saying it but I do get a real sense of fulfilment and satisfaction looking after a patient and the family in this setting. The other day I was in that situation, I'd come on like an early afternoon shift and was helping out the morning staff and they said, "Look we've got to get this body in a bag," and I thought, "I've seen so many dead people because I'm working in palliative care and yet I can't cope with this. I'd much rather go and clean the pan room." The very first ward I was in I came on and there was someone dead and I had to take them off to the morgue and I hated that. I didn't even know them".

A few participants sought assistance from their family members in the absence of staff support but found family became confronted when participants retold the events. Kate's reflection was typical of how alone and isolated the participants felt with having no or limited opportunities to share their experience of a dying patient:

"I was getting really down because I couldn't believe how upset I was and how no one at home understood. I would try and talk to my boyfriend and he'd say, "I don't want to hear about it. That's terrible. Don't tell me because I don't understand." No one understands outside of the ward what you are feeling inside and they can't know unless they see what you see. They can't know. They can never know".

In the absence of support from nursing staff in the clinical setting or family, two participants talked about how they attempted to make sense of this event through reflective writing. Ellie wanted support and actively sought it out following the death

of her patient. However, she found the support inadequate. This led her to ultimately process the events by herself, which she achieved in part by reflecting on the incident during the writing of a reflection paper:

"I talked with my mentor on the way home in the car and she told me about her experiences and how she coped. It didn't really help me and I was left thinking I didn't understand the whole thing. So I just coped. I suppose one good way was that I did my final reflective paper on that particular experience. It helped me to look at things more in perspective and use a lot of that experience later on. I really had to deal with it myself".

Francis also found writing about her experience to be helpful. Through the writing process she was able to make meaning out of her experience that assisted her preparation for future encounters:

"It really always affected me. I wrote a couple of pages during my university education on it. I felt I went from seeing something absolutely tragic, to being able to move through it, and as I moved, see things differently".

On limited occasions, nursing staff supported the participants. Kate's experience showed staff offered guidance on what she needed:

"As a nursing student [these encounters] will ruin you if you don't have coping skills, or the ability to be self reflective or an outlet to vent your feelings. You won't be comfortable with your emotions".

The magnitude of grief the participants felt was at times very pronounced and emotionally exhausting. They often found solace in sharing their story with their

peers, as a means of soliciting support. For many participants, talking with their peers offered a means of reflection and letting go of the memory. Nicholas conveyed:

"I cried at the end of the week. I cried and I don't cry much. I haven't cried for a long time and that was the first time I cried. I cried in front of the students. It helped a lot. To let it all out helped but I felt as though I'd released a burden off my shoulders. The other students could relate to this and were surprised to see me cry. They responded very well. The other students were all female. I don't know why it helped to let go, maybe not the crying, but the discussion that followed".

As previously mentioned, all participants expressed some level of grief at the time of their patient's death. For the majority, this grief continued to affect them for substantial periods of time and formed a repository in their memory. Half the participants in the second interviews spoke of the sadness and pain which had continued with them into their new graduate year. Francis gave the best example of how the experience had continued to permeate her nursing practice and become interwoven in her personal life, demonstrating the substantial effect the experience had on her:

"To this day it really upsets me because I felt so absolutely helpless. I could not do anything for this woman. I would have only seen her one or two times. There was no closure or follow-through with her as well... I felt how sad it was. ... Sometimes I just didn't know what to say to the poor woman. I thought I don't know what to say to you. Being so inexperienced in nursing what can you say to someone dying. It affected me pretty much. I didn't realise how much. It still has an impact on me now, even though it's been years it still affects my nursing care, and bits and pieces of my life".

Barbara's story highlights the degree to which a memory associated with a dying patient evoked an emotional response in her, and how long this grief had remained with her:

"It was a weird feeling. You knew that he had gone and you knew you had to clean the room. Someone else wanted the space but you'd walk past and look in there and still expect to see them in there. It was like an emptiness [that I felt]. For the rest of that week and even when I went back and did my 6-week block on the same ward, I still walked past expecting to see him".

Closure for most of these participants was not something afforded to them, due largely to the way in which clinical placements were organised in their undergraduate program. Their role as a student limited their capacity to seek closure in many ways.

As Francis said:

"I was always sad never knowing how she went in the end. As a student, you can't go in and ring up and say I was a student last week how's that patient".

Few participants conveyed a desire or insight into promoting closure for themselves.

Maddie was an example of how closure was initiated as a means of reconciling what she understands is happening to her patient.

"More than likely he wouldn't be there [next time], so I went up to the patient and I wanted to say good bye to him. I just knew he was dying and because I believed I'd see him up there later [in an afterlife], I wanted to say goodbye".

6.2.4 Theme 4: The Buck Stops With You: Being Responsible for Care of the Dying

This theme emerged from the second interviews conducted with six of the original participants. Their stories showed very early on, in assuming the new graduate nurse role, participants came to appreciate the responsibility and individual accountability they had in caring for dying patients and their families. Francis expressed the role delineation and tension felt by these participants in their transition from student to registered nurse:

"You know it's my responsibility to look after them properly. That was the biggest thing that came from being a student to registered nurse, because the buck stopped with you".

In previous encounters with dying patients, participants were given the opportunity in their student role to relinquish responsibilities or opt out completely from the care. In their new graduate role the participants' professional accountability was much more explicit to a dying patient, along with their moral accountability for their actions. The emphasis on accountability further contributed to the confrontation they felt when they engaged with dying patients.

There was evidence of moving beyond providing care focussed on procedural and technical activities necessary to comply with their program's requirements to pass in clinical placement. The sense of responsibility the participants expressed came from the participants no longer viewing themselves as an outsider to the care activities. Now they were actively involved, determining and controlling the delivery of care.

This was in direct comparison to their student role where they were directed to carry out individual tasks by other nursing staff. As Francis said:

"You have to take responsibility, you had to deal with the families, as a student you could just watch the RN deal with the family, watch the RN do this, help them do things but you would be under supervision or on a learning experience. It can be very daunting [being the registered nurse] I had to take responsibility and it was totally different. It was the biggest thing I noticed when I came out, no more excuses".

Avoiding the reality of being with a dying patient and their family was no longer possible or a reality.

For these participants looking after the dying patient constituted being prepared, able to communicate and deal with a dying patient and their family. Previously in their student role, care activities had focussed primarily on the provision of comfort measures and negated the psychological and spiritual dimensions of patient and family care. It became evident to these participants that they held the principal caregiver role among the other healthcare professionals. They saw that their responsibility involved ensuring all of the dying patient's needs were met holistically.

All participants spoke of their desire *to care for the dying properly* which included being their advocate. The advocacy role was more pronounced for some participants as a result of their experiences and had led to this awareness. As Cathy said:

"You want to look after them in a more palliative way but the ward staff they're focussed on getting people well and home. It's frustrating and sort of a conflict. They don't recognise the difference".

These participants understood the difference but it created for them additional tension. The clinical staff were almost exclusively oriented to curative care, and as Francis said:

“When they had dying patients they would try and get them moved to a palliative care unit”.

In general, the participants thought the clinical staff found it hard to accept and know what to do with a deteriorating dying patient. This set up an inner conflict for the participants who, as a result of the tension, felt somewhat inadequate in ensuring the patients’ needs were met. Often they were a single voice, as Donna showed when she spoke up at a handover:

“I feel it’s my purpose is to make these patients’ last few days as fulfilling as possible but you know I don’t feel like I’m achieving anything. It’s very hard”.

Donna’s frustration at the inability of the other staff to see what she is seeing was evident. She went on to tell me how making this comment at handover resulted in the staff being distant with her, making her feel alone and isolated.

However, underpinning this desire to do the right thing by their patients, the participants continued to feel inadequate in their capacity to provide effective fundamental palliative care. Their newly acquired role exacerbated the participants’ feelings of inadequacy as Donna said:

“I didn’t have the knowledge, the counselling skills or communication skills ... it’s only now that my communication skills as a person and nurse are really just beginning to develop. Back then [as a student] I

didn't have those communication or counselling skills. I didn't have the knowledge about palliative care nursing".

On reflection, Donna acknowledged that her skills were only beginning to develop. The limited generalist palliative care knowledge and skills held by the participants impeded their capacity to carry out the care required. This impediment, along with the pressure of being responsible, further contributed to their feelings of inadequacy.

