# NURSES' EARLY EXPERIENCES WITH PATIENT DEATH

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### ABSTRACT

*Chronic stress and 'burnout' have been extensively researched in nursing populations, but very* little is known about the impact of specific acutely stressful or significant events. A novice nurse's first encounter with patient death may pose considerable cognitive, emotional and clinical challenges. Using a mixed methods design, this study explored the clinical circumstances, impact and challenges and rewards of nurses' early experiences with patient death. A convenience sample of practicing New Zealand Registered Nurses was recruited using email invitations. In the 1<sup>st</sup> phase, 174 participants completed an online questionnaire exploring the clinical circumstances, preparedness, support mechanisms and impact of their Earliest Memorable Patient Death (EMPD). A sub-sample of twenty volunteers then participated in the 2<sup>nd</sup> phase, individual semi-structured interviews, providing detailed descriptions of their EMPD experiences. Most nurses reported EMPDs during undergraduate training (61%) or first year of qualified practice (23%). Over 80% of EMPDs occurred in acute medical, surgical or specialty settings in public hospitals, some involving paediatric or sudden unexpected deaths. *Whilst some participants described a rewarding, 'learning experience', others reported acute* helplessness, guilt or marked ongoing distress. Whilst little can be done to control the clinical circumstances of nurses' early death encounters, by better preparing and supporting novice nurses it may be possible to minimise more negative factors such as unexpected elements, feelings of inadequacy, exclusion and role conflicts, and facilitate coping, sharing the experience, personal and professional growth, and other positive outcomes. Nurses' early experiences with patient death appear to have a powerful lasting impact on their professional and personal lives. The nature of these experiences may influence ongoing attitudes to care of the dying, future career direction and ultimately, patient care. The findings have significant implications for timing and content of future interventions better to prepare and support novice nurses experiencing patient death for the first time. Relatively little has previously been published about nurses' early experiences with patient death, and the exploratory, inductive methodology underlying this research allowed the nature of these experiences to emerge. More research is needed in this important area.

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## LIST OF ABBREVIATIONS

EI	Emotional Intelligence
EMPD	Earliest Memorable Patient Death
IPA	Interpretative Phenomenological Analysis
NZ	New Zealand
PDIS	Patient Death Impact Scale
PDPS	Patient Death Preparedness Scale
PTSD	Post Traumatic Stress Disorder
RN	Registered Nurse
SIT	Stress Inoculation Therapy

### **INTRODUCTION**

This research was conducted with a sample of Registered Nurses (RNs) currently practicing in a major metropolitan city in New Zealand. Nursing is a stressful job, with high rates of turnover and attrition. Where areas are understaffed, nurses experience higher rates of injury, sick leave and burnout, further exacerbating shortages. Nursing shortages have serious implications for all health consumers - low nurse-patient ratios are significantly associated with higher rates of patient morbidity and mortality (Aiken, Clark, & Sloan, 2002; Needleman, Buerhaus, Mattke, Stewart, & Zelevinsky, 2002). Although empirically far more challenging to measure than deaths and surgical complications, the quality of care provided by nurses is also of value to health consumers. Nurses who have the clinical knowledge, coping skills and collegial support (from other well prepared and supported nurses) are more likely to provide patient care beyond the competent, safe performance of tasks. Research addressing nurse preparation, support, stress and coping has substantial potential benefit to everyone in society. Most people will, at some stage, find a nurse is involved in the care of a loved one, or that they, themselves require nursing care. At a time when people are often most vulnerable, they will look not only for competence, but caring. Without adequate preparation and support, nurses cannot be expected to deliver either.

This research focuses on one aspect of nursing preparation and support by exploring nurses' early experiences with patient death. Nurses spend more time delivering care to dying patients than do any other health professional. For decades, researchers have suggested that student nurses' first experiences with patient death can have a significant influence on practice, and attitudes regarding death and dying can be quite established by the time nurses qualify (Chen, Del Ben, Fortson, & Lewis, 2006; Golub & Reznikoff, 1971; Hurtig & Stewin, 1990). Nurses who find early encounters with death and dying very difficult can experience feelings of inadequacy, helpless, defensiveness or distress and coping mechanisms such as suppression, distancing and avoidance may be adopted (Cooper & Barnett, 2005; Kent, 2004; Terry & Carroll, 2008). This may impact on the quality of care nurses deliver, their job satisfaction, turnover and attrition. It is also possible that the thoughts, feelings and behaviours associated with care of the dying patient and their family may influence the way nurses respond to the daily demands of other patients in their care.

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In her seminal work based on a six-year study, The Nurse and the Dying Patient, Quint (1967) highlighted the central role of the nurse in caring for the dying patient, and advocated for adequately preparing nurses to provide such important and demanding care, and supporting them through their early encounters with patient death. Quint proposed that when novice nurses faced patient death and dying without adequate preparation and support, this resulted in negative attitudes to care of the dying, increased death anxiety, and subsequent avoidance of death and dying. Quint made recommendations to improve nursing death education, and felt that this could have a society-wide impact, by in turn improving end-of-life care. Quint's work is still often cited today, not because her recommendations have been actualised, but because so many of her observations and criticisms remain accurate for today's novice nurses. In the forty-plus years following the publication of Quint's book, researchers have continued to highlight the inadequacies of nursing undergraduate death education. Newly qualified nurses report feeling anxious, overwhelmed, ill-prepared, inadequate and unskilled when faced with the challenges of caring for dying patients (Allchin, 2006; Beck, 1997; Frommelt, 1991; Thrush, Paulus, & Thrush, 1979). Years of research findings support experiential learning as the most preferred and effective way to teach nurses about caring for dying patients and their families, but an international move to degree-based nursing training has shifted much of nursing education away from the bedside and into the classroom.

#### Nursing in New Zealand: Workforce Challenges

Around the world, political, social and scientific forces continue to impact on nursing workforce and education trends, the nature of healthcare settings and patient populations. New Zealand nurses have much in common with those in other OECD countries, facing similar contemporary nursing workforce issues, population health challenges, and a rapidly changing system of healthcare delivery (Finlayson, Aiken, & Nakarada-Kordic, 2007; Health Workforce Advisory Committee, 2005; North, 2007). New Zealand is a small, remote country, local nursing research in its infancy, and data specific to nursing in New Zealand can be difficult to locate (Hughes, 2007). Accordingly, this thesis frequently draws on research conducted outside the New Zealand nursing context. It is important, however, to acknowledge the unique nature and defining features of nursing in New Zealand. Early European settlers established New Zealand as a rural country, and although it remains well-known for sheep and dairy farming, today more than 85% of New Zealand's population are urban-dwellers (Statistics New Zealand, 2006). Distinctive geography makes healthcare delivery to the rural population of New Zealand challenging, but New Zealand nurses are well-known for resourceful and innovative practice (Hughes, 2007). New Zealand's population is predominantly Anglo-Saxon, but is becoming increasingly ethnically diverse, with growing Maori, Asian and Pacific Island populations (Health Workforce Advisory Committee, 2005). The proportion of New Zealand residents who were born overseas has been steadily increasing over the past decade, with 2006 census figures showing that 29.9% of New Zealanders were born overseas.

Reflecting international trends, nursing training has undergone significant change over the last 20 years, and what was once provided by hospital boards is now the exclusive domain of universities and polytechnics. Today, undergraduate education for New Zealand RNs is delivered by tertiary providers as a three-year bachelor's degree programme. Although the last New Zealand hospital school of nursing closed in 1989 (Gage & Hornblow, 2007) the most recent available statistics show that more than half of New Zealand nurses practicing in 2000 had trained under this 'old' hospital-based nursing system (Nursing Council of New Zealand, 2000).

The New Zealand nursing workforce faces a number of challenges, including endemic shortages, low workforce participation, an aging workforce (with 25% of RNs over the age of 50) and high turnover and attrition (District Health Boards New Zealand, 2006; North et al., 2005). New Zealand figures indicate that, at any one time, 30-40% of nurses intend to leave their jobs within a year (Cobden-Grainge & Walker, 2002) and a decade after they initially register, approximately 50% of New Zealand RNs are no longer working as nurses (New Zealand Health Information Service, 2000). Although there is an increasing amount of international research looking into the reasons nurses leave, there is very little published research on attrition from nursing or nursing training in New Zealand (North et al., 2005).

New Zealand's Maori and Pacific Island populations are significantly over-represented in morbidity and mortality statistics, but representation of these groups in the nursing profession is relatively low, with 7.5% of active nurses and midwives identifying as Maori, and 2.9% as Pacific Islanders (New Zealand Health Information Service, 2004). Aggressive international recruitment of New Zealand nurses, including New Graduates, contributes to shortages, and New Zealand is increasingly reliant on nurses from overseas, with large numbers of nurses originally training in the UK and Ireland, and smaller numbers from Australia, the Philippines, India, South Africa, North America and the Pacific Islands now (North, 2007).

#### Terminology

In New Zealand, the professional development of RNs is modelled on an adaptation of Benner's (1984) levels of practice. The classifications proposed by the National Professional Development & Recognition Programmes Working Party (2004), and widely adopted by employers of New Zealand RNs, have been used within this thesis. Transition through these levels, depicted in Figure 1, does not occur automatically with time working in a specialised area of practice, but requires evidence of professional development including competencies met, further education, contribution to quality improvement, and participation in leadership.

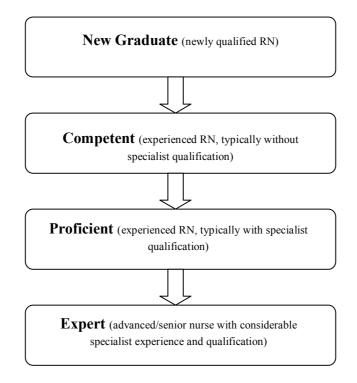


Figure 1: Professional development pathway of NZ Registered Nurses

As seen in Figure 1, newly-qualified RNs are referred to as New Graduates – and in this thesis, the term New Graduates is used to describe newly-qualified New Zealand RNs in the first 12 months of their practice. Although there are many existing RNs who gained their registration through historical training schemes or internationally recognised qualifications, New Zealanders who want to qualify as RNs today must complete a three-year Bachelor's degree qualification. In this thesis, the education nurses receive prior to qualification is referred to as 'undergraduate' nursing training, but it is recognised that not all RNs have Bachelor's degrees. The expression 'novice nurse' is used to collectively describe all neophyte nurses – both nursing students and New Graduates.

### THE NURSE AND THE DYING PATIENT

Modern society faces change at an accelerating pace, and although the inevitability of death remains a constant, the nature of dying has been dramatically changed by medicalisation and technology. Healthcare delivery has also changed significantly, and the media swing wildly between catastrophic reports of the short-fallings of health systems and health professionals, and proclaiming the benefits of the latest medical advancements and life-saving measures. The information available through the media and online has created a new, more informed and opinionated generation of healthcare consumers. These changes have also impacted significantly on the nature of nursing, but some elements at the core of nursing have remained relatively unchanged. Although nurses are often depicted on television in dramatic life-saving roles, today's nurses continue to face challenges and rewards in their often unavoidable interface with patient suffering, death, dying, grief and loss.

A thorough review of the expansive literature on nursing, death and dying is beyond the scope of this thesis. Accordingly, this chapter provides only a brief introduction to the nature of nursing encounters with patient death and dying, then focuses more specifically on research into death education, and health professionals' preparation for and attitudes towards early encounters with patient death.