Donna, along with the majority of participants, found the support for her to be minimal both in the new graduate program and in the clinical setting. Donna drew from a concurrent personal experience as a means of supporting her professional practice supplemented by a rotation to a specialised palliative care unit.

"Looking after [dying patients] and the support for new grads was so minimal. It wasn't till my own father died and I went to an oncology unit at the hospital, that I actually learnt the proper way to care for a palliative care patient".

All participants expressed the need to be more adequately prepared to assume the responsibilities in caring for dying patients and their families when they were a registered nurse. Generally the participants found they had gained enormous benefit from their initial experiences as a student in caring for a dying patient. Not having the pressure of being in the registered nurse role while learning about the dying process was significant, as highlighted by Cathy:

"Well, I think it was good to have the exposure. I think it would have been a lot more confronting. The exposure on the clinical placement was definitely helpful. You are not directly dealing with the person when you are on placement, you are in a preceptor role with another nurse and their dealing

with it and you are observing and being taken through the process of what's going on and pre-exposure when it's not your responsibility as well. I think if you didn't have that pre-exposure I think it would be a lot more difficult".

Having the experiential learning in the clinical setting was recognised by all participants as being highly valuable. However, while the participants saw value in being exposed to the dying patient before registration as a nurse, they also criticised the lack of preparation offered by their initial nursing program and subsequent new graduate programs, in addition to the limited support shown by clinical staff at the time of their patient's death. No participants spoke about their education program specifically preparing them for their role or responsibilities in caring for a dying patient and their family. During the second interview, Donna revealed the paucity of resources she and several other participants felt were available to prepare them for their encounter:

"I really had nothing to draw on apart from talking to nurses and not those on the ward; their knowledge is inadequate on the wards".

Three participants had either taken the option of a palliative care elective and or taken up a specialised palliative care clinical placement as part of their rotation in new graduate programs. They described the valuable contribution these learning experiences made to their ability to perform in the registered nurse role across a number of acute-care settings. Cathy said:

"I chose to work in a palliative care unit, but for me that was a good foundation for preparing me for when I was a registered nurse. I definitely think the amount of exposure and maybe also because I did the palliative care elective and chose to do that line of learning, that it helped me a lot as well. They [other students] need to do a placement

[in palliative care] because you can tell the difference of who had dealt with dying people before".

Several participants said upfront that they had wanted to be exposed to a dying patient before registration because this was a responsible way to manage their feelings before they had to be 'in control'. Ellie said:

"I didn't want to freak out and seem totally unprofessional and incompetent when I'm supposed to be in control [as the registered nurse]".

Francis appreciated that assuming the registered nurse's role or being an 'experienced nurse', did not necessarily equate with the ability to care and cope with dying patients and their families. While in her new graduate program, Francis witnessed another registered nurse's behaviour which reinforced to her the need to have the knowledge and skills in care of the dying:

"I felt really overwhelmed that at the end of this persons' life, this experienced nurse was panicking and going on and couldn't control herself. I didn't know what to do. I'd chosen this [palliative care] elective so I had a bit of an idea of what to expect and what to do and how to handle the family as part of our course. The elective had been only 3 or 4 months earlier and [it] was still fresh in my mind and that helped me".

Francis was overwhelmed by the nurse's selfish behaviour that culminated in the needs of the dying patient not being met. Furthermore, Francis was surprised by the lack of knowledge and skills displayed by this nurse, who had many years of experience. Francis had deliberately chosen to participate in a palliative care elective during her undergraduate program and consolidated this learning further by undertaking a rotation in a palliative care specialist unit during her new graduate

program. These experiences helped Francis to gain some insights into what was needed to support dying patients. On further reflection, she felt that this type of learning was a necessary component to being prepared to deliver this type of care in an optimal way for both patient and herself.

When these participants were on clinical placement in their student role control over the delivery of care to a dying patient was ascribed by the registered nurses. Two of the participants described how disengaged and peripheral to the care activities they had felt, as a student, as compared to what it was like when they assumed the registered nurse role. Ellie said:

"You've got more control over everything. They're your patient, you don't have anyone telling you what to do and you can establish a rapport with the patient yourself. You're not waiting for the nurse to give you permission to give this or that. You know when to wash them and you can do mouth care but usually you are under the registered nurse who is looking after them".

For Ellie it is about the relationship she has created with the person, which allows her to understand more fully the holistic needs of the dying individual.

The four themes and three sub-themes formulated present a phenomenological description of what it means to students and new graduate nurses to care for dying patients and their families in an acute-care hospital. The first three themes were the result of the first interview conducted with the participants as an undergraduate nursing student in their final semester. The first theme formulated: *Being Confronted* demonstrated that the phenomenon of caring for a dying patient was confronting for participants. Three sub-themes: *Being repulsed at the physicality of death; Being*

intimate with the dying and Being lost were developed around this theme reflective of the many levels of confrontation faced by the participants.

A second theme followed which showed the significant loss participants experienced on the death of their patient and the grief reactions they experienced akin to those any person experiences with a significant loss. A second theme emerged: *Being transformed by death*. This theme illustrated the transforming nature many participants experienced which caused them to re-think their future practice. The third theme was named: *Grieving the loss of a patient*. While each of these themes primarily arose from the first interview, at times, some participants still experienced them to a lesser degree in their new graduate role. A final theme evolved from the second interview conducted with participants on completion of a new graduate program as a registered nurse. This theme conveyed the responsibility the new graduate nurses sensed they now owned and was named: *The buck stops with you: Being responsible for the care of the dying*. In contrast to the first three themes the self awareness by the participant of the responsibilities associated with a dying patient and their family, was now explicitly apparent.

Exemplars were chosen which best represented the participants experience in each of these themes. The phenomenological description and the exemplars aimed to create resonance in the reader that would generate a shared understanding. Generating this shared understanding serves to make visible the student and new graduate nurse's experience. Gaining visibility in this way, gives voice to an under-represented group in curriculum development. Using these findings to inform future curriculum development in undergraduate nursing programs will better meet the needs of students

and new graduate nurses in caring for a dying patient and their family in an acute-care hospital.

6.3 Conclusion

This chapter has presented the findings generated from the ‘text’ of the participant interviews conducted in phase two of the study. Four themes and three sub-themes were constructed using all three procedural approaches in van Manen’s (1990) thematic analysis. Each theme is illustrated with exemplars to create resonance in the reader. The final chapter, chapter seven presents a discussion on the key results which arose from phase one of the study and the findings generated from phase two of the study. Drawing on these two aspects enables the experience of caring for a dying patient and their family to be considered holistically and comprehensively. The final chapter concludes by detailing the implications for education and practice and proposes recommendations for future research.

CHAPTER 7

DISCUSSION and IMPLICATIONS

The final chapter presents a discussion on the three major findings which emerged from this study. Following this is a discussion on the implications for education and practice, concluding with recommendations for research. The final section of this chapter presents the strengths and limitations of the study and overall conclusions.

7.1 Discussion of Findings

The first section of this chapter addresses the study's research question: *What is the Australian student and new graduate nurse's experience of caring for a dying patient and their family in an acute-care hospital?* Three major findings emerged from the participants' experience of caring for adult dying patients and their families in an acute-care hospital. The first finding identified that on most occasions, participants felt bereaved following a patient's death. This finding is discussed in the first part of the discussion. The second finding showed participants were at risk of being vicariously traumatised by the experience of caring for a dying patient. This finding is addressed in the second part of the discussion. Thirdly, the study identified the phenomenon of caring for a dying patient triggered participants' learning, leading them to transform their practice. The third finding is presented as the final part of the discussion.

7.1.1 Bereavement

Many of the participants felt bereaved when patients died. A state of bereavement exists when an individual experiences a major loss of a significant person in their life (Zerwekh, 2006). Bereavement facilitates adjustment to the loss of

a significant other (Corless, 2010) by allowing the person to be aware of loss, to express sadness and to reflect on the meaning of the loss. Accommodating loss involves an adjustment to all dimensions of being human: emotional, physical, psychological and spiritual, in order that person is able to re-shape their life without the significant other. The first major finding was that the majority of participants needed the experience of bereavement so as to adjust to the loss they experienced as a result of caring for a dying patient.