#### **Contemporary Death and Dying**

Although the inevitability of death remains a constant, the nature of death and dying in society has changed significantly. Thanks largely to a reduction in infant mortality, life expectancy has increased. Medical and technological advances mean fewer people die from accidental death or infection. The ultimate impact of these changes is perhaps not a cheerful thought; members of contemporary society have an increased likelihood of death in old age, following a prolonged dying period, from chronic disease processes (Röcke & Cherry, 2002). Although sudden unexpected death still occurs, modern death is more often medically-managed and institutionalised. Most people would prefer to die in their own homes, surrounded by family, but the widespread use of advanced medical technology, even at the end of life, makes it more

common to die in medical institutions, under the care of healthcare professionals (Brabant, 2003). This isolation and professionalisation (Timmermans, 2005) of contemporary dying means death is no longer an observable part of every day life in communities and homes in the modern western world. As well-known thanatologists Leming and Dickinson (2007) have observed, modern Americans typically avoid encounters with death and dying wherever possible, leaving most people ill-prepared for the inevitable personal challenges associated with bereavement and mortality. Dying has become hidden and mysterious - the unspoken, frightening fate of hospital and rest home patients. Today, people are often reluctant to talk or think about death, and may not have personal encounters with death and dying until they are well into adulthood. This 'death denial' (Kellehear, 1984) is common in many societies, including most of the New Zealand population (Buchanan, 2005).

Despite, or perhaps because of this death-denial, recent decades have seen a growth in popularity of thanatology - the study of bereavement, death and dying. Numerous undergraduate courses are now offered, typically focussing on psychological, sociological, anthropological and ethical issues. Leming and Dickinson (2007) attribute this increased societal interest in death and dying to greater media coverage, emerging ethical issues, and the mysterious, hidden societal status that death holds. Although formal study of thanatology is available only to the few, the attitudes and expectations of all members of modern society are now influenced by the vast information available through the internet and media. This, of course, means that nurses are now encountering new, more informed health consumers, who may have developed opinions and expectations regarding the management of their death, or that of a loved one. Nurses caring for the sick and dying retain a Nightingale-esque core to their practice, but today must contend with myriad contemporary societal demands, technological challenges, ethical dilemmas and legal minefields. Nurses involved in patient death and dying may be responsible for coordinating culturally safe holistic assessment, family education and support, complex symptom management, and involvement in end-of-life decision making including palliative care discussions, advanced directives and not-for-resuscitation orders (Copp, 1999; Mallory, 2001; Mitchell, Sakraida, Dysart-Gale, & Gadmer, 2006).

#### **Palliative Care and The Good Death**

Modern medicine has an impressive arsenal of tests and interventions to diagnose, treat, cure, prevent and even eliminate disease. Ultimately, however, everyone will eventually come to the end of their life. With medical technology's increasing power to prolong life, people began to realise that this could also prolong dying, and suffering, and cause major ethical dilemmas. Accepting that death was eventually an inevitable outcome for all, some began to turn greater attention to utilising medical science (and developments in other caring disciplines) to improve the care of the dying.

Palliative care has developed in an effort not only to achieve a good death, but also to make the most of what living a person with a life-limiting illness may have left, and is defined by the World Health Organization (2003) as:

...an approach that improves the quality of life of patients and their families facing the problems associated with 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.

The concept of a 'good death' has received considerable attention in the literature of numerous disciplines (Costello, 2006; Low & Payne, 1996; McNamara, Waddell, & Colvin, 1995). Ideals will be influenced by the beliefs, attitudes and previous experiences of an individual, and the role they play in a death (e.g. patient, nurse or family member). This said, a 'good death' is typically characterised by personalised, dignified care, awareness and open communication, preparedness, acceptance and excellence in clinical management including good symptom control. In contrast a bad death might involve gruesome or traumatic circumstances, suffering, fear, distress, anonymity and a lack of dignity and control (Gott et al., 2008; Kring, 2006; Miyashita et al., 2008; Rietjens et al., 2006).

Hospice care has developed over the last few decades, with multi-disciplinary teams working together to help patients with life-limiting illnesses achieve a good death and make the most of what life they have left. Dame Cicely Saunders was a nurse, social worker and doctor who founded St Christopher's, in London, which is commonly regarded as the first modern hospice

(Leming, 2003). The first New Zealand hospice opened in 1979 and the first hospital palliative care service was established in 1985 (Carter, McKinlay, Scott, Wise, & MacLeod, 2002). New Zealand palliative care is delivered, at no charge to the patient, through hospice inpatient, day and community care and hospital palliative care teams. The specific nature and availability of services varies significantly between communities, and particularly between urban and rural settings (Knight, 2006).

#### **Death in the Acute Setting**

As discussed above, the palliative care movement has led to a wealth of literature and substantial clinical developments around nursing the dying in oncology or palliative care and hospice settings, including people's own homes. Although this has transformed end-of-life care for many patients who die from cancer and other terminal illnesses, most deaths occur in public hospitals and rest homes, without specialised hospice or palliative-care input. Data suggests that 58% of American adults who die from chronic illness do so in hospitals, 22% at home and 20% in rest homes (Weitzen, Teno, Fennell, & Mor, 2001). The latest national figures from England show a similar trend, with 58% of all deaths occurring in National Health Service (NHS) hospitals, 18% at home, 17% in care facilities and 4% in hospices (The Lancet, 2008). As depicted in Figure 2, New Zealanders most commonly die in public hospitals or residential care facilities (predominantly rest homes and geriatric hospitals).

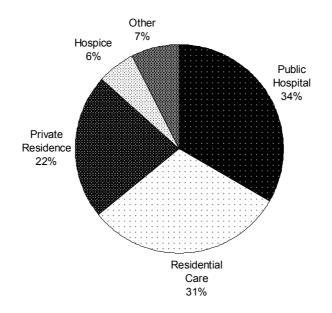


Figure 2: Place of Death (NZ Mortality Data 2003)

Source: Chris Lewis, New Zealand Health Information Service, personal communication, April 13, 2008

The nature of patient death in the acute setting is likely to be relevant to this study, as student nurses typically spend a significant number of clinical training hours in acute wards on public hospitals, and often begin work in medical or surgical wards (KPMG, 2001). This makes it likely that nurses' early clinical encounters with death and dying will occur in acute settings, where the very fact that a patient is 'dying' is often undiagnosed (Becker et al., 2007; Ellershaw & Ward, 2002) and the principles and practicalities of palliative care do not fit easily into the busy routine of hospital life (Pincombe, Brown, & McCutcheon, 2003). For a novice nurse with little experience assessing or meeting the needs of dying patients and their families, and a typically high 'task-orientation', the needs of the living can easily overwhelm those of the dying.

The problematic nature of caring for the dying in hospitals has long been well documented (e.g. Glaser & Strauss, 1965; The SUPPORT Principal Investigators, 1995). A smaller body of research exists on the experiences of nurses who encounter death and dying in general medical or surgical wards (Stoller, 1980; Thompson, McClement, & Daeninck, 2006) and in specialised acute settings such as intensive care (J. M. Badger, 2005; Hadders, 2007). Although skilled delivery of palliative care can facilitate a 'good death', the majority of acute-care patients still die without palliative care input. Recent published studies examining the charts of patients who died in Australian, Italian and German hospitals all highlighted inadequate symptom management and limited recognition of psychosocial and spiritual needs of dying patients and their family members (Becker et al., 2007; Parish et al., 2006; Toscani, Di Giulio, Brunelli, Miccinesi, & Laquintana, 2005).

Even when a death is expected, and the focus of care is changed, basic palliative care delivered by general staff in an acute surgical or medical ward is inherently different from that provided by specialists in, for example, a hospice or oncology setting. Palliative care has been defined by the European School of Oncology (ESO) as "...the person-centred attention to physical symptoms, and to psychological, social and existential distress and cultural needs in patients with limited prognosis, in order to optimise the quality of life of patients and their families or friends" (Ahmedzai et al., 2004, p. 2194). In their proposed international palliative care framework, the ESO went on to differentiate between the *specialised palliative care* provided by experts and the *basic palliative care* delivered by all healthcare professionals responsible for

care of patients at the end of life. Palliative care seeks to attend to psychological, social, existential, cultural and physical needs of the patient and family. These might be regarded as ambitious and idealistic goals for even the most experienced nurses in acute hospital wards, who typically face large, high-acuity patient loads, understaffing, and severe time constraints.

#### **Death Education**

This review focuses on the death education of student health professionals (particularly nurses) regarding death, dying and bereavement. Database searches of CINAHL, PSYCHINFO and MEDLINE yielded several decades of research literature examining the death education provided to medical and nursing students and other student health professionals.<sup>1</sup> Much of the death education literature focussed on specialised palliative care education for qualified health professionals. Participation in such postgraduate education is typically elective, and naturally favoured by health professionals employed in areas where encounters with death and dying are not unusual. The needs and experiences of these populations are considered different to those of the undergraduate nurse, and accordingly, a more general review of the palliative care education literature is considered outside the scope of this review.

Only a few decades ago, death and dying was given little or no curriculum coverage in the training of health professionals (Dickinson, Clark, & Sque, 2008; Noppe, 2007). Although most modern medical and nursing undergraduate programmes in the US and UK offer some death and dying content, the average time spent on these topics, what is taught, in what style, how well and by whom remains highly variable (Dickinson, 2007). The quality of death education is important. Teaching about death and dying can have unpredictable effects and in some cases has, for example, been associated with an increase on general death anxiety scores (for a meta-analysis see Maglio & Robinson, 1994). Despite changes in practice and a growing research literature, the evidence regarding the effectiveness of contemporary death education is far from conclusive, and the optimal content and approach to death education remains unclear.

<sup>&</sup>lt;sup>1</sup> A recent report which on cancer and palliative care educational needs touches on New Zealand undergraduate nursing education in these areas (Kent et al., 2008), but other research specifically describing New Zealand nursing training providers' current or historical approaches to death education was not located.

Evaluations of undergraduate death and dying education programmes are characterised by small sample sizes, non-experimental or quasi-experimental design, lack of replication, and inconsistent results (Mooney, 2005). Outcome measures used to evaluate novice death education interventions are capricious, and include measures of: participant satisfaction (e.g. Deeny, Johnson, Boore, Leyden, & McCaughan, 2001); generic death anxiety (e.g. Mooney, 2005); attitudes to care of the dying (e.g. Barrere, Durkin, & LaCoursiere, 2008; Frommelt, 1991); self-efficacy (McConville & Lane, 2006); behavioural intention and behaviour when encountering patient death (e.g. Hainsworth, 1996; Smith-Cumberland, 2006).

Subjective reports from students used to evaluate new death education initiatives are often positive, but surveys of newly qualified nurses and doctors typically demonstrate that they feel unprepared for encounters with death and dying, dissatisfied with undergraduate end-of-life education, and desire more coverage of death-related issues (e.g. Birzholz, Clements, Cox, & Gaume, 2004; Ferrell, Virani, Grant, Coyne, & Uman, 2000; Frommelt, 1991; Hopkinson, 2001; Mooney, 2005). In addition to mixed evidence, barriers to better delivery of death education include lack of suitable instructors, lack of palliative care clinical placements and the fact that nursing undergraduate education is already 'tightly packed' leaving little room for additional material (Lloyd-Williams & Field, 2002). Death education is typically integrated into the overall nursing curriculum, perhaps given brief attention in developmental, pharmacology and chronic illness papers (American Association of Colleges of Nursing, 1998; Kent et al., 2008). Self-directed learning is also assumed in many courses, but a content analysis of 50 popular nursing textbooks revealed that less than 2% of the content was devoted to end-of-life care issues and the quality of that content was, at times, dubious (Ferrell, Virani, & Grant, 1999).

#### Innovative approaches to death education

Surveys of the teaching style and content of undergraduate nursing and medical death education indicate that the didactic teaching of readily-examinable material remains the favoured approach (Burney-Banfield, 1994; Downe-Wamboldt & Tamlyn, 1997; Lloyd-Williams & MacLeod, 2004). Although in today's often-large undergraduate health science classes such a teaching style is perhaps most straight-forward, researchers and students have long been advocating more experiential learning, beyond the mere acquisition of knowledge and skills (Maglio & Robinson, 1994). Experiential approaches to death and dying education allow nurses to participate and

apply knowledge and then reflect on what they have experienced. Numerous innovative examples of experiential undergraduate death education were located in the literature, and were typically well received by student participants. A mixture of drama and group discussion was used to promote awareness and reflection on care of the dying amongst a group of student nurses from Northern Ireland (Deeny et al., 2001). Online video clips, including three death and dying scenarios, were shown to first-year nursing students to facilitate learning about difficult situations (McConville & Lane, 2006). Following in the footsteps of Elisabeth Kübler-Ross, undergraduate health professionals in some courses are given the opportunity to learn from dying patients themselves (Block & Billings, 2005). In a New Zealand study, first-year medical students spent time with an 'assigned' terminally ill person and their family, and produced written reflections (MacLeod, 2001). Similarly, an American study gave a volunteer sample of undergraduate nursing students the opportunity to become Palliative Care Companions, spending time with a dying patient in a companionship role, rather than providing direct nursing care (Kwekkeboom, Vahl, & Eland, 2005).