Participants frequently ascribed the status of a *significant person* to people they cared for who were dying. This status came from the participants' emotional investment in establishing a deeper and more meaningful relationship with a dying patient than compared to most other patient encounters they had experienced. In this context, participants equated the loss of a patient in their professional life to the loss of a significant person in their personal life. The extent of the loss felt by the participants was linked to the strength of the relationship they had established with the dying patient. Thus the level of participation in being bereaved was determined by the strength of the relationship. The strength of the relationship was pivotal to how participants determined the value of loss in relation to themselves. This explains why in some instances not all dying patients affected participants to the same degree as the strength of the relationship between participants and patients varied.

The dominant expression of bereavement displayed by all participants was their emotional response. The responses, as described by the participants, included: anger, crying, exhaustion, fear, frustration, helplessness and a sense of loss. These responses are common grief reactions. A grief reaction "is the intense emotional response to

loss” (Zerwekh, 2006, p. 132). While emotional responses are common they should not be considered in isolation as they are just one facet of being bereaved. Other studies report grief reactions as the most common expression of bereavement demonstrated (Allchin, 2006; Beck, 1997; Cooper & Barnett, 2005; G. R. Johnson, 1994; Loftus, 1998; Quint, 1967; Van Rooyen et al., 2005). The study by Van Rooyen et al. (2005) identified some of their participants’ engaged in prayer as a means of managing their bereavement.

In this study, the participants’ grief reactions are typical of those displayed following the loss of a significant person from an individual’s life (Attig, 2004; Love, 2007; Schultz & Bruce, 2005). The variety of participant grief reactions reflects what is already known, that grief is personally constructed and individually expressed (Attig, 2004; Currer, 2001; Scultz & Bruce, 2005). Furthermore, the duration and intensity of the grief reactions appeared dependent on the value the participants placed on the loss of the patient from their professional life. The literature identifies that the intensity of grief is directly related to the amount of emotional investment a person has made in another individual (Currer, 2001; Wakefield, 2000). Understanding that grief reactions are an individual response is important when acknowledging nurses, as a group, are also made up of individuals. This means nurses also express grief individually, yet frequently are seen as a homogenous group (G.R. Johnson, 1994).

This study has shown that students and new graduate nurses need space and time following a patient’s death, just like any other member of the community who lose a significant person. The sense of personal space offers individuals time to adjust to loss. Accommodating loss and letting go of the emotional pain consists of individuals

adjusting all dimensions of being human. This process of adjustment allows individuals to make meaning of the experience that moves them forward to let go (Corless, 2010). There are no time limits on when this adjustment to loss is finalised. For many, it is an ongoing process throughout life. Bereavement is therefore critical to enabling the process of adjustment to loss to take place.

Phase one of the study results found undergraduate nursing curricula did not address the topic of bereavement in any depth. Consequently most participants were inadequately prepared to recognise and understand their own feelings of bereavement. This lack of recognition and understanding was one of the contributory factors that led to participants being unable to make meaning from this experience. As a result, this further compounded the participants' feelings of confrontation. The presence of a bereaved state and the underlying processes of adjustment to loss move individuals towards making meaning and understanding out of what is perceived as a disordered and chaotic experience (Johnson & Bourgeois, 2003). Contingent on a state of bereavement being present and the process of adjustment activated, an individual must possess the necessary knowledge and skills to identify and deal with the process. For many participants, their stories reflected they did not have this knowledge and skill which could have been acquired either through the education program, or through education and support in the clinical setting, or both. The result for many was that the participants' grief remained unresolved. For some of the participants, this grief carried over into their new graduate year.

Evidence of this lack of recognition of a bereaved state was found in phase two of the study findings. The majority of participants told of the limited and adhoc support

offered by their education program, or the clinical setting or both, following a patient's death. Support which provides an opportunity for participants to verbally express their feelings and thoughts facilitates making meaning of the experience. It is likely that one of two factors compounded the participants' capacity to move forward. These are either the lack of, or limited support offered by the clinical setting, or their education program. In the absence of any planned and timely support being implemented, it is probable that this lack of support was a contributory risk factor for psychological stress and unresolved feelings.

This study highlighted the failure of undergraduate nursing curricula designers and hospital clinical staff to recognise and address the participants' need to engage in a period of bereavement. Bereavement is an individual state influenced by a person's age, cultural background, education, ethnicity, gender, and socioeconomic status (Corless, 2010). During this state, people engage in a range of rituals for example: funerals, memorials, daily prayer and wakes, as a mark of readjustment to the loss they have experienced in their life. While the practice of bereavement is universally accepted in our community, the full scope of this practice has not translated into the acute-care hospital. The study by Gerow, et al., (2010) found that caring rituals offered some closure however when these rituals were challenged or became interrupted it caused the nurse to have a level of disquiet. This suggests nurses, as members of the wider community need to access fully the practices of bereavement, just like anyone else. Denying students and new graduate nurses this opportunity renders them at risk of compromising their own health. This risk is further compounded due to the increased exposure to multiple deaths encountered in acute-care hospitals by students and new graduate nurses. Because students and new

graduate nurses are often not previously exposed to bereavement, unsupported exposure may lead to a response called vicarious traumatisation marked by increased rates of sick leave, nurses leaving the profession, inappropriate behaviours towards patients, families and other staff, high levels of anxiety and stress. The implications of this finding for education and practice will be presented in the second section of this chapter.

7.1.2 Vicarious Traumatisation

The second major finding was that when patients or their families or both shared their *trauma* associated with dying with the participants, it triggered similar reactions in the participants to those the dying patient experienced. McCann and Pearlman (1990) named this concept vicarious traumatisation, following work with counsellors and clients who have experience of trauma. The concept of vicarious traumatisation applies equally to nurses caring for dying patients. The risk for vicarious traumatisation is present when an empathetic relationship is established between participant and dying patient. An empathetic relationship is established based on the need for the nurse and patient to arrive at a mutual understanding of the situation (Mok & Chiu, 2004). During this relationship, patients may express their inner-most feelings and thoughts about death and dying, leading to parallel states of fear, helplessness and grief being felt by the nurse (Dunkley & Whelan, 2006). The development of vicarious traumatisation is not solely reliant on the sharing of feelings and thoughts. It is also contingent upon the past experiences, personal history and coping style of the individual who is the recipient of this shared information (McCann & Pearlman, 1990). In relationships where self- disclosure is present and involves a major life event, such as dying, it is more likely to be of significance to those involved (Brown, 2009).

In caring for dying patients, nurses, of all health professionals are most likely to be closest to the patient. The information participants were exposed to during this relationship were for example; the patient's feelings and thoughts on dying and their suffering. The nature of this disclosure was confronting for all involved. For many participants this was the first time they had engaged in a deeper connection with a patient and exposed to the disclosure of such private and sensitive topics. It also prompted the participants to reflect on their own mortality often for the first time. So the patient's feelings and thoughts when disclosed to the participants often precipitated parallel responses. These responses were further heightened by the amount of time spent with the patient and their family, and the degree of emotional investment the participant placed in establishing a more intimate relationship.

Based on the study participant's stories, neither the education program nor the clinical staff they worked with identified with them the anticipated feelings that may arise when caring for a dying patient and their family. This lack of awareness further contributed to the intensity of the feelings experienced. These factors placed the participant at a higher risk of emotional pain and sadness when the patient died. Furthermore it influenced how the participants felt and behaved following a patient's death. Other studies report this finding (Cooper & Barnett, 2005; G.R. Johnson, 1994).

The vast majority of participants' expressed anger, anxiety, fear, helplessness and sadness as a result of the relationship they experienced with a dying patient. Other studies report these states being present in their participants (Allchin, 2006; Beck,

1997; Cooper et al, 2005; G.R. Johnson, 1994; Kelly, 1999; Loftus, 1998; Quint, 1967; Van Rooyen et al., 2005). Several authors have acknowledged that the presence of these states are personally intrusive, likely to recur and be disruptive to any individual's well-being (Clemans, 2004; Dunkley & Whelan, 2006; McCann & Pearlman, 1990). One participant however did not convey she was traumatised by her encounter with a dying patient. In fact she felt she had grown as a result of her interactions. This may have been due to the education and support she had received in her paid nursing role, not as a result of her student experience. The literature has also identified, that investing emotionally may act to increase confidence, self-worth, feeling secure in their role and promote professional growth in some nurses (Cooper & Barnett, 2005; Saunders & Valente, 1994).