Acknowledging palliative care's multidisciplinary approach, a group of educators in England (Wee et al., 2001) have been delivering inter-professional workshops in palliative care to undergraduate nursing, medical, social work, occupational therapy and physiotherapy students. These innovative workshops help to foster inter-professional teamwork, and have been well received by students for several years. In recent reviews of medical and nursing undergraduate palliative care education Lloyd-Williams and MacLeod (2004) and Dickinson (Dickinson, 2007) also advocated a more interdisciplinary approach to death education.

Death education curricula are often designed by experienced health professionals with years of death and dying experience and expertise, but several studies have revealed that novice nurses have plenty of insightful suggestions of their own to make. Twenty years ago, New Graduates interviewed by Degner and Gow (1988) suggested death education should commence with preparation for care of the dying, including opportunities to explore their own feelings around death and dying, followed by supervised clinical experience with expected death in a palliative setting and patient death despite aggressive treatment in an acute setting. Similar suggestions were made by students interviewed by Hopkinson (2001) who also valued opportunities to reflect on real and hypothetical end-of-life care situations with experienced practitioners. More

recently Birzholz, Clements, Cox & Gaume (2004) asked a group of nursing honours students to design their own death dying course curriculum, the students identified learning needs which closely paralleled end-of-life care competencies identified by the American Association of Colleges of Nursing (1998) and proposed a creative mix of didactic and experiential learning approaches, with multidisciplinary teaching input.

The End-of-Life Nursing Consortium (ELNEC) project was initiated in 2001 in an effort to address the education needs of end-of-life care providers in the USA. Over 722 undergraduate nursing faculty have participated in a train-the-trainer course, which provides them with the resources and strategies to teach eight modules integrated in the undergraduate curriculum: Nursing Care at the End of Life; Pain Management; Symptom Management; Ethical/Legal Issues; Cultural Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement; and Preparation for and Care at the Time of Death (American Association of Colleges of Nursing, 2008). Findings from a recently published quasi-experimental study suggest that ELNEC undergraduate death education is associated with a significant improvement in attitudes toward care of the dying patient (Barrere et al., 2008).

#### **Summary**

Nurses play an important role in the care of the dying patient. Significant changes to medical technology and healthcare delivery have changed the way that people die. Palliative and hospice care movements have made the facilitation of a 'good death' an acceptable and more achievable goal for health professionals, but the application of these ideals is often limited. Many deaths occur in acute settings, the dying of the patient can go undiagnosed, or active treatment can continue up right up to and (where lengthy resuscitations are initiated) even beyond the point of death. Nurses must negotiate complex ethical and legal minefields, busy workloads, high interpersonal demands and personal emotional responses, to attend to the needs of the dying. For a novice nurse, care of the dying is a highly anticipated experience. Despite decades of research, innovative ideas and a repeated call for more experiential learning in death education, nurses continue to report dissatisfaction with this aspect of their undergraduate training, feeling inadequately prepared to cope with many aspects of end-of-life care.

## REALITY SHOCK: TRANSITION FROM STUDENT TO HEALTH PROFESSIONAL

Students of nursing, medicine and other health-related disciplines often find that there is a yawning gap between theory and practice, between classroom and clinical setting and between expectations and realities of their professional roles. New Graduates set out full of enthusiasm, expectancy, idealism and drive to apply their newly acquired knowledge and skills to 'make a difference' to others. Unfortunately they also face a 'reality shock' – exposure to resourcing issues, limitations, errors, failures, suffering, anger and - eventually - death, dying and bereavement.

#### Personal Growth and Socialisation of Health Professionals

Medical educators have recognised the need to address biopsychosocial issues in patient populations for some years now. It is only more recently, however, that there have been increased efforts to address medical students' own self-awareness and facilitate humanism, caring, personal growth and well-being, in doctors of the future (Novack, Epstein, & Paulsen, 1999). Medical and nursing students are typically young and some will have, essentially, been students all their lives. New Zealand research indicates that 60% of first-year undergraduates are under the age of 25 ("Young nurses on the way," 2008).

Early encounters with professionally and personally challenging situations can have a powerful influence on the behaviour and attitudes of novice health professionals. Research conducted with thirty-two US residents indicated that important personal growth occurs during interns' early clinical training, and that care of dying patients can be a significant trigger for such growth (Levine et al., 2006). Medical sociologist Frederic Hafferty (1991) published research which demonstrated that early experiences with death and dying had an important role in the socialisation of medical students. Socialisation is a process of culture acquisition, where individuals who seek to be group members learn and adopt the interests, skills, knowledge, attitudes and values of (Novack et al., 1999). Doctors and nurses learn much about their professional role though exposure to the culture of their professions, rather than the formally

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taught curriculum. Reflecting this, formally recognised didactic and clinical death and dying education make up only a part of the learning process for doctors and nurses. Numerous authors have observed that an informal but powerful 'hidden' curriculum is taught through contact with the behaviours, attitudes and values of other health professionals (Block & Billings, 2005; Rhodes-Kropf et al., 2005).

Hafferty (1991) also observed that medical students, under considerable academic pressure, tended to be preoccupied with memorising scientific facts, and gave considerably less attention to the development of their behaviour, attitudes and values as a doctor. Overwhelming work, fatigue and lack of personal time for reflection have also been identified as barriers to personal growth (Levine et al., 2006). Arguably, as nursing education becomes more academically demanding and medicalised, nurses are also become focussed on the science of nursing, paying less attention to the (less examinable) art of caring.

#### **Transition from Student to New Graduate Nurse**

There is very little empirical research around the factors influencing retention and attrition of student and New Graduate nurses (Gaynor, Gallasch, Yorkston, Stewart, & Turner, 2006). It is known, however, that early career nurses face uniquely stressful challenges (Chang & Daly, 2001). Nurses face a reality shock when transitioning from student to New Graduate, and that this can lead to job dissatisfaction, burnout, turnover and even abandonment of nursing (Delaney, 2003; Kramer, 1974). Role stress or role conflict occurs when a disparity exists between an individual's perception of the role expectations and the reality or performance of that role, and it is well established and internationally recognised as a potent stressor for nurses (e.g. Lambert, Lambert, & Ito, 2004). As noted by Corwin (1960, as cited by Chang & Daly, 2001) novice nurses often face significant role conflict when entering the clinical environment as New Graduates. Novice nurses can be dismayed to discover that their preconceived professional ideals are unachievable in the real-world employment setting. Although this has been recognised for over half a century, it seems the transition is no easier for the contemporary New Graduate nurse. With an international move to degree-based nursing training, today's tertiary-providers of undergraduate nursing education have been criticised for failing to address a growing theory-practice gap. Employers have established specialised support programmes, in

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an attempt to move away from the 'sink or swim' approach and ease the transition for New Graduates. Comprehensive programmes offering adequate supervision and support have been associated with improved retention, job satisfaction and performance of New Graduate nurses, both overseas and in New Zealand (Gordon, 2008; Halfer, 2007). Pilot testing of Nurse Entry To Practice programmes in New Zealand showed promising results (Ministry of Health, 2004) and the Nursing Council of New Zealand and Clinical Training Authority have published standards for the provision of support to New Graduate employees. Important features of supportive programmes include assignment of clinical preceptors, initial shared workloads, study days, goal setting and assessment (Ministry of Health, 2007; Nursing Council of New Zealand, 2005).

#### Early Nursing Experiences with Death and Dying

At a time when new nurses are only just adjusting to the intense physical and social intimacy of patient care, they may also find themselves in the potentially challenging and rewarding reciprocal relationship with a dying patient and their family. Working with dying patients and their families can be trying, and may represent the novice nurses' first exposure to suffering, distress, fear of death or grief. It is, however, well documented that working with terminal patients and their families can offer rewards, satisfaction and important learning opportunities (e.g. Block & Billings, 2005). Even when an inexperienced nurse manages to cope with the inherent interpersonal demands that these situations can present, the event of a patient death severing an established nursing relationship can, in itself, be extremely difficult to face.

Studies have revealed that, rather than being fearful of death itself, student nurses are most often anxious about how they should act and what they should say when encountering patient death, dying patients and their families (Cooper & Barnett, 2005). Student nurses report anxious anticipation of dealing with bereaved relatives, caring emotionally for the dying and witnessing suffering (Kiger, 1994). Novice nurses can be very inexperienced in communicating with distressed patients and family members, and may not have the clinical knowledge to answer the 'difficult questions', so often report feeling very anxious about saying 'the wrong thing' (Brent et al., 1991; Cooper & Barnett, 2005).

Several studies have identified encounters with death and dying as some of the most stressful events novice nurses encounter (Delaney, 2003). In a phenomenological study conducted with Hong Kong nurses and exploring the most memorable early experiences from nursing training, many nurses recalled incidents involving death and dying. Where these 'critical incidents' were recalled as positive overall, they had served to reinforce and motivate nurses regarding their professional identity, but negative incidents had made some nurses consider leaving the profession (Wong & Lee, 2000). Several other researchers have suggested that nurses' early encounters with death and dying are influential both personally and professionally (Brent et al., 1991; Hurtig & Stewin, 1990; Quint, 1967).

#### **Summary**

Novice nurses, and other health professionals, face important challenges as they transition from student to health professional. Particularly demanding early career experiences can be acutely stressful and even distressing, but also represent important opportunities for personal and professional growth. Encounters with patient death and dying have been identified as some of the most stressful and anxiously anticipated experiences faced by novice nurses. As early experiences and socialisation are powerful forces shaping the behaviour and attitudes of health professionals, it is desirable to provide support and positive role models during these potentially formative encounters.

## THEORETICAL PERSPECTIVES: STRESS, COPING AND NURSING

A comprehensive review of the vast and diverse literature on stress and coping is beyond the scope of this thesis. Instead, this chapter briefly introduces the concepts of chronic occupational stress and burnout, and then focuses on acutely stressful occupational encounters. Evidence indicates that nurses' early encounters with patient death can be highly anticipated and stressful events. Almost thirty years ago, Parkes (1985) conducted interviews with 150 first-year English student nurses and found that the most frequently reported stressful episodes were those involving dying patients. In a large, international survey of student nurses, patient death and talking with dying patients were amongst the most commonly identified stressors in four of the five countries surveyed (Burnard et al., 2008). This chapter provides a theoretical framework for understanding the cognitive, emotional and behavioural components which may influence the way that novice nurses cope with potentially stressful events such as early encounters with patient death.

#### **Chronic Stress and Burnout**

Stress has been variously defined in the literature, but for the purposes of this review stress is defined in terms of the appraisal an individual makes over themselves and their environment. Accordingly, stress is experienced when an individual perceives that they have insufficient resources available to cope with a demanding, challenging, harmful or threatening situation (Lazarus & Folkman, 1984). Although some stress is unavoidable, it is considered advantageous to avoid excessive stress because it is correlated with numerous undesirable physiological and psychological outcomes, including illness, illness behaviour, depression, anxiety and decreased job satisfaction (Hubbard & Workman, 1998).

#### Stress in the nursing population

Chronic work stress can have cumulative effects, and the term 'burnout' has become popularised, to describe a gradual depletion of resources characterised by loss of job satisfaction, depersonalisation and weariness (Maslach, Schaufeli, & Leiter, 2001). There is a prolific literature describing stress and 'burnout' amongst nurses and other health professionals (e.g. Bennett, Lowe, Matthews, Dourali, & Tattersall, 2001; Shirom, 2003). A burnt-out nurse feels exhausted, inefficient and cynical – hardly the patient and willing provider of care and attention that sick, dying or distressed patients and families might hope for. A recent large survey of Australian and New Zealand nurses showed high workplace stress was significantly associated with poorer physical and mental health (Chang et al., 2007). Burnout has also been significantly associated with poorer supervisor- and self-rated job performance, and more reported absences from work for mental health reasons and sick leave (Parker & Kulik, 1995). For over twenty years, researchers have been recommending stress management and communication training for nurses, including adequate needs assessment and evaluation (Llewelyn & Fielding, 1987). However, a review of the literature found little evidence of effective stress management interventions for this population.

In addition to the inherently stressful demands of many nursing roles, there are concerns about the potential detrimental effects of chronic occupational exposure to the distress, suffering, pain or grief of others. These cumulative effects are variously described as vicarious traumatisation, secondary traumatic stress, empathic stress and compassion fatigue. More research into this area, and the possibility that vicarious resilience can develop (Hernandez, Gangsei, & Engstrom, 2007) is needed.

#### **Acute Stressors**

Although there is a prolific literature examining the effects of chronic occupational stress in health professionals, less is known about the impact of acutely stressful events or the relationship between acute and chronic secondary stress (Hemingway & Smith, 1999; Wicks, 2006). Evidence suggests that novice nurses experience particularly high levels of stress and distress (Jones & Johnston, 1997). Although they report many stressors common to other novices, including financial difficulties and adjusting to work and academic requirements, acutely stressful clinical experiences also appear to contribute significantly to the stress of novice nurses (Burnard et al., 2008; Last & Fulbrook, 2003; Reicherts & Pihet, 2000).

#### Patient death as an acute stressor

Taylor (1995) observed that events are more likely to be perceived as stressful if they are negative, uncontrollable, overwhelming or ambiguous. Often meeting many of these criteria, encounters with patient death and dying are recognised as significant sources of chronic occupational stress for nurses working in a variety of settings and countries (e.g. Foxall, Zimmerman, Standley, & Bene, 1990; Glazer & Gyurak, 2008) Less attention has been focussed on individual patient deaths as acutely stressful events. A study by O'Connor and Jeavons (2003) surveyed 274 Australian nurses regarding occupational critical incidents (extraordinary, powerfully emotive events). Deaths were considered highly critical, particularly unexpected, morally distressing, or unusual deaths, deaths following prolonged resuscitation, or the death of a child, baby, or person known to the nurse. More than half of participants reported that a cardiac or respiratory arrest was the most frequently encountered and stressful experience they had encountered in the previous year. Very little research could be located examining stress and coping associated with nurses' earliest encounters with patient death.

#### Coping

Although a great deal of research has been published on work stress and coping, relatively little progress has been made (Dewe & Cooper, 2007; Folkman & Moskowitz, 2004). Coping, the behaviours and cognitions used to manage stress (Tennen, Affleck, Armeli, & Carney, 2000) remains conceptually complex, and theoretically underdeveloped. The factors which help one individual to flourish when faced with adversity, whilst another is overwhelmed, warrant further investigation, and the demand for interventions to improve stress management and coping is high.

An increasingly large and well-developed literature examining general aspects of coping within nursing populations is emerging (see Lambert & Lambert, 2001 for a review), but most studies are conducted with experienced nurses, and focus on chronic stress and burnout. Studies examining how nurses cope with death and dying have been conducted almost exclusively with populations who choose to work in areas where death and dying is frequently encountered, such as palliative care workers (Hulbert & Morrison, 2006) and paediatric oncology nurses. (Hinds et al., 2003). Of notable exception, Hopkinson, Hallett & Luker (2005) conducted a small

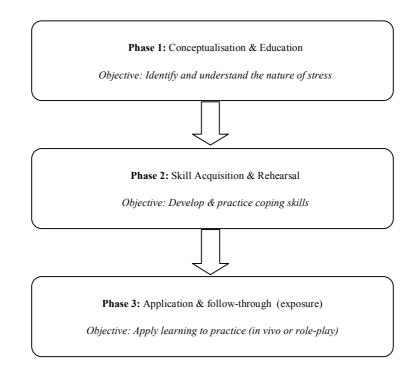
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qualitative study exploring the experiences of newly qualified nurses caring for dying patients, proposing a model of coping described as a 'translucent web' involving relationships, resources, learning, measuring, revising and controlling involvement.

The following section focuses on theoretical perspectives relevant to coping with occupational exposure to acutely stressful situations, including Stress Inoculation Training, social support, emotional intelligence and emotional expression and benefit-finding.

#### **Preparing for stress: Stress Inoculation Training (SIT)**

Stress Inoculation Training (SIT) is a cognitive-behavioural stress-management approach originally developed by Meichenbaum and colleagues for use with clinical populations (e.g. Meichenbaum & Deffenbacher, 1988), but has also been shown to effectively reduce state and performance anxiety, and enhance performance under stress in non-clinical populations (e.g. Saunders, Driskell, Johnston, & Salas, 1996). The three overlapping phases of training are depicted in Figure 3.



#### **Figure 3: Three Phases of Stress Inoculation Training**

Adapted from (Saunders et al., 1996)

#### Stress Inoculation Training for novice nurses

The SIT approach leaves individuals armed with coping responses, in an effort to increase coping efficacy (an individual's belief in their ability to respond and perform well in stressful situations) and reduce the chances an individual will feel overwhelmed when encountering stressful events. Several researchers have recommended that undergraduate nursing includes some instruction in stress management giving student nurses a chance to identify their personal reactions to stressors and potential coping strategies (e.g. Burney-Banfield, 1994; Chang et al., 2006). The stressful nature of nursing is well recognised, and several researchers have recommended that undergraduate nursing includes some instruction in stress a chance to identify their personal reactions to stressors and potential coping strategies (e.g. Burney-Banfield, 1994; Chang et al., 2006). The stressful nature of nursing includes some instruction in stress management giving student nurses a chance to identify their personal reactions to stressors and potential coping strategies (e.g. Burney-Banfield, 1994; Chang et al., 2006). For some decades researchers have also suggested that student and novice nurses might more effectively deliver and cope with end-of-life care, if they were prepared with improved, more applied death education which helped to strengthen their personal resources through in-classroom teaching, modelling, role play and rehearsal of coping strategies (Frommelt, 1991; Parkes, 1985).

A stress management intervention which adopted some of the features of SIT was tested with a group of significantly distressed second-year student nurses in Scotland. The six-session intervention included didactic teaching of coping skills, self-monitoring of distress, problem solving and scenario-based application of techniques to classroom and clinical settings. The randomised control design showed stress management significantly reduced state anxiety, but no effect was detected on measures of examination performance, sickness or absence (Jones & Johnston, 2000). SIT has also shown promise with a number of relevant related occupational samples. A controlled trial of SIT provided evidence that it reduced occupational stress in Registered Nurses working in the acute care setting, and suggested that the acquisition of coping skills was the most important phase (West, Horan, & Games, 1984). A repeated-measures cross-over design also showed that SIT was effective in reducing personal, emotional and general stress and improving academic performance in a group of 1<sup>st</sup>-year law students.

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#### Social support

When reflecting on stressful situations, people often appreciate the resources offered by a supportive network. Psychologists have differentiated between structural social support (a more objective, quantitative measure of the number of social supports available) and functional social support (a more subjective, qualitative measure of the types of support people can or do offer). Functional social support can come in a variety of forms, including esteem e.g. encouragement from a friend; informational e.g. the advice of a colleague; instrumental e.g. a loan from a parent; and emotional e.g. a caring hug from a partner (Lyons & Chamberlain, 2006). There is robust evidence that social support is an influential factor in coping with stressful events, with two main models existing to explain this relationship. The main or direct effects model states that social support has general mental and physical health benefits which are exerted both at times of stress and non-stressful times. The stress-buffering model proposes that social support is beneficial (S. Cohen & Wills, 1985).

Increasing evidence suggests that social support is also a factor in the development of Post Traumatic Stress Disorder (PTSD). Meta-analyses have found social support to be one of the highest correlates of PTSD (Brewin, Andrews, & Valentine, 2000; Ozer, Best, Lipsey, & Weiss, 2003) and it seems that, where adequate, social support can be a protective factor, and when inadequate, it may increase risk of PTSD (Charuvastra & Cloitre, 2008).

#### Social support amongst health professionals

The nature of social support is important - in a beautifully illustrative example given by Taylor (1995), the comforting support offered to a lost child by a stranger is likely to be ineffective and even rejected. Research has indicated that nurses prefer to talk about patient death experiences with colleagues, and are reluctant to seek emotional or professional support from 'outsiders' (J. M. Badger, 2005; Barnard, Street, & Love, 2006; Spencer, 1994). Peer support is often gained informally, but formalised support groups have been formed by and for health professionals coping with occupational death and dying exposure (Zane, 1992). Student nurses also report receiving support from peers and nursing mentors (Brown & Edelmann, 2000) and specifically report talking about their first patient deaths with other student nurses as an effective coping strategy (Cooper & Barnett, 2005).

The use of humour as a coping strategy widely adopted by nurses is noted by several authors (J. M. Badger, 2005; Dean & Major, 2008; McCreaddie & Wiggins, 2008) and serves as an illustration of the unique language and approach used by nursing peers to provide support to each other following stressful patient encounters.

#### **Emotional Intelligence & Emotional Expression**

The concept of Emotional Intelligence (EI) generated considerable interest in both the popular (Gibbs, Park, & Birnbaum, 1995) and research literature (e.g. Mayer & Salovey, 1995) at the end of the last century. The assessment, conceptualisation and application of EI remains controversial today (Zeidner, Roberts, & Matthews, 2008), but skills associated with EI, including the perception, appraisal, regulation and expression of emotion (Mayer & Salovey, 1995) are very useful to nurses and other health professionals who often encounter emotive and interpersonally demanding situations (Kooker, Shoultz, & Codier, 2007; McQueen, 2004). Recently published research has found EI is correlated with clinical performance of staff nurses (Codier, Kooker, & Shoultz, 2008) and mental health in nursing students (Montes-Berges & Augusto, 2007). On-the-job learning may provide opportunities for health workers to develop EI (Clark, 2006).

For many years, psychological researchers have suggested that repression of emotion could have negative psychological or physical consequences. It is only more recently, however, that the purposeful disclosure of feelings and thoughts has been reliably associated with positive outcomes (Frattaroli, 2006). Written reflection on upsetting or traumatic events appears to be particularly beneficial (Frisina, Borod, & Lepore, 2004; Smyth & Pennebaker, 1999). This has potential significance for nursing populations, as reflective practice, including written case studies and exemplars, is already widely used to facilitate learning (Usher, Tollefson, & Francis, 2001). Pfund, Dawson, Francis & Rees (2004) published a descriptive account of the use of written emotional expression to facilitate student nurses' coping, but no other relevant research could be located.

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#### **Benefit-finding**

Psychological research has long been focussed on the negative sequalae of acutely stressful events, but reflecting an increasing interest in positive psychology (Seligman & Csikszentmihalyi, 2000) researchers have started to examine positive outcomes after traumatic events (Helgeson, Reynolds, & Tomich, 2006). Variously described as post-traumatic growth (Tedeschi, Park, & Calhoun, 1998), stress-related growth (Park, Cohen, & Murch, 1996), or benefit-finding (Affleck & Tennen, 1996), individuals who have experienced traumatic events often report benefits including increased personal strength, better personal relationships and greater appreciation of life's possibilities (Tedeschi et al., 1998). Benefit-finding has been associated with the experience of a variety of challenging or traumatic events, including diagnosis with cancer (Carver & Antoni, 2004), bereavement (e.g. Holland, Currier, & Neimeyer, 2006), rape (e.g. Burt & Katz, 1987) and disaster (Joseph, Williams, & Yule, 1993; see Linley & Joseph, 2004 for a review).