The vast majority of participants had little experience of being with a dying person, were unprepared for the depth and intensity of the relationship and the responses it evoked. There was no evidence that participants had any concept of maintaining their own wellbeing following the experience. Phase one of the study results confirmed the paucity of education on death and dying the participants received from their program. The impact of this lack of education was revealed in phase two of the study findings. The participants' stories revealed how they felt personally inadequate about their performance in the clinical setting when caring for a dying patient. This increased participants risk for vicarious traumatisation. Dunkley and Whelan's (2006) finding suggests any professional group whose work is based on empathetic engagement, exposure to 'others' trauma and who have a lack of self-management strategies are at risk of acquiring vicarious traumatisation. Further substantiation is provided by Sinclair and Hamill's (2007) study. This study showed when patients share their

feelings about a cancer diagnosis with oncology nurses it is likely to contribute to these nurses acquiring vicarious traumatisation (Sinclair & Hamill, 2007). Both facets of this experience, educational and clinical, would have contributed significantly to the participants being at risk of developing vicarious traumatisation when caring for dying patients. More adequate educational preparation might have protected the nurses against being vicariously traumatised.

This study demonstrates a link between the adequacy of the education provided and the participant's risk for vicarious traumatisation. Because participants in this study received little, if any, knowledge and skill development in self-care strategies to promote their well-being the risk for vicarious traumatisation was heightened.

Knowledge and skills in managing patient disclosure on the trauma of dying is crucial to how a nurse performs both at the time and into the future. Dunkley and Whelan's (2006) study showed when counsellors had poorly developed skills to manage their own feelings, their work was compromised. This may also be true for nurses, given the similarities between the role of counsellors and nurses and the intimate relationship and disclosure experienced when caring for dying patients.

This is the first study to show the sustained nature of the unresolved feelings and lack of adjustment participants experienced and how this became a part of the individual's frame of reference as a new graduate nurse. Other studies have reported the presence of unresolved, traumatic feelings in new graduates in relation to patient death (Boyle & Carter, 1998; Brisley & Wood, 2004; Ferguson & Mabgood, 2007; Hopkinson et al, 2003; Maben & Macleod, 1998). However, the direct link between a student's experience of patient death and how they respond as a new graduate nurse on a

subsequent encounter has not been made. This evidence is important for understanding the cumulative effects of vicarious traumatisation and the impact this has on individual nurses and the profession as a whole. The implications of this second major finding are discussed in the second section of this chapter.

7.1.3 Caring for the Dying is Transformative

The third major finding showed many participants' worldview of their practice was transformed as a result of the experience of caring for a dying patient. The experience caused many participants to be personally challenged. For a few participants being personally challenged resulted in them exploring and being open to alternative ways of thinking about their practice. For those participants who undertook this exploration, a state of readiness must also have existed for a transformation of this magnitude to take place. This state of readiness was most likely attributed to the participant's maturity as a learner based on a capacity to use critical reflection skills. Furthermore, their frame of reference was shaped by past experiences and expectations of death and dying and was frequently obtained from the paid nursing employment undertaken in tandem with their undergraduate program. The limited knowledge and skill development on death and dying identified by the phase one of the study results supports the view that the participant's maturity more likely stemmed from personal and professional experiences rather than as a direct consequence of their education. The use of critical reflection skills enabled the participant to interpret their understandings and create new meanings. This emancipatory act created a desire to change practice in some participants.

In this study other conditions were present which acted to enhance the likelihood of the experience being transformative for participants. They were: being in an

empathetic relationship with a patient and their family; seeing similarities to the participant's life experiences and the phenomenon being the first encounter with death. When experiences are intensely personal, cumulative or involve death, change within an individual is more likely to occur (E.D. Taylor, 2008). Other studies report these conditions as being pivotal to the experience to promote personal growth and meaning (Kiger, 1994; Quint, 1967). However it is not named as a transformational learning experience.

In this study transformational learning is offered as the theoretical framework for understanding how the experience of caring for a dying patient triggered in the participants a desire to change their practice. Transformational learning from this experience was the direct consequence of immersion in the clinical setting, particularly in the absence of substantive education on death and dying in the classroom. Immersion in the clinical setting facilitated engagement with dying patients leading to participants developing and changing their personal understanding of death. Having only classroom or theoretical learning is insufficient for transformational learning to occur. Transformational learning requires that an individual has had experience in the real world, for that experience to be contextually bound (Baumgartner, 2001) and subsequently critically reflected upon (Cranton, 2002).

The experience of caring for a dying patient caused several participants to reflect on what death and dying meant to them. It was this reflection that enabled the participants to change their practice. All study participants had been exposed to either a single or cumulative experience of caring for a dying patient in an acute-care

hospital. However only a few participants possessed the skills of critical reflection and/or had a clinical facilitator that identified the experience as a teaching moment to promote reflection that led to transformational learning (Baumgartner, 2001). Critical reflection is pivotal to an individual making meaning out of an experience. This is particularly so when the experience is perceived as an uncontrollable and chaotic event (Johnson & Bourgeois, 2003). Through this act of making sense, new understandings are generated that evoke profound changes in individuals (Baumgartner, 2001).

The participants' new understandings of what it means to care for dying patients affected their practice in two ways. Firstly, for several participants their practice changed by adopting a holistic approach to nursing. This meant the participant was more aware of the need to address all dimensions of being human, i.e. the emotional, psychological, physical and spiritual, when providing nursing care. Participants gained first hand experience responding to a dying patient as a 'whole person' rather than an assemblage of independent parts. Through this engagement, most of the student participants came to understand the importance of holistic nursing, with several expressing that they had not seen this modelled in previous clinical placements.

Those who did not come to this understanding needed to have clinical staff or facilitators, or both, able to identify and use this opportunity as a teaching moment to illustrate a palliative care approach. This was because little support was provided by either the education program or staff in the clinical setting to make sense of the experience through reflection with the participants. The opportunity therefore to make

meaning of this experience was often missed. Other studies also report this finding (Beck, 1997; Cooper & Barnett, 2005; G.R. Johnson, 1994; Kelly, 1999; Van Rooyen et al., 2005).

Secondly, a few participants indicated they were considering palliative care as a specialty option post graduation following completion of their new graduate program. These participants demonstrated a paradigmatic shift in moving from a curative orientation to care to embrace a palliative care philosophy. To gain maximum satisfaction in their practice this means these participants will need to relocate to a specialty palliative care setting. The competing curative and palliative care orientations co-existing in an acute-care hospital create undesirable tensions that make the participants seek an alternative setting in which they can practice comfortably.

In all participants the generation of new understandings was strongest in the student participant recounts, compared to the new graduate nurses. This is probably because inclusion in the study required the student participant to have had at least one experience of caring for a dying patient. This initial experience seemed to provoke more impact as compared to the new graduate role where they were likely to have had cumulative experiences. Quint first identified that a students' first encounter with dying patients was more likely to shape the individual's future nursing practice than any other, as it prompted them to consider their personal understanding of death or to shift their views or to re-examine their beliefs and values (1967). In her view, undertaking this reflection caused students to become more attentive and thoughtful in their practice (Quint, 1967). On this basis, Quint advocated the importance of the student's first encounter with dying patients as pivotal to shaping future practice. This

finding is supported by Wong and Lee's (2000) retrospective study with qualified nurses who, on recall, identified the importance of this initial death experience on their future practice.

The generation of new understandings was not dependent on the experience being positive. In phase two of the study most participants described their initial experience of caring for a dying patient negatively. This negativity stemmed from the level of confrontation participants experienced in response to feelings of personal inadequacy triggered by not being prepared during their education program. This finding is further substantiated by the phase one of the study results which identified students were most likely to be unfamiliar with the dying process after receiving minimal opportunity to develop knowledge and skills. Both phase one and two of the study showed the personal inadequacy felt by the participants was the result of limited educational preparation and support offered in the clinical setting to guide their practice.