Benefit-finding has, in turn, been associated with positive health outcomes including less depression and greater well-being (Helgeson et al., 2006). In cancer survivors, post-traumatic growth in the year after diagnosis has been associated with lower distress and depression at five to eight year follow-up (Carver & Antoni, 2004). Whether benefit-finding can be 'harnessed' as a coping tool, is less clear. The relationship between benefit-finding and posttraumatic stress symptoms (Jackson, 2007; Joseph et al., 2005) and benefit-finding has been positively associated with rumination and intrusions (Linley & Joseph, 2004). There is a call for more research in this area, to develop more comprehensive theoretical models of mediating and moderating variables, explore associations between benefit-finding and distress and apply these findings clinically to help those exposed to acutely stressful, potentially traumatic experiences.

#### Benefit-finding and occupational death exposure

When we listen to a dying patient, and stay near – to share, touch, care and not be afraid – we discover that the challenge of helping a patient die comfortably is as rewarding as helping a patient recover (Norton, 1985, p. 1099).

Health professionals and volunteers who frequently encounter death and dying often report positive, rewarding or satisfying aspects to their experiences. Elisabeth Kübler-Ross felt that her experiences with dying and bereaved individuals were more life-enriching than any others (Kübler-Ross, 1975). Descriptive studies have identified benefit-finding in nurses and others who encounter death and dying in their work (Bluck, Dirk, Mackay, & Hux, 2008; Fris, 2007; Wallerstedt & Andershed, 2007) but fewer quantitative, empirical studies have scrutinised the factors involved in benefit-finding. Anderson and Gaugler found that personal growth, defined as "gains in tolerance, compassion, forgiveness and hope" (2006, p. 308) was associated with the patient death experiences of clinical nurse assistants working in rest homes, and that disenfranchised grief was negatively correlated with personal growth. Linley and Joseph (2005) found that positive psychological changes were associated with social support and an approach acceptance death attitude in a sample of funeral directors. There is plenty of opportunity for further research in this area.

#### Summary

This chapter has provided an overview of theoretical frameworks related to coping with acutely stressful events. Although current research is limited and largely idiographic in nature, there is some evidence that early encounters with patient death are potentially stressful and salient events for novice nurses. In addition to preparing nurses appropriately for the clinical demands of such encounters, it is important that nurses are adequately resourced to cope with the emotional consequences. Previously identified potential facilitators of coping include stress inoculation therapy, social support, emotional expression and benefit-finding.

### **RESEARCH RATIONALE & METHODOLOGY**

This chapter outlines the research rationale and methodological approach adopted to explore nurses' early experiences with patient death. Both quantitative and qualitative cross-sectional data were gathered to explore the nature of these experiences, and elucidate factors which may have implications for future research and intervention. A two-phase mixed-method design was considered to be the most appropriate to answer the research questions (see Figure 4). In Study One, a brief purposefully-designed online questionnaire was used to gather initial data from a convenience sample (N = 174) of Registered Nurses. Participants were asked to recall their earliest memorable experience with patient death, and answer questionnaire items focussed on the clinical circumstances surrounding that event. In Study Two, a subsample of the questionnaire participants (N = 20) took part in an individual semi-structured interview, where they were asked to describe their earliest memorable experience with patient death experience with patient death.

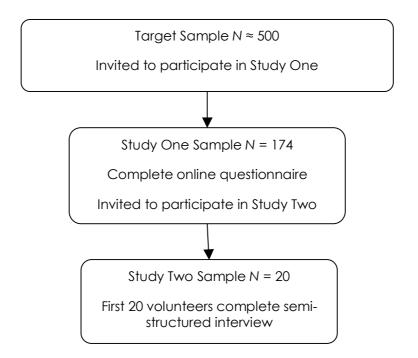


Figure 4: Participant Recruitment Flow Diagram

#### **Mixed-Methods Approach**

The theoretical drive of this research was one of discovery, rather than testing. A research design that placed greatest emphasis on the collection of qualitative data was most suited to explore fully nurses' early experiences with patient death. Adopting a mixed-methods approach, this quant $\rightarrow$ QUAL research design used quantitative data gathered in Study One to complement the primary, qualitative data gathered from Study Two (Cresswell, Plano Clark, Gutmann, & Hanson, 2003; Morse, Niehaus, Wolfe, & Wilkins, 2006). Table 1 outlines the key research questions addressed by each study. The questionnaire phase complements the interview data by identifying some of the contextual and clinical factors associated with nurses' earliest memorable patient death experiences. Shedding some light on these factors will help to target interventions by identifying when and in what situations nurses are first experiencing patient deaths.

## **Research Questions**

The use of two phases to this study helped to increase breadth and depth of exploratory data. Whilst these addressed different research questions exploring nurses' EMPDs, some overlap also occurred.

Research Question		Study
Research Question	One	Two
At what point in their professional development, and under what clinical circumstances do nurses' earliest memorable experiences with patient death occur?	✓	
Do nurses' feel that their undergraduate training prepared them adequately for early nursing encounters with death and dying?	✓	✓
What is the nature of nurses' earliest memorable experiences with patient death?		✓
Do nurses' earliest memorable patient deaths have an impact on them, personally or professionally?	✓	✓
What cognitive, emotional and clinical challenges do nurses face when they experience patient death for the first time? How do nurses cope with these demands?		✓
Do nurses recall positive, rewarding and satisfying aspects to their earliest memorable patient death experiences? What factors are associated with such aspects?	✓	✓

#### Table 1: Key Research Questions Addressed by Studies One & Two

## **Interpretative Phenomenological Analysis (IPA)**

Study Two applied the principles of phenomenological research to this investigation of earliest memorable patient death experiences. Phenomenological psychological research uses first-hand accounts of individuals' experiences (Langdridge, 2007). As stated by Giorgi & Giorgi, phenomenology aspires to be faithful to the experience and the context of the phenomenon of interest, rather than attempting to control it or reduce it to "a convenient number of identifiable variables" (Giorgi & Giorgi, 2003, p. 26). The assumption underlying the phenomenological approach is that there are common elements or 'essences' underlying experiences. In comparing and contrasting hermeneutic and empirical approaches to phenomenological research in psychology, Hein and Austin (2001) noted that these significantly different methods could yield

remarkably similar 'end products' in terms of analyses. Both approaches reflect a shared meaning which combines the participant's description of an experience, and the researcher's interpretation of that description.

Interpretative Phenomenological Analysis is an explicitly interpretative approach to analysis of identified descriptive themes, engaging with existing theory and research. The researcher attempts to move beyond a third person account of participants' experiences, interpreting the meaning of the cognitive, behavioural and emotional components that have been described (Larkin, Watts, & Clifton, 2006; Smith, 1996). Although a self-aware researcher can minimise the influence of his or her perspective, it is acknowledged and accepted that many aspects of this research will be influenced by the interplay between researcher, participant and subject matter (Smith & Osborn, 2003; van Manen, 2006). Whilst it is not possible to provide a very real description of that experience when IPA research is conducted with sensitivity and responsiveness (Larkin et al., 2006).

Communication and interpretation of lived experience are limited by what can be conveyed through language (Hein & Austin, 2001). Of course, more is communicated in an interview than is evident from the explicit meaning of words, and the transcription process can disguise or alter original emphasis (Oliver, Serovich, & Mason, 2005). The researcher's nursing background may have facilitated interpretation of implicit meanings and nuances conveyed by the interview participants, although participants were encouraged to provide more detail wherever meanings were unclear.

A semi-structured interview is considered the ideal data collection method for IPA, allowing participants to tell their story whilst giving the researcher flexibility to build rapport and use probes in a way which is sensitive to participants responses, concerns and interests (Smith & Osborn, 2003). IPA seeks to explore the meaning that participants give to an experience. It does not attempt to provide an objective account, but explores how participants make sense of an experience, and what those experiences mean to them.

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Although the researcher must attempt to see the participant's own perspective, it is accepted that the researcher has an active, 'interpretative' role (Smith & Osborn, 2003). Participants' descriptions of their cognitive and emotional responses to events are both constructed and limited by their verbal and non-verbal expression, and final accounts are shaped by the extent to which the researcher understands and empathises with the perspective of participants (Brocki & Wearden, 2006). This means that the account produced represents both the reflection of the participants on their own experience, and the way the researcher interprets that reflection (Smith, Jarman, & Osborn, 1999).

## **Ethics**

Death and dying are sensitive topics, and the researcher tried to be mindful at all times that conducting qualitative research can pose risks to both participants and the researcher (Dickson-Swift, James, Kippen, & Liamputtong, 2008). Access to professional counselling services was made available to all participants. Researcher supervision included frequent opportunities for reflection and debriefing. Ethics approval for both studies was granted by the University of Auckland Human Participants Ethics Committee (see Appendix A).

# **STUDY ONE: ONLINE QUESTIONNAIRE**

## METHOD

This chapter describes the method of Study One, an online questionnaire surveying the earliest memorable patient death experiences of 174 currently-practicing New Zealand nurses. A description of the participant population and recruitment of the participant sample is given, as well as an overview of the development and distribution of the purpose-built questionnaire.

## **Participant Recruitment**

Participants were recruited from a sample of Registered Nurses, all of whom were currently practicing in a major metropolitan region in New Zealand and enrolled in postgraduate nursing papers at the University of Auckland. As enrolment in selected postgraduate papers is a requirement of local Nurse Entry to Practice (NETP) programmes, a large number of recently-graduated nurses (those who had graduated within the last 12 months) were included in this sample. Other nurses in this population were typically undertaking advanced nursing qualifications including postgraduate Certificates, Diplomas and Masters degrees.

As there was no intention to use the data for inferential purposes, a sample size calculation was not undertaken. Email invitations containing comprehensive participant information were sent to approximately 500 Registered Nurses in the target population. These emails were distributed through third-parties, to protect participant confidentiality. To improve response rates, the researcher attended class meetings for selected postgraduate papers. At these classes, information flyers about the project were distributed, and the aims of the research were outlined, as was the role of participants. One hundred and seventy participants answered the questionnaire in full, and four participants completed only the demographic section, after indicating that they had not yet encountered a patient death in their nursing practice. Participant demographics are detailed in the results section.

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## **Questionnaire Development and Distribution**

A brief, anonymous online questionnaire was developed specifically for the project, to maximise acceptability and response rate amongst the target population of Registered Nurses undertaking postgraduate papers (see Appendix C). All nurses enrolled in the postgraduate papers had access to email and the internet through the university, making an online questionnaire highly accessible and flexible, as it could be filled out quickly and easily from home, work or university at any time of the day or night. Due to the sensitive nature of the research topic, it was also desirable to allow participants to remain anonymous. Previously conducted studies using online surveys have demonstrated satisfactory acceptability with a variety of professional nursing populations (e.g. AbuAlRub, 2006; Marjanovic, Greenglass, & Coffey, 2007).

The questionnaire was developed following a review of related research, and in consultation with Registered Nurses, nurse educators and academic staff. Several early drafts were distributed to a convenience panel of currently-practicing Registered Nurses for informal review and comment. Although a number of general death anxiety and death attitude measures have well-established psychometric properties (for an overview, see Neimeyer, Moser, & Wittkowski, 2003), most of these scales do not address the nursing context. The inclusion of death attitude measures specifically developed for and tested with nursing populations (e.g. Frommelt, 1991; Mazor, Schwartz, & Rogers, 2004) was considered, but rejected, as these measures did not directly address the aims of this research.

With limited empirical research guiding the formulation of questions, and mindful of the diverse and complex circumstances which can surround the death of a patient, every effort was made to avoid arbitrarily restricting participants' perspectives to response categories (Patton, 2002). Accordingly, and in response to feedback from the pilot study, forced choice questions were limited and several questions included an open-ended 'other' or 'please specify' response option. As participants were asked to give details regarding an event which may have occurred many years ago, a 'do not remember' response option was provided where appropriate.