This study, while clearly identifying how the experience of caring for dying patients or their family was for participants also showed that critical reflection, either in the education program or the clinical setting, was almost non-existent. Only two study participants explicitly undertook critical reflection for themselves. Phase one and two of the study showed little emphasis was given to critical reflection skills in the context of caring for a dying patient. While critical reflection knowledge and skills may have been taught elsewhere in the education program, the student and new graduate nurses' experiences showed almost no capacity to transfer this knowledge and skill to the experience of caring for a dying patient. Critical reflection is pivotal in prompting

new learning in this context (Barrere et al., 2008). According to Neese (2003) critical reflection on death and dying experiences has the potential to create a change in self-concept, worldview and meaning schemes, enabling nurses to integrate new ways of knowing into their everyday practice. The education and practice implications of this third finding are addressed in the second section of this chapter.

7.2 Implications for Education and Practice

In light of these findings, there are several implications for tertiary institutions and acute-care hospitals to consider in the design and implementation of education programs to support the on-going development of nurses. This however is not the sole responsibility of tertiary institutions. Hospital new graduate programs should extend and consolidate the information provided at an undergraduate level with the responsibilities and accountabilities related to the role of a new graduate nurse. Thus, the provision of knowledge and skills in a seamless transition between sectors will further assist in making this area of practice more visible, allowing for the consolidation of new learning with prior experiences.

Both sectors also need to recognise the shared responsibility they have for supporting the learning needs of the future generation of nurses and for better communication of these needs. Communication of the need for this support could then be relayed back to the tertiary institution and followed up either individually and or in the embedded debriefing sessions.

7.2.1 Education

The major findings of this study highlighted that participants had minimal knowledge and skills on death and dying. This was corroborated with findings from two

perspectives which provide an impetus for re-examining the current provision of education on death and dying. Education in this discussion represents the interplay between classroom, simulation and clinical learning environments. This study has highlighted the need for undergraduate curricula to better meet the learning needs of students and new graduate nurses. The need is to provide education which sensitises students to caring for a dying patient through the provision of knowledge and skills on death and dying at an undergraduate level. The goal for new graduate programs is to harness the knowledge and skills already developed and to consolidate and extend these as the new graduate nurse matures into their professional role. The importance of education being conceptualised in this way is also highlighted by Sheehan and Malloy (2010).

Firstly, it is suggested that any education implemented be cohesively and systematically presented, consist of experiential learning activities and have well defined learning outcomes to assist in the overall evaluation of the student's learning and efficacy of the program. A further consideration is that education on caring for a dying patient should be located as a core component of the curriculum and specifically named. Use of this strategy means the unit of study is visible to students and has a legitimate space in the overall curriculum. This approach to palliative care undergraduate education is also supported by the work of the PCC4U (2005) project. It is anticipated that through the provision of more relevant education, improvements in the nurse's experience will occur. The following are ways in which the provision of education on death and dying can be enhanced.

7.2.1.1 Grief and Bereavement models

The inclusion of education on the bereavement and grief processes in undergraduate nursing curricula is warranted. This would facilitate students and new graduate nurses understanding of bereavement, associated grief responses, and assist them to make sense of their loss and move forward. Incorporating several different models acknowledges that people express their grief and bereavement uniquely. This knowledge supports students and new graduate nurses to anticipate the feelings that arise and normalise how they themselves are likely to feel. Preparing students to anticipate these feelings is likely to reduce feelings of confrontation when exposed to the experience. Embedding a range of experiential learning activities into the curriculum is an important strategy to promote increased understanding of one's own and others' mortality. It is from this self reflection on an individual's own mortality that empathy for others dying is likely to be achieved (Sheehan & Malloy, 2010).

7.2.1.2 Communication skills

Recurringly, students and new graduate nurses spoke of their difficulties communicating with dying patients and the stress this caused them. This need illustrates the role experiential learning can play in developing the knowledge and skills for practice prior to entering the reality of caring for a dying patient. A mixture of case studies, simulated laboratory exercises and role plays reflecting real life experiences on death and dying would be beneficial. Alavi (2005) suggests this approach is valid when teaching students about aspects of nursing that have potential to elicit disgust and distress.

The main benefit students are provided with is an opportunity to rehearse how to communicate while receiving feedback in a safe environment. This approach facilitates communication skill development specific to the context of death and dying. The benefits for students are the provision of a frame of reference to call upon, and a repertoire of things to say when caring for a dying patient, leading to a diminished feeling of being overwhelmed. Repeated rehearsal affords the student with a higher level of competence and confidence prior to engaging in the reality of caring for a dying patient and is likely to lead to increased performance. This approach equally applies to other skills related to care of the dying (Sheehan & Malloy, 2010).

7.2.1.3 Strategies for Self Care

Given the risk of vicarious traumatisation in nurses demonstrated by this study, the importance of embedding both knowledge and skill development in self care strategies is highly desirable. Several strategies are proposed as it is considered no one approach would be suitable for all learners. Scaffolding core support strategies from the commencement to the end of the program to inform students of the importance for self care is suggested. This would assist learners to develop these skills as they mature as a learner. Creating informal support networks within peer groups, such as peer mentoring, within the academic program is also desirable. Feedback from the participants suggested sharing stories with their peers was initially a more comfortable and safe way to express how they were feeling. Establishing this type of informal de-briefing would support students to commence sharing their experience and as a starting point to reflect on what has happened and how they were feeling. This learning could be further consolidated using formal de-briefing sessions following clinical placement, conducted by an academic conversant with a palliative care approach.

Embedding critical reflection skills into the education program is highly important in achieving transformational learning from this experience. Other authors also support their inclusion (Alavi, 2005; Kirkham, Harwood, & Hofwegen, 2005). Several strategies are required to promote this level of skill development. The participants spoke of how talking with their peers held significant value to them. Developers of undergraduate nursing curricula need to ensure that the design of their programs provides opportunities for students to explore and discuss their feelings when encountering a patient death. This should also be extended into the design of hospital new graduate programs. New graduate nurses also expressed the need to discuss their feelings. Verbalising feelings and thoughts helps to make sense of what may be a meaningless encounter for the student or new graduate nurse. A practical strategy therefore is that specific de-briefing sessions are integrated into the program design of both undergraduate and new graduate nurses programs. For further reflection to occur it is also recommended that reflective writing activities are an integral feature of teaching and learning. This strategy consolidates the verbal expression previously undertaken in the de-briefing sessions.

One of the implications for clinical practice found by this study is the need to promote the ability to self-reflect on experiences with dying patients in undergraduate and new graduate nurses. This is central to learning and also to make meaning out of the experience. Participating in the reflection process will enable undergraduate and new graduate nurses to move forward and engage with the next dying patient optimally. This is important in terms of how undergraduate and new graduate nurses process the loss of a significant person in their life and the associated suffering they experience. In order to engage on a daily basis with the dying, a solid foundation of knowledge

and skill must be embedded within education experiences to develop self-care strategies.

This study therefore recommends a model of clinical group supervision be instituted to formalise the process of reflection as a means of explicitly valuing its role in the students' learning and its place in curriculum design. This model of supervision involves staff specifically trained to facilitate reflection in students by combining the theoretical and practical learning of their course undertaken scheduled placement. Part of this training would see staff being conversant with a palliative care approach to ably assist students and new graduate nurses to optimally adjust to the loss they have experienced. Several studies attest to the value of this model in terms of the support it offers students, the personal growth which occurs as a result of students being encouraged to reflect on their practice and the capacity to better meet the emotional needs of students in a more timely manner (Carver, Ashmore & Clibbens, 2007; Clouder & Sellars, 2004; Lindgren & Athlin, 2010). A further benefit is the reorientation of nurse academics back into the clinical setting that helps to diminish the theory – practice gap divide often perceived by students and industry.

7.2.1.4 Facilitation of learning in the clinical setting

Given the pivotal role the experience of caring for a dying patient plays in transformational learning, the clinical environment must be viewed as a key learning environment. Assigning this value to the clinical environment requires staff who facilitate clinical learning in tertiary institutions be provided with education in a palliative care approach. A workshop outlining the key principles of practice could be offered prior to staff commencing clinical facilitation. Completion of independent experiential learning activities would also aid in these staff being more aware of their

own feelings towards death and dying. Having this awareness is more likely to make the facilitator sensitive to the needs of the student. A workshop of this type could be conducted to further develop the clinical facilitator's skills in teaching. A focus of this workshop would be the experience of caring for a dying patient as a teaching moment, and the role critical reflection plays in transformational learning. Emphasis would therefore be on increasing the facilitator's capacity to foster critical reflection in their students through the experience of caring for a dying patient. In addition to increasing their knowledge and skills, the facilitators would also be better at understanding the need to support students' adjustment to the professional loss they have experienced and assist them in moving forward. Thus, a more explicit acknowledgement of bereavement would be engendered. The role the clinical setting plays in the professional development of the undergraduate nurse in relation to death and dying cannot be underestimated (Kwekkeboom et al., 2005; Sheehan & Ferrell, 2006; Thompson, 2005).