To ensure appropriateness and acceptability, a pilot questionnaire was distributed to a convenience sample of nurses, networked to the researcher through a social networking website.

Participants in the pilot sample were selected to represent a range of demographic groups, were currently practicing in a variety of employment settings, and they had had no previous input into the questionnaire design. Participants in the pilot sample were encouraged to provide confidential feedback via the social networking website. Following review of the completed pilot surveys (N = 19) and consideration of the feedback, small wording amendments and layout changes were made. Statements regarding participants' current attitudes to care of dying patients and prior exposure to death and dying were included amongst the impact scale items, as several pilot participants expressed frustration that these aspects of their experiences were not acknowledged within the pilot questionnaire.

Questionnaire data collection, design and formatting, including the use of skip logic, were facilitated by online provider, SurveyMonkey (www.surveymonkey.com). Participants accessed the online questionnaire by clicking on a link embedded in an email which invited participants to take part and provided them with information about the research (see Appendix B). As recommended by Dillman (2007), the first page of the online questionnaire consisted of an instructional, reassuring welcome screen (reproduced in Figure 5) and straightforward first question.

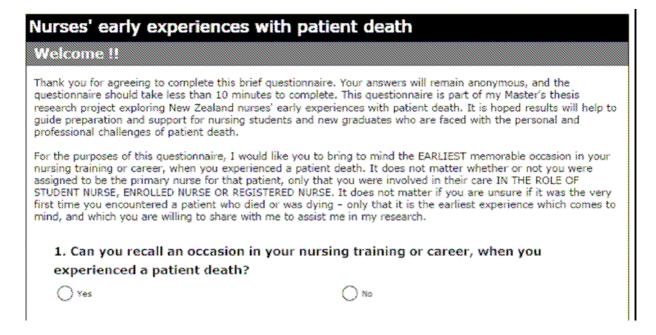


Figure 5: Reproduction of First Page of Online Questionnaire

Participants who indicated that they had not yet experienced a patient death were automatically presented with the final, demographic section of the questionnaire. Those who indicated that they had experienced a patient death were then asked to respond to a series of questions, in relation to their earliest memorable patient death.

#### Clinical circumstances of earliest memorable patient death (EMPD)

Questions exploring the clinical circumstances of participants' EMPD were developed to measure a number of patient and participant/nursing-related factors. Patient-related items asked the approximate age of the patient who died, the extent to which the death was expected and the clinical setting of the death. Items relating to the participant asked the participant's age and nursing status at the time of the EMPD, and the extent and nature of nursing care that they provided.

#### Impact

The next section of the questionnaire contained a series of statements with Likert Scale style response options. Items included in this section were developed in an attempt to quantify the personal or emotional impact of the EMPD. The question format and impact scale items are shown in Figure 6.

#### 9. To what extent do you agree or disagree with the following statements:

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	N/A or Do Not Remember
My earliest memorable patient death was more upsetting than any other event in my early nursing career	0	0	0	0	0
I was not affected much by my earliest memorable patient death	0	$\bigcirc$	$\bigcirc$	$\bigcirc$	0
In the days and weeks immediately after it happened, I spent a lot of time thinking about my earliest memorable patient death	0	0	0	0	0
My memories of my earliest memorable patient death are very vivid	0	0	0	0	0

#### Figure 6: Reproduction of Patient Death Impact Scale Items

A number of additional statements were included with the impact scale items, following feedback from practicing Registered Nurses who informally reviewed the developing questionnaire and those who completed the pilot questionnaire. Although these statements

were not directly relevant to the goal of measuring impact, pilot participants indicated that the inclusion of these statements at this point added significantly to the acceptability and face validity of the questionnaire.

#### **Preparedness**

A scale was developed specifically for this questionnaire to measure how well participants felt that their undergraduate nursing training prepared them for nursing encounters with death and dying. The statement *My undergraduate (student) nursing training prepared me well to:* was followed by five items covering important dimensions of preparedness for nursing encounters with death and dying. Selection of items on the preparation scale was guided by a review of research evaluating death education for undergraduate nurses (e.g. Degner & Gow, 1988; Frommelt, 2003; Lloyd-Williams & Field, 2002). These items included: dealing with personal reactions to patient death; care for bereaved relatives; and providing end-of-life care (see Figure 7).

#### 11. My undergraduate (student) nursing training prepared me well to:

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	N/A or Do Not Remember
Deal with my personal reactions to patient death	0	0	0	0	$\bigcirc$
Confidently provide end-of-life care	0	0	0	0	0
Communicate with dying patients and their families	0	0	0	0	$\bigcirc$
Care for bereaved relatives	$\bigcirc$	0	0	0	$\bigcirc$
Know what patient death would be like	0	0	0	$\bigcirc$	$\bigcirc$

#### Figure 7: Reproduction of Patient Death Preparation Scale Items

#### Support

Three questions addressed social support: an item measuring to what extent participants knew where to get support if they were upset about their EMPD, a question specifically asking if they had talked to anyone about their EMPD, and a follow-up question for those answering in the affirmative, asking who it was that they had talked to.

#### Positive, satisfying and rewarding aspects

Participants were asked if their EMPD had any positive, satisfying or rewarding aspects, either personally or professionally, and those who answered in the affirmative were given a drop-down box to specify their answer.

#### **Data Analysis**

Questionnaire data were exported from SurveyMonkey into an Excel spreadsheet, and then entered into SPSS 14.0 for Windows, for analysis. The large proportion of newly-graduated nurses in the sample resulted in non-normally distributed data on many demographic variables. In keeping with the exploratory nature of this study, the analysis was primarily descriptive in nature. Where appropriate, both medians and means are reported to give a better indication of central tendency. Limited inferential testing was justified, due to non-random sampling and limited pre-existing theoretical or empirical background for hypothesis testing. Judicious nonparametric testing was used to identify factors which were significantly correlated with finding positive, rewarding or satisfying aspects of an EMPD, and to calculate correlations between preparedness and impact scale scores. Psychometric testing, including inter-item correlations, Principal Component Analysis and internal reliability checks, was undertaken on items in the impact and preparedness scales. A content analysis (Joffe & Yardley, 2004) was undertaken on open-ended responses where participants identified the positive, rewarding, or satisfying aspects of their EMPDs.

## RESULTS

This chapter outlines the results from the first phase of this research, Study One, in which 174 currently-practicing Registered Nurses completed a purpose-designed online questionnaire exploring their earliest memorable experiences with patient death (EMPD). Wording *in italics* represents wording of questions and response options, as they were presented in the questionnaire. For further detail, a reproduction of the online questionnaire can be consulted in Appendix C.

#### **Participants**

Although often unreported, response rates for research conducted with nursing populations vary widely for both paper and pencil and online questionnaires (F. Badger & Werrett, 2005). One hundred and seventy participants answered the questionnaire in full, and four participants completed only the demographic section, after indicating that they had not yet encountered a patient death in their nursing practice. This generated a response rate of approximately 35% which compares favourably with other published studies (for a meta-analysis see Cook, Heath, & Thompson, 2000), given that participants were offered no incentive to participate and invitations were predominantly sent to the work email addresses of district-health board staff nurses, which receive a large volume of group or bulk emails. Participants' ages ranged from 21-63 years of age (M = 34.64, Mdn = 33, SD = 10.79) and had gained their first nursing qualification from <1 - 41 years prior (M = 10.89, Mdn = 7, SD = 10.80). A high proportion of participants (27%) were in their first year of practice following initial registration, and this influenced the non-normal distribution of many variables. Although this may have affected the representativeness of the sample, the large subsample of New Graduate nurses provided valuable recent, local data which were most relevant when considering future interventions. Participants came from a wide variety of nursing education backgrounds and eras. The vast majority (80%) gained their first nursing qualification in New Zealand, but nurses who had undertaken their training in the UK (6%), India (5%), other South Pacific countries (4%) and other European, Asian and African countries (5%) were also represented. The sample reflected the ethnic diversity of Auckland's nursing workforce, and participants were currently employed in a wide range of clinical settings (see Table 2). It is not known how many male nurses were invited to participate, but as around 6.4% of New Zealand Registered Nurses are male (New

Zealand Health Information Service, 2004) it seems that male nurses may have been underrepresented, with only five male nurses (2.9% of participants) completing the questionnaire.

## **Recall of Death Experience**

Whilst 170 of the participants were able to complete the online questionnaire in full, with reference to an EMPD, four participants indicated that they could not recall any occasion in their nursing training or career, when they had experienced a patient death. Through skip-logic integrated into the online questionnaire, these participants completed only the demographic section. All four participants who could not recall an EMPD had graduated from New Zealand nursing training programmes within the last 18 months, and were currently employed in acute clinical areas.

#### **Clinical Circumstances of Earliest Memorable Patient Death (EMPD)**

One of the key research objectives was to 'paint a picture' of the range of circumstances related to participants' early experiences with patient death. Identifying when and under what circumstances nurses' EMPDs occur will help future interventions designed to prepare and support nurses through these experiences. The online questionnaire featured items about the patient who died, including their approximate age, the extent to which their death was expected and their clinical environment (e.g. medical ward, rest home) at the time. A number of nurse-related factors were also measured, including the nurse's age and nursing status at the time of their EMPD, and the level and nature of their involvement with care of the dying patient and their family.

#### **Patient factors**

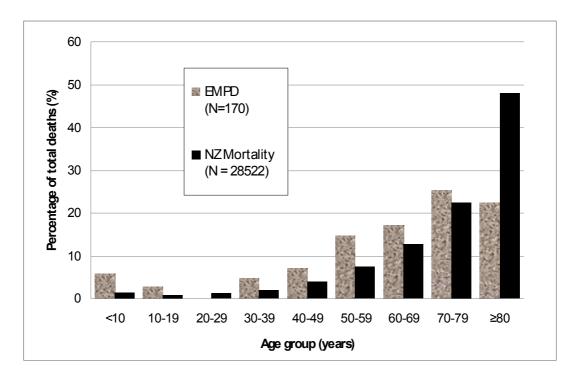
Participants faced a diverse range of clinical circumstances when encountering patient death for the first time. Although 51.8% of patient deaths were *Somewhat expected* and 22.4% were *Expected*, nearly a quarter of participants (22.4%) reported that their EMPD involved the *Unexpected, Sudden death* or *Traumatic/accidental death* of a patient. Six participants (3.5%)

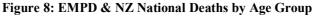
Variable	Frequency	(%)
Ethnicity		
NZ European	97	(55.7)
Chinese	18	(10.3)
Other European	17	(9.8)
Indian	15	(8.6)
Other Asian	9	(5.2)
Pacific Island	7	(4.0)
European & Maori	4	(2.3)
Maori	2	(1.1)
Other	5	(2.9)
Current workplace		
Surgical ward	27	(15.5)
Medical ward	26	(14.9)
ICU or NICU	15	(8.6)
Community	15	(8.6)
Paediatrics	15	(8.6)
Theatre or recovery	14	(8.0)
ED or A&E	11	(6.3)
Oncology/Haematology	10	(5.7)
Research/Leadership	10	(5.7)
Hospice/Palliative care	7	(4.0)
Rehabilitation	5	(2.9)
Other speciality	19	(10.9)

Table 2: Questionnaire Participants' Ethnicity & Current Workplace

indicated that they did not remember the extent to which the patient's death was expected – all six reporting limited involvement in care of the patient prior to death, and were in their early training at the time of the event.

Figure 8 shows the reported distribution of patient ages at time of death, which to some extent reflects the typical New Zealand mortality-by-age distribution. For 15 participants (8.8%), their EMPD involved an encounter with the death of an infant, child or teenager. No participants described EMPDs in which a patient between the ages of 20-31 had died, although low mortality and most common causes of death for this age group do make nurse-contact less likely. Notably, although participants were asked *What was the approximate age of the patient who died?*, many provided precise answers (e.g. specifying that the patient was 79 or 81 years old, rather than 'rounding' to the nearest decade). This tendency to vividly recall patient details was also evident in Study Two.





2007 NZ National mortality data from Statistics NZ website (www.stats.govt.nz)

The clinical settings where participants' EMPDs occurred are summarised in Table 3. Over 80% of EMPDs occurred in acute hospital settings with surgical and medical wards alone accounting for 70.6% of EMPDs. Although a large proportion of New Zealanders die in

residential care, relatively few EMPDs (7.1%) were reported in geriatric care facilities. Only two EMPDs occurred in hospice settings and five in the community. These figures reflect the time novice nurses spend in these clinical environments in undergraduate clinical placements and early employment.

Clinical Setting	Frequency	(%)
Medical ward	77	(45.3)
Surgical ward	43	(25.3)
Geriatric care or rest home	12	(7.1)
ICU or NICU	7	(4.1)
Theatre or recovery	6	(3.5)
Community	5	(2.9)
Emergency department	4	(2.4)
Hospice	2	(1.2)
Other *	10	(8.2)

Table 3: Clinical Setting of EMPD

\*Including: CCU, paediatrics, mental health and maternity

#### **Participant factors**

Participants most frequently encountered their EMPD as a *Student Nurse - Early in training*, (44%), *Student Nurse – Late in training* (17%) or as a *New Graduate Registered Nurse* (23%). At the time of their EMPDs, 23 participants (13%) were *Registered Nurses – Qualified > 1 year*. Only two participants were Enrolled Nurses and one participant could not remember what her status was at the time.

The extent of involvement participants had with care of the dying patient and family during their EMPDs was measured; relatively few participants (11.8%) reported that they ...*cared* 

extensively or intensively for the patient who died, whilst 25.6% . . .had cared for the patient on a number of occasions, and 42.4% of participants . . .had limited or no involvement in the care of the patient prior to his or her death.

Participants' ages at the time of their EMPD ranged from 17 years to 55 years (M = 23.67, Mdn = 21, SD = 7.56) highlighting substantial differences in this potentially influential variable. In more recent years, the profile of newly-graduated nurses in New Zealand has matured, with some novice nurses bringing considerable life experience to their early experiences with patient death.

The nature of participants' involvement in care of the dying patient and their family was measured using a multiple-choice question with an open, *Other* response option and results are summarised in Table 4. Surprisingly, 49% of participants reported that presence at the time of death was a feature of their EMPD. It is possible that the intended meaning of this item was misinterpreted, and this large proportion includes some participants who were present in the post-mortem period. Other aspects of EMPD reported in the open response option included involvement with the organ donation process, assisting in theatre, assisting a funeral director and discovering a deceased patient.

Nursing Care	%
Providing comfort cares	61
Post-mortem care	52
Presence at the time of death	49
Comforting distressed family members	40
Providing symptom-relieving medications	36
Resuscitation efforts	17
Breaking bad news to family	11
Other	6

 Table 4: Nature of Participants' Nursing Involvement During EMPD

## Impact

Participants were asked *To what extent do you agree or disagree with the following statements:* and presented with a series of statements relating to the personal impact of the EMPD, along with statements describing their current attitudes to care of the dying and previous exposure to patient death. Likert Scale style responses were coded as follows: *Strongly Agree* = 4, *Somewhat Agree* = 3, *Somewhat Disagree* = 2, *Strongly Disagree* = 1. No neutral option was given on the Likert Scale, but where participants (n = 5) indicated *N/A or Do Not Remember*, this was treated as missing data, and they were excluded from analysis.

Initial analysis of an inter-item correlation matrix indicated that the four items included to assess the personal or emotional impact of the EMPD were significantly correlated, and further psychometric assessment of these four items was undertaken accordingly. A Principal Components Analysis (PCA) revealed a single factor solution which explained 52.94% of the variance. Factor loadings ranged from 0.64 to 0.8 (see Table 5).

Item	Statement	Impact Factor Loadings	М	Range	SD
Upset	My earliest memorable patient death was more upsetting than any other event in my early nursing career	0.74	2.50	1-4	1.11
Affected	I was not affected much by my earliest memorable patient death (Reverse coded)	0.74	3.11	4-1	0.93
Rumination	In the days and weeks immediately after it happened, I spent a lot of time thinking about my earliest memorable patient death	0.80	2.85	]-4	0.97
Vivid	My memories of my earliest memorable patient death are very	0.64	3.05	1-4	0.92

Table 5: Patient Death Impact Scale (PDIS) Items & Factor Loadings (n = 165)

These four items had a Cronbach's  $\alpha = 0.70$ , and Spearman-Brown split-half reliability coefficient = 0.64. With relatively robust psychometric properties, including acceptable face and content validity, clear underlying factor structure and acceptable internal consistency, these four EMPD impact items were analysed as a Patient Death Impact Scale (PDIS). The sum of scores of all four preparedness items was calculated to give a PDIS total for each participant. This was used as a measure of the personal impact of participants' EMPDs, with possible PDIS totals ranging from 4 (indicating minimal personal/emotional impact) to 16 (indicating maximal personal/emotional impact).

As can be seen in Table 5, all items on the impact scale produced a full range of responses, a tendency to somewhat agree with items Upset, Rumination and Vivid and somewhat disagree with item Affected. The item Upset was the most negatively worded, with equal distribution along the response scale. Responses to the item Affect were skewed towards disagreement, with 71% of participants strongly or somewhat disagreeing with the statement, indicating participants felt that they were, in fact, affected by their EMPD. Responses to the next two items were skewed towards agreement, with 76% of participants strongly or somewhat agreeing with the statement *My memories of my earliest memorable patient death are very vivid* and 70.6% of participants strongly or somewhat agreeing with the statement *In the days and weeks immediately after it happened, I spent a lot of time thinking about my earliest memorable patient death*.

Calculated total PDIS scores ranged from 4 to 16, with 3 participants scoring the lowest possible impact score, and 11 participants scoring the highest. Overall, the distribution of the scores was negatively skewed, with a fairly high average PDIS score (M = 11.56, SD = 2.83) indicating that, on average, participants felt their EMPDs had had a significant impact on them.

#### **Preparedness**

A Patient Death Preparedness Scale (PDPS) was developed specifically for this questionnaire, to measure participants' satisfaction with the death education they received in their early nursing training. The statement *My undergraduate (student) nursing training prepared me well to:* was followed by a number of items shown in Table 6, with Likert scale style response options. Likert Scale responses were coded as follows: *Strongly Agree* = 4, *Somewhat Agree* = 3, *Somewhat Disagree* = 2, *Strongly Disagree* = 1. Where participants (n = 10) indicated *N/A or Do Not Remember*, this was treated as missing data, and they were excluded from analysis. Inter-item correlations ranged from 0.59 to 0.80. Principal Component Analysis (PCA) was conducted on the five preparedness items to reveal the scale's underlying structure. PCA extracted a single factor which explained 74.49% of the total variance. Factor loadings ranged from 0.83 to 0.91 (see Table 6). The five-item scale had good internal consistency (Cronbach's  $\alpha = 0.91$ ), which was not improved by removal of any item. The Spearman-Brown coefficient of unequal length for this scale was calculated at 0.81, indicating a high split-half reliability.

Item	Statement	Preparedness Factor Loading	М	Range	SD
Reaction	Deal with my personal reactions to patient death	0.83	2.09	1-4	0.92
EOLCare	Confidently provide end- of-life care	0.88	2.18	1-4	0.93
Talk	Communicate with dying patients and their families	0.91	2.16	1-4	0.92
Grief	Care for bereaved relatives	0.87	2.07	1-4	0.89
PatientDeath	Know what patient death would be like	0.83	2.02	1-4	0.92

Table 6: Patient Death Preparedness Scale (PDPS) Items & Factor Loadings (n = 160)

With relatively robust psychometric properties, including good face and content validity, clear underlying factor structure and high internal consistency, these five preparedness items were analysed as a Patient Death Preparedness Scale (PDPS). The sum of scores of all five preparedness items was calculated to give a PDPS total for each participant. This was used as a measure of how well participants felt their undergraduate nursing training had prepared them for nursing encounters with death and dying. Possible PDPS totals ranged from 5 to 20, where 20 represented the greatest reported preparedness (strongly agreed they were well prepared in relation to all items).

All items had a full response range (strongly disagree to strongly agree). Scores for all items tended towards a 'somewhat disagree' response. No item had more than 10 participants give a "strongly agree" response, indicating that very few participants felt particularly well prepared for any of the listed aspects of patient death and dying. Although there was relatively little difference between items, participants felt least well prepared to Know what patient death would be like. Calculated total PDPS scores were non-normally distributed and ranged from 5 to 20 (M = 10.54, Mdn = 10.5, SD = 3.95). A notable cluster of nurses (n = 27) scored the minimum possible PDPS total of 5, indicating the highest possible level of dissatisfaction with their undergraduate nursing training in preparing them for nursing encounters with death and dying. Relatively few participants reported high levels of overall preparedness, with only 12 participants scoring >15 on their total PDPS. Participants with polarised total PDPS scores came from a variety of countries, training backgrounds, eras and institutions and analysis of raw data showed no obvious features characterising the groups of participants who felt most or least prepared by their training. Further inferential testing was not undertaken due to the large number of variable associations, limited empirical justification for testing, and significant possibility of spurious findings.

#### **Preparedness and Impact**

Encouraged by the psychometric properties of the final PDPS and PDIS, and the intuitivelysupported possibility of a relationship between undergraduate training preparedness for encountering death and the impact of participants' EMPDs, total scores from these scales were correlated using Spearman's rho for nonparametric data. A statistically significant, albeit weak, negative relationship was found between participants' PDPS and PDIS total scores,  $r_s = -.17$ , p (one-tailed) = .017.

## Support

Social support has been identified as an important factor in coping with stressful events, including occupational encounters with death and dying (e.g. Chang et al., 2006; Hulbert & Morrison, 2006). There was an even spread of responses to the statement *I knew where to get support if I was upset about my earliest memorable patient death* with 21.2% of participants strongly agreeing, 31.8% somewhat agreeing, 22.4% somewhat disagreeing and 24.6% strongly disagreeing. Participants were asked: *Did you talk to anyone about this experience with patient death*? Those who answered in the affirmative (N = 141) were then asked to specify who it was that they discussed their EMPD with. The majority of participants who shared their EMPD with others had more than one confidant, as demonstrated in Table 7. It is acknowledged that a number of these confidant categories overlap.

Confidants	Frequency
Friend (Health professional)	90
Senior Nurse	51
Partner	49
Tutor or educator	47
Parent or other family member	43
Student nurse	41
Friend (Non-Health professional)	39
Charge nurse	33
Preceptor	32

\*Church minister, counsellor

13

## **Positive, Satisfying and Rewarding Aspects**

In addition to identifying potentially stressful or challenging factors associated with participants' early experiences with patient death, this research sought to investigate factors which were associated with reporting of positive, satisfying or rewarding experiences. When asked *With regard to this experience with patient death, do you remember feeling that there were any positive, satisfying or rewarding aspects for you personally or professionally?* just over half (53%) of participants answered in the affirmative.

Prior research has provided some evidence that nurses who are well prepared for care of dying patients report more positive attitudes to care of the dying (Frommelt, 1991). In this sample, nurses who reported positive, rewarding or satisfying aspects of their EMPD reported, on average, higher overall preparedness scores as measured by PDPS total (N = 88, Mdn = 11) than nurses who did not report positive aspects (N = 72, Mdn = 10). Results of a Mann-Whitney U indicate that this difference is statistically significant U = 2487, p = 0.019, r = -0.19.

Statistically significant associations were also found between reporting positive, satisfying or rewarding aspects and both talking about the EMPD with others afterwards  $\chi^2(1) = 9.02$ , p = 0.003, Phi = 0.23; and the extent of nursing involvement by participants  $\chi^2(2) = 10.34$ , p = 0.006, Cramer's V = 0.23.

Participants who indicated that there were positive, rewarding or satisfying aspects to their EMPD were then given a comment box to specify their response. Many responses were lengthy and detailed. A content analysis (Joffe & Yardley, 2004) revealed six key themes (summarised in Figure 9). All but four statements fit well into these six themes, and where statements demonstrated thematic overlap, they were counted in more than one theme. Inter-rater reliability testing was undertaken using an independent (postgraduate student, Registered Nurse) rater, and 84% agreement occurred. Cohen's Kappa, a more conservative coefficient of agreement (J. Cohen, 1960), was calculated at  $\kappa = 0.80$  indicating a substantial strength of agreement (Landis & Koch, 1977).

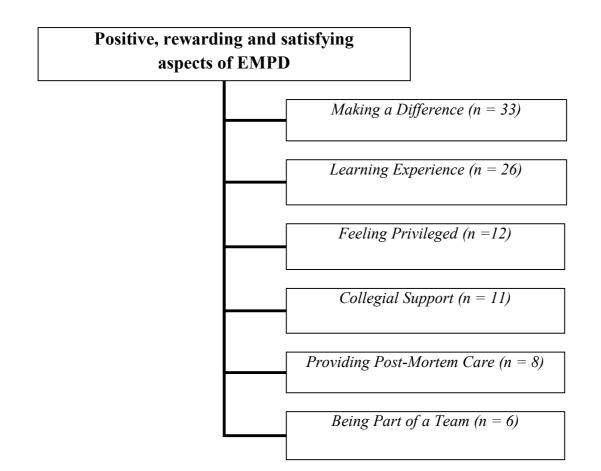


Figure 9: Positive, Satisfying & Rewarding Aspects of EMPDs

The most frequently occurring key theme was *Making a Difference*, with 33 participants citing satisfaction with aspects of their nursing care, describing a sense of 'making a difference' or taking pride in meaningful connections made with dying patients and their families. Providing comfort cares to the dying patient was an often-repeated theme:

"I am happy to see that my patient died comfortably, without suffering"

"Knowing that by making my tiny patient comfortable, I was easing some of his parents" immediate distress"

"As the patient was terminal, the care we provided was a relief and we could still make a difference"

Participants also described meaningful interactions with family members of dying patients. Several nurses felt satisfied that they had built a good rapport with family members, assisted with resolution of family 'issues' and facilitated family presence at the time of death:

"The family had spent time with the dying patient and were present in the room at the time of death. I thought that was rewarding"

"It was satisfying being able to organise for her to die at home.. And it was somewhat satisfying watching her make peace with family and friends - the family were brought closer together"

Many statements implied that provision of quality care to dying patients was intrinsically rewarding, but receiving recognition from family or colleagues was also appreciated:

"We had extremely rewarding feedback from family in terms of our care of both patient and them – mentioned in the death notice"

"Rewarding - it's such an emotional time, and for a moment you were welcomed as part of the family and when they thank you for taking care of him in his last few hours"

"Another staff nurse assisting me commented on how well she thought I had talked with the family"

...

Twenty six participants pointed out that their EMPDs had provided them with a beneficial or necessary *Learning Experience*. For some, it was largely viewed as an opportunity to attain professional skills and knowledge:

"I will be able to perform better comfort cares for a palliative patient after this"

"I learnt more about the cause of the patient's death, and what emergency protocols to follow during the time of death"

#### Others viewed their EMPD as an indispensable life experience:

"A necessary experience to nurse the continuum of the life cycle"

"We need to deal with death at some stage in our career or life. It helped me to better understand life and handle the situation. I personally think it is a necessary life experience"

# Several participants reported changes to death attitudes, decreased death anxiety and improved personal and professional self-efficacy for future encounters with patient death and dying:

"I was surprised and pleased to find I was able to cope with caring for a client who was dying and felt I was able to contribute effectively both pre and post mortem"

"I took the experience to help me deal with later stressful deaths"

"Mystery around dying and death of a sick person was dissipated, as it was well controlled with supportive care and pain relief and not the scary image reflected in the media of 'out of control' pain"

"First death was peaceful so having a positive first experience helped me not become afraid of caring for dying patients"

"Become more brave and knowing what to be expected in the same situation. I was scared before when thinking of dealing with a deceased body!"

# Others indicated that they had experienced more complex or significant personal and professional growth as a result of their encounter:

"I used all my training and life experience to ensure I did not avoid the hard tasks and awkward moments of listening to him and his worries. Responding to his anger and sadness was difficult, and realising that sometimes my dedicated silence was more embracing than anything I could ever try to say was a key to my future practice. . . the reality is that all we are is who we meet. Maybe this is even more true for nurses than many other professions"

\*\*\*

Twelve participants described a sense of *Feeling Privileged* in their experience with patient death, with nine participants specifically using the word 'privilege' in their description of positive aspects of their EMPD:

"I felt I was in a very privileged position to allow the process to run as smoothly as possible and to be present for what can be such a beautiful, though sad, experience"

"It was a loving and special moment I was privileged to share"

"A true privilege to be with and caring for a patient and family at the end of life"

\*\*\*

*Collegial Support* from nursing peers and other interdisciplinary team members was a noted positive aspect of 11 participants' experiences. This support often involved the mentorship or practical assistance of a senior nurse:

"I was fortunate to have a senior nurse with me who talked me through the whole process as we performed the cares"

" I remember feeling relieved that on this particular day I was working with a preceptor who was willing to show me how to lay out the patient but also talked about the changes in a nurses role once a patient died"

Informal peer debriefing after the event and other collegial gestures which acknowledged the potentially challenging nature of the nurse's early experience with patient death were also appreciated:

"The doctors on call at the time both came to see me afterwards as I was very upset about this patient's death and the senior staff nurse who I was working with was very supportive"

"The charge nurse was brilliant the way she supported me....then sent me off duty an hour before I was due to finish so I could process what had happened"

As previously mentioned, 88 participants were involved in post-mortem care during their EMPD. Of this group, 51 reported positive aspects and eight participants specifically mentioned *Providing Post-Mortem Care* as a rewarding, satisfying or positive aspect of their experience. Some described the process of providing post-mortem care, and the 'improved' appearance of the deceased patient, as inherently satisfying:

\*\*\*

"I was able to help with laying out the body... the person looked clean, nicely presented and peaceful... one of the flowers from a bunch that had been in the room was placed on the pillow beside the person"

Providing a patient with gentle, respectful post-mortem care also seemed to facilitate a personal and professional sense of satisfaction or 'closure':

"Completing the laying out procedure with respect and dignity for the patient gave me some closure"

"The 'laying out' was done with dignity and care. There was a spiritual belief which supported all the care given. There was recognition of a life well lived"

\*\*\*

# Six participants reported a sense of *Being Part of a Team*, characteristically those who had been involved in resuscitation attempts:

"During the resuscitation...I felt that I was part of the 'team'. I was drawing up the drugs and getting the IV stuff ready for the docs..."

"I was happy that I also became a part of the team and tried to save his life"

Other rewarding, satisfying and positive aspects not specifically mentioned above (n = 4) were: being present at the time of death with a patient who was otherwise alone; feeling that the patient was 'at peace'; facilitating a 'dignified death', and feeling that the patient's suffering had come to an end.

## **Summary**

Descriptive data from this, purpose-designed online questionnaire provide an initial 'snapshot' of the clinical circumstances and personal impact of nurses' EMPDs, who they discussed this event with, and how well their undergraduate training prepared them for encounters with death and dying. Interesting data were also generated regarding the positive, rewarding or satisfying aspects of EMPDs, where participants were able to report experiencing these. Participants reported on a diverse range of encounters, with a broad response range on all variables. Results from this study will be discussed, analysed and critiqued in the following chapter.

# STUDY TWO: SEMI-STRUCTURED INTERVIEWS

## **METHOD**

This chapter details the method of Study Two, in which 20 currently practicing New Zealand nurses took part in semi-structured interviews exploring their earliest memorable patient death (EMPD) experiences. A description of this self-selected sample is given, followed by details of the semi-structured interview procedure and data analysis. The chapter concludes with a brief reflexive statement by the researcher.

## **Participant recruitment**

Study Two participants were a self-selected sub-sample of Study One, who volunteered to participate in a further interview study. Upon completion of the online questionnaire, all participants were automatically presented with a 'thank you' page (reproduced in Figure 10).

## Nurses' early experiences with patient death

Thanks so much for completing this questionnaire !!

Obviously, a questionnaire is limited in the extent to which it can capture an experience as complex as nursing a patient who dies. As an additional part of my thesis research, I will be conducting face-to-face interviews, to give nurses the opportunity to more fully share their first experiences of patient death.

IF YOU WOULD BE INTERESTED IN PARTICIPATING IN AN INTERVIEW, lasting approximately thirty to forty-five minutes, and at a time and location of mutual convenience, please email me: NatalieSpackman@gmail.com or phone or text message me: 021 656 497. Your questionnaire details will remain anonymous and will not be linked to your interview data.

#### Figure 10: Reproduction of Final Page of Online Questionnaire

Participants from Study One who contacted the researcher with an interest in participating in Study Two, were sent an interview participant information sheet (see Appendix D) via email, and subsequently, an interview time was scheduled. After twenty interviews had been conducted, a large amount of rich data had been collected, with evidence of data saturation, and further interview volunteers were declined. A purposeful or theoretical sampling approach was used in the interview study. Purposeful sampling does not prioritise representativeness and empirical generalisation to a population, instead selecting cases which are likely to be rich in information and provide useful insights about experiences of interest (Patton, 2002). Since Interpretative Phenomenological Analysis (IPA) seeks to understand participants' experiences, whilst still relying on the participant's ability to describe their emotions, cognitions and behaviours (Larkin et al., 2006), the interview sample was made up of nurses aware that they would need to articulate their earliest memorable experience with patient death. Although the inevitable influence of 'volunteer bias' on this sample is acknowledged, the self-selection of nurses who felt able to communicate their experiences was essential to meet the study aims. Participant demographics are reported in the results chapter.

## **Semi-Structured Interview Procedure**

Individual face-to-face interviews were conducted in private offices at hospital and university sites, or in the participant's own home; the venue and time was largely determined by the participants. Interview participants were often attending interviews before or after work, and general conversation about the participant's workplace was often initiated, facilitating a relaxed and conversational tone, whilst he or she completed consent (see Appendix E) and demographic forms (see Appendix F). All interview participants had completed the online questionnaire and received information priming them to the interview topic. Many participants reported that they had been reflecting on their earliest memorable patient death leading up to the interview, and this was likely to have contributed to the rich, detailed narratives provided by many interview participants.

After being given the opportunity to ask any questions, a digital voice recorder was switched on to record the interview. The researcher began each interview with a statement to the effect of: "Tell me everything you can remember about your earliest memorable patient death." Interview participants then spoke without interruption, describing their earliest memorable patient deaths, until they indicated that they had nothing further to add. At this point, the researcher used a set of probing questions to guide further exploration of the experience, and encourage discussion of aspects not fully covered in their spontaneous account (see Appendix G). Wherever possible,

open-ended questions were used, and leading questions were avoided, in an explicit attempt to allow the subject matter to "...show itself 'as itself'....in its own terms" (Larkin et al., 2006, p. 108).

At the conclusion of the interview participants were asked 'Is there anything else I should have asked you?' and were given the opportunity to add any final comments. Several participants requested that the recorder be stopped at this point, typically to discuss more general aspects of their nursing experiences with patient death. Any issues discussed after the recorder was switched off remained confidential and were not included in the results of this study.

In order to attend fully to the interview participants, the researcher wrote no notes during the interview, but took time as soon as possible after each interview was completed, to record any significant body language, emotional content or other salient impressions which may not have been captured by the audio recording. A full, verbatim transcript was made by the researcher, inclusive of written indicators of pauses and emphases, and emotional expression including laughter or sighs.

## **Data Analysis**

When analysing the transcripts, the researcher attempted genuinely to represent the participants' experiences, whilst also acknowledging the limitations and complexities of the conversations and the interplay between participant and researcher. The goal was to move beyond a descriptive narrative, to reflect the interpretation of the researcher, including the application of psychological theories to participants' accounts (Brocki & Wearden, 2006). Generous verbatim