7.3 Practice

7.3.1 New Graduate Programs

Hospitals, as providers of transition programs, need to be cognisant of the education on death and dying students receive as part of their undergraduate program. It is suggested this could best be achieved by working in partnership with tertiary institutions in developing new graduate programs. A key person from the tertiary institution could act as a liaison person providing this information. By working collaboratively, new graduates would then be the recipients of transition programs which extend and refine their knowledge and skills on death and dying through

continuing education. This approach acknowledges that clinical knowledge evolves over time (Schlairet, 2009).

7.3.2 Continuing Professional Development

This study has demonstrated the need for organisations to prepare their clinical staff in a palliative care approach. A possible means by which this could be undertaken is to provide continuing professional development to increase staff understanding of a palliative care approach. The provision of comprehensive continuing professional development may lead to a cultural change within acute-care hospital organisations to adopt a palliative care approach, potential to lead to new knowledge development in more experienced staff, the building of a supportive clinical environment and the provision of role models who practice in a palliative care approach. Two policy documents further advance this argument. Recently (March, 2010) a minimum standard of 20 hours continuing professional development has been set by the Nursing and Midwifery Board of Australia. Legislating for this standard provides a mandate for individuals to maintain, improve and broaden their knowledge, expertise and competence relevant to their context of practice (Nursing and Midwifery Board of Australia [NMBA, 2010]). It also means healthcare organisations are responsible for ensuring registered and enrolled nurses, under this legislation, are provided access to relevant and contemporary education to meet this new requirement. The guidance document on Health System Reform and Care at the End of Life (PCA, 2010) offers a further impetus for the provision of education on a palliative care approach. This document promotes the need for all health care professionals whose role interfaces with end of life care are educated to ensure the provision of high-quality care at the end of life is achievable for all.

A further implication for clinical practice identified by this study is the need to promote a safe environment in which students and new graduate nurses can learn to care for the dying. This necessitates that the clinical areas have skilled staff able and willing to support students and new graduates at the time of, and following, a patient death. It is also suggested that new graduate programs provide specific support structures such as an educator and/or scheduling individual or group de-briefing times so that the new graduates can share their stories of death. Such an approach requires a staff member with appropriate facilitation skills and knowledge of a palliative care approach. Writing a reflective journal focussed on patient death experiences throughout the course of their transition program may offer an alternative means of promoting reflection thereby fostering resolution of the grief experience.

All clinical staff in an acute-care hospital should be the recipients of continuing professional development on a palliative care approach. This would assist staff in better understanding the needs of students and new graduate nurses while they encounter a dying patient. Having clinical staff more informed and skilled in dealing with bereavement will help to promote this process in students and new graduate nurses. Increasing the knowledge and skills of the acute-care hospital staff will result in the more timely intervention of support at the time of a patient's death to students and new graduate nurses.

7.4 Strengths and Limitations of the Study

To date, no study has explored Australian student and new graduate nurses' experience of caring for a dying patient and their family. Furthermore, no studies have investigated this multi-dimensional phenomenon using a mixed method study design.

An additional strength of this study has been the inclusion of a longitudinal element seeking to determine if the participant's experience changed over time. Previously conducted studies have only studied the participant's experience from a single perspective and from one time interval only.

The second phase of this study was conducted with participants from a single institution offering a university undergraduate nursing program located in one state of Australia. This limits the generalisability of the findings. The qualitative study findings may have varied if participants were recruited from other institutions and the study conducted in other geographical areas of Australia. Greater diversity of participants from other cultures and countries would have further broadened our understanding of this phenomenon. In spite of this, the depth of understanding gained from the small sample size offered the opportunity to determine what it means to live the experience of caring for dying patients and their families. However, the quantitative study of the content and process of death and dying education drew data from across Australia therefore the implications for education both in pre-registration programs are applicable to a much wider range of settings. The reader is able to make judgements of transferability through the presence of detailed descriptions of the setting, the participants, data collection and analytical processes used and exemplars to illustrate the findings.

7.5 Recommendations for Future Research

This study while able to determine the breadth of curricula practices currently used to provide education on death and dying was unable to confirm the best approaches and content to be employed by undergraduate nursing programs. Future

research into what constitutes the best learning processes and the most appropriate content are needed. Along with the development of learning outcomes on caring for the dying, this will assist in ensuring that all Australian students on graduating from their nursing program leave with core knowledge and skills in a palliative care approach. Part of this research would also be to systematically evaluate the effectiveness of this education on death and dying to determine its efficacy in new graduates.

This study proposes the concept that students and new graduate nurses are at risk of developing vicarious traumatisation due to the traumatic nature associated with caring for dying patients and their families. The reality of a nurse's practice is that they are often exposed to multiple deaths, adding further weight to the argument for development of vicarious traumatisation. Studies on vicarious traumatisation have been extensively undertaken with counsellors and social workers but relatively few studies have been conducted in other health professionals, particularly nurses. A study examining this concept with students and new graduate nurses in acute-care hospitals would offer insights into the magnitude of risk and ways in which it can be managed. Such a study would inform the educational preparation of undergraduate and new graduate nurses, identify appropriate support systems for implementation by education providers and health care organisations and raise awareness in the nursing profession of the potential impact caring for dying patients and their families has on students and new graduate nurses.

Given the significant role the clinical environment plays in students and new graduate nurses learning about caring for a dying patient this study also proposes research be

undertaken into which model of clinical supervision most appropriately promotes learning when caring for dying patients. Research in this area would assist education programs and organisations to identify how best to support the learning requirements of students and new graduate nurses.

During the conduct of this study it was identified that no information exists on the content and learning processes that constitute a new graduate program. This deficit warrants further investigation so that new graduates are better supported by their education program to carry out their role when caring for dying patients. A final recommendation for future research is that a study be undertaken to investigate the efficacy of Australian new graduate nursing programs in supporting new graduates when caring for dying patients is adequate.

7.6 Conclusions

Conducting a two-phase, mixed method Australian study incorporating a longitudinal element has enabled comprehensive knowledge to be gained on the experience of caring for dying patients and their family in an acute-care hospital. The participants of this study identified they were inadequately prepared for this role. This can be attributed to the perceived deficiencies in the educational experiences these participants received during their undergraduate and new graduate nursing programs. Validation as to the existence of these perceived deficiencies was confirmed by the evidence gathered on the current curriculum practices existing among Australian undergraduate nursing programs and reported by the phase one of the study results. Further validation was gained by seeking a deeper understanding of

the participant's experiences through their stories as a final semester student and subsequently as a new graduate nurse.

This chapter has presented a discussion on the major findings which emerged from this two-phase mixed method study. By sharing the participants' stories, this study gives a voice to a group of students and nurses who until now have been relatively invisible when undergraduate nursing curricula are designed. Against a backdrop of inadequate preparation by Australian undergraduate nursing curricula three major findings emerged. Firstly this study has shown the need for the participants to be supported while bereaved following the death of a patient. The study has also highlighted that students and new graduate nurses are at risk of developing vicarious traumatisation as a result of this experience. Furthermore, this study shows that the experience of caring for a dying patient and their family provides the capacity for transformative learning to take place which can lead to nurses building a more meaningful practice.

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GLOSSARY

Acute-care hospital

In this study was defined as either a public or private hospital comprising an array of health services inclusive of medical – surgical wards but which excluded community and outpatient services

Dying patient

A person expected to die soon regardless of treatments given. Cessation of biological, social existential and cognitive function.

Family

The word family is used to define those closest to the patient in knowledge, care and affection. (PCA, 2005b, p.6)

Hermeneutics

Is the theory and practice of interpretation. To interpret a text is to come to understand the possibilities of being revealed by the text.

Hermeneutic phenomenology

Tries to be attentive to both the descriptive (phenomenology) methodology because it wants to be attentive how things appear, let things speak for themselves. It is also concerned with the interpretive (hermeneutic) methodology because it claims there are no such things as uninterpreted phenomena

Life limiting illness

This term is used to describe illnesses that can be reasonably expected to cause the death of the patient within a foreseeable future. This definition is inclusive of both malignant and non-malignant illnesses (PCA, 2005b, p.6).

Lifeworld

Husserl defined this term as the world of immediate experience

New graduate nurse

A student recently graduated from a university bachelor level program

Palliative Care

An approach that improves the quality of life of individuals and their families facing the problems associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care approach

A set of skills expected of every health professional who provides care for someone with a life limiting illness.

Palliative Care Australia (PCA)

The peak national body responsible for the provision of quality care to all those dying regardless of the setting through the development of policy and standards

Patient

The word is used to describe recipients or potential recipients of palliative care. (PCA, 2005b, p6)

Phenomenology

Is the science of phenomena based on modes of reflection, it is a discipline which attempts to describe how the world is constituted

Primary care provider

Any health professional who takes on the role of providing care to a person regardless of the underlying cause whose substantive work is not in the area of palliative care

Undergraduate nursing student

A person undertaking a three-year Bachelor of Nursing degree at university, over 17 years of age, having completed Higher School Certificate with a University Admissions Index.

Specialist palliative care services

Health professional who substantive training and work is in palliative care and either accepts full responsibility for care or works indirectly with other health professionals to provide specialist advice

Text

Is the transcription of the in-depth interview to a written text to all for reflection on the text and interpretive insights to be made possible.

APPENDICES

APPENDIX 1

Dear (insert name of the Dean)

Date to be inserted

Re: Collection of Information Related to the Provision of Death and Dying Education in Undergraduate Nursing Programs

The purpose of this letter is to explain and seek your assistance with the collection of data for my PHD studies. My study is titled: **‘The Education Experiences of Nursing Students who Care for the Dying Person and their Family in a Hospital Setting’**. I am currently a post graduate student enrolled at the University of Western Sydney, Hawkesbury Campus.

My study is concerned with the provision of education related to Death and Dying in undergraduate Bachelor of Nursing programs. The data collected forms the first phase of the study and will assist in determining current curricula trends.

The University of Western Sydney Hawkesbury Campus Human Research Ethics Committee has granted ethics approval on 11th September 2000 – Committee Approval No: HREC 00.33

The study aims to:

- describe the education provided in undergraduate nursing curriculum to support nurses practice in caring for the dying person and their family.
- explore the coping strategies undergraduate and novice nurses employ in caring for the dying person and their family, in hospital settings.
- determine how well the nurses were prepared by their nursing education program to care for the dying person and their family.

It is intended that the results of this study will inform the future development of nursing curricula and provide insights into the experiences nurses have when caring for the dying person and their family. All Australian universities who offer Bachelor of Nursing programs have been forwarded a copy of this Survey. A copy of the report detailing the collated information from the survey will be forwarded to each of the responding universities, upon completion of the study.

I would appreciate you forwarding the attached Survey to the most relevant Faculty staff member for completion. I have also requested that their contact details be provided so that I may follow up with a telephone conversation, should the need arise to pursue a response in more detail.

Identifying information related to the university name and geographical location will be removed and stored separately in a locked filing cabinet accessible only by the researcher. No identifying information, either written or verbal, on individuals or on universities will be provided or published in connection with this study.

I would be grateful if you would complete the survey and return it to me in the attached envelope by **Thursday 30th November 2000**.

Enquires regarding the survey can be directed to me on (W) 02 45 701 897 or via e-mail at: amanda.johnson@uws.edu.au

Should you require any further information regarding the study, have concerns or a complaint then please contact the researcher directly or if an independent person is required - The Executive Officer UWS Hawkesbury Research & Consultancy Unit, on 02 45 701 688 or postal address: Locked Bag No 1 Richmond 2753.

Kind Regards

Amanda Johnson

APPENDIX 2

Dear Participant

I am writing to invite you to participate in a study titled: **‘The Experiences of Nursing Students who Care for the Dying Person and their Family in a Hospital Setting’**.

The purpose of the study is to gain a better understanding of the experiences nursing students have in caring for the dying person and their family in a hospital setting. The study will be conducted over a period of time and will involve you in your final year of the Bachelor of Nursing program and during your first year out as a practising Registered Nurse.

The study aims to: 1. describe the education provided in undergraduate nursing curriculum to support nurses practice in caring for the dying person and their family; 2. explore the coping strategies undergraduate and novice nurses employ in caring for the dying person and their family, in hospital settings and 3. determine how well the nurses were prepared by their nursing education program to care for the dying person and their family.

The benefits of the study are to: 1. improve the nursing care provided to the dying person and their family through the provision of quality undergraduate education programs, which offer relevant theoretical and practice components in their curriculum; 2. contribute to the future curriculum design of the university’s Bachelor of Nursing Program and 3. outline the range of coping strategies students and newly registered nurses use to support their practice when caring for the dying person and their family.

Your Involvement in the Study:

You will be requested to attend a total of three interviews during your participation in the study. Each interview will be scheduled at 6-month interval and held over the following time periods August/Sept 2001; April/May 2002 and November/December 2002. Each interview will be for 1 – 1 1/2 hours duration only.

The purpose of the interviews are to record, in your words, your experiences of providing nursing care to a dying person and their family. You will be asked to tell the researcher about your experiences and to describe your thoughts and feelings associated with those experiences.

Scheduling of the interviews will be at mutually convenient times and locations. My contact with you over the 18-month period will be via the contact details that you provide to me.

Your interviews will be audiotaped and to ensure confidentiality, your name and any personal identifying characteristics will be removed from the tape prior to being transcribed into a written text. The tapes will be held in a locked filing cabinet with access limited to the researcher. A copy of the written text will be forwarded to you after each interview, for your information and clarification that it reflects a true and accurate record of the recount. The transcription of your taped interview will need to be shown to the researcher’s supervisors for the purposes of ensuring reliability during the analysis phase of the study.

Your participation in this study is completely voluntary and you may withdraw at any time. Your non - participation or subsequent withdrawal will not affect your progress or individual grades in any way.

If you have any questions or concerns regarding the study please contact me on 02 45 701 897 or via e-mail amanda.johnson@uws.edu.au or an independent person – The Executive Officer UWS Hawkesbury Research & Consultancy Unit can be contacted on 02 45 701 688.

Kind Regards

Amanda Johnson
(Researcher)

APPENDIX 3

University of Western Sydney Hawkesbury Campus

Faculty of Health & Centre for Research in Healthy Futures

Project Title:

The Experiences of Nursing Students who Care for the Dying Person and their Family in a Hospital Setting

CONSENT FORM

- I understand the information from this study will be used to 1. improve the nursing care provided to the dying person and their family through the provision of quality undergraduate education programs, which offer relevant theoretical and practice components in their curriculum; 2. contribute to the future curriculum design of the university's Bachelor of Nursing Program and 3. outline the range of coping strategies students and newly registered nurses use to support their practice when caring for the dying person and their family.
- I understand I am requested to complete 3 interviews at 5 – 6 month intervals; one interview midway through the final year of my Bachelor of Nursing Program and two interviews during my participation in a hospital based New Graduate program, in June & November 2002. These interviews will consist of recounting my experiences of caring for a dying person and their family from clinical practice. I understand the interviews will be of 1-1 1/2 hour's duration & will be scheduled at a mutually convenient time and location to me & the researcher.
- I understand that the researcher will need to maintain regular contact with me to discuss the research and schedule interview times. I agree to provide the researcher with contact details for this purpose.
- I understand the researcher will consult with me following transcription of the tape and during the analysis phase to ensure that the narrative remains truthful to what is conveyed during the interview.
- I understand my name will be coded during the taped interview and transcription phase of the data collection. My name, contact details and audiotapes will be kept separately from the data, in a locked filing cabinet accessible only by the researcher.
- I understand that for the purposes of reliability my transcript will be shown to the researcher's supervisors during the analysis phase of the study.
- I understand I am free to withdraw at any time from this research study and that my non-participation or withdrawal will not affect my progress or individual grades in any way.
- I understand that the information supplied by me in the form of an audiotaped interview and resulting transcript will be held under security by the researcher for a period of 5 years in a locked filing cabinet, located on campus which is only accessible by the researcher.
- I understand any questions concerning the study can be directed to the researcher – Amanda Johnson on 02 45 701 897 or via e-mail: amanda.johnson@uws.edu.au.

- I understand that the recounting of the clinical experiences via the interviews may evoke some level of discomfort or unresolved issues for me. In these instances the researcher will offer support and if necessary refer me to the following professional counsellors: UWS H Counselling Service – Janice Poulson 02 45 701 401 or Wendy Farrell Whelan Wentworth Area Health Service Bereavement Counsellor on 02 47 34 2000 For students who identify themselves as Indigenous Australians referral may be made to: Dennis McDermott located on campus in the Men’s Health unit on extension 1713 or Link Up 47 59 19 11 or Dharruk Aboriginal Medical Service 02 98 32 13 56.
- I (the participant) have read the information above in conjunction with the Plain Language Participant Information Letter and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw at any time. I agree that research data gathered for the study may be published, provided my name is not used.

Signature _____ Date _____
 (Participant)

Print Name _____

Signature _____ Date _____
 (Principal Researcher)

Print Name _____

The University requires that all subjects are informed that if they have any complaint concerning the manner in which a research project is conducted it may be given to the researcher or if an independent person is preferred, to the Executive Officer, Human Research Ethics Committee, Research and Consultancy Unit, University of Western Sydney Hawkesbury Campus 2753 or telephone 02 45 701 688.

APPENDIX 4

Survey

Death & Dying in Australian Undergraduate Nursing Programs

Q 1 How would you best describe the **Curriculum approach** within your undergraduate nursing program which implements education pertaining Death and Dying:

- 1.1 Integration of material throughout subjects/modules
 - 1.2 Offering of an Elective subject
 - 1.3 Designated sub module on Death & Dying within a teaching unit
 - 1.4 Random coverage by independent teaching sessions
 - 1.5 No information related to Death & Dying is included
 - 1.6 A combination of approaches: please specify
-
-
-

Q2. In your Bachelor of Nursing curriculum, at what **stage** of the program do your teaching sessions on Death & Dying occur?

- 2.1 First year, Semester 1
- 2.2 First year, Semester 2
- 2.3 Second year, Semester 3
- 2.4 Second year, Semester 4
- 2.5 Third year, Semester 5
- 2.6 Third year, Semester 6
- 2.7 At no stage

Q3. Tick the appropriate box below, which indicates, most appropriately, the **average number of teaching hours** allocated to Death & Dying in your program?

- 3.1 0 hours
- 3.2 < 2 hours
- 3.3 2 -4 hours
- 3.4 5 - 10 hours
- 3.5 11 - 15 hours
- 3.6 15 - 20 hours
- 3.7 > - 20 hours

Q4 Which **category of health professional** provides the classroom teaching in your program? (Tick the relevant box)

- 4.1 Nurse Academic
- 4.2 Medical personnel
- 4.3 Clinical Nurse Consultant Palliative Care
- 4.4 Clinical Nurse Consultant Oncology
- 4.5 Social Worker
- 4.6 Grief & Bereavement Counsellor/Coordinator
- 4.7 Pastoral Care Worker
- 4.8 Registered Nurse Clinical area
- 4.9 Other Academic: please specify _____
- 4.10 Other: please specify _____

Q5 Do you provide your nursing students with a **specific Clinical Placement** on caring for the dying person and family? (Please tick the appropriate box)

5.1 Yes (if yes, go to question 6)

5.2 No (if no, go to question 7)

5.3 Not Specifically (that is, it is subject to the clinical experiences the student is randomly allocated too)

Q6. If yes, please identify the specific clinical setting/s by placing a tick in the relevant box. (You may tick more than one response)

6.1 General Medical

6.2 Residential Aged Care

6.3 Obstetric Unit

6.4 Gynaecology Unit

6.5 Paediatric Oncology Unit

6.6 Adult Oncology Unit

6.7 Haematology Unit

6.8 Palliative Care Unit

6.9 Designated Hospice

6.10 Community Health

6.11 Community Based Palliative Care Team

6.12 Home Hospice

6.13 Other: please specify _____

Q7 Describe the **teaching strategies** used in your program to provide education on Death & Dying? (You may tick more than one response) ****question reworded****

7.1 Formal lectures

7.2 Case Studies

7.3 Small Group Discussions

7.4 Self Directed Learning Activities

7.5 Role Plays

7.6 Journal Writing

7.7 Clinical Experiences

7.8 Learning Package

7.9 No Strategies used

7.10 Other: please

specify _____

Q8. If more than one teaching strategy has been identified, please nominate the strategy **primarily** used in your program?

Q9 From the list below please tick the **content areas** specific to Death & Dying, covered by your program. (You may tick more than one response)

9.1 Grief, Loss & Bereavement

9.2 Communication Skills

9.3 Nurse's Role

9.4 Psychological Aspects

9.5 Spiritual Issues

- 9.6 Cultural Diversity
- 9.7 Ethical & Legal Issues
- 9.8 Gender issues
- 9.9 Physical Issues in Caring for the Dying Person
- 9.10 Caring for the Deceased Person
- 9.11 Role of the Multidisciplinary Team
- 9.12 Supporting the Carers
- 9.13 Other: please specify _____

Q10 From the methods below identify how your program **evaluates** the student's knowledge, skills and attitudes related to grief, loss and bereavement across the lifespan. (You may tick more than one response)

- 10.1 Written Tests/Examinations
- 10.2 Oral Interview/Viva
- 10.3 Case Study
- 10.4 Completion of a Workbook involving case studies/self directed activities
- 10.5 Observation of Clinical Practice in the Clinical Setting
- 10.6 Small Group Tutorial Discussions
- 10.7 Component not specifically evaluated
- 10.8 Other: please specify _____

Any other comments you would like to add.

Or you may wish to contact me directly either via phone: 02 45 701 897 or email: amanda.johnson@uws.edu.au.

For future follow up it would be appreciated if the contact details below were completed by the person completing the survey tool This information allows me the potential to have further contact with you and further discuss the curriculum via way of a telephone interview.

Contact Details to assist with Future Follow up regarding education related to Death & Dying:

Name: _____
Designation: _____
Location: _____
Address: _____ _____ _____
Telephone Number: ()
Email Address: _____

Thankyou for completing and returning the survey.

APPENDIX 5

DISSEMINATION OF FINDINGS

Referred Publication

Johnson, A., Chang, E. & O'Brien, L. (2009). Nursing the dying: A descriptive survey of Australian undergraduate nursing curricula. *International journal of Nursing Practice*, 15,5 417-425.

Conferences

Johnson, A., Chang, E., & O'Brien, L. (February, 2010). *Rattling the curriculum cage: The time for reform is now*. Paper presented at the 3rd National Palliative Care Education Conference, Queensland University of Technology, Brisbane, Queensland

Johnson, A., Chang, E., & O'Brien, L. (November, 2008). *Grieving the loss of a patient: How adequately prepared are Australian nurses for this emotional roller coaster ride?* Paper presented at the 9th Annual Interdisciplinary Research Conference, School of Nursing and Midwifery Trinity College Dublin, Ireland

Johnson, A., Chang, E., & O'Brien, L. (June, 2004). *The nurses experience of caring for a person dying and their family: issues and policy for nursing education*. Paper presented at the International Palliative Care Nursing Research Conference, Prato, Tuscany Italy.

Johnson, A., Chang, E., & O'Brien, L. (May, 2004). *Facing the challenge in undergraduate nursing curricula: Educating nurses to care for the person dying and their family*. Paper presented at the 2nd National Palliative Care Education Conference, Adelaide, South Australia.

Johnson, A., Chang, E., & Chenoweth, L. (February, 2002). *Teaching Death and Dying: The Challenges for Nursing Education*. Paper presented at the 13th International Nursing Research Congress Conference, Brisbane, Queensland.

Johnson, A., Chang, E., & Chenoweth, L. (May, 2001). *Creating an Environment for Nursing Students to Care for the Dying Person and their Family*. Paper presented at the Wentworth Area Health Service Annual Palliative Care conference, Leura, New South Wales.

Workshops:

Johnson, A. Invited Speaker; Higher Research Degree Ethics Workshop – *Interviewing on Sensitive Topics*. University of Western Sydney; School of Nursing and Midwifery. August 2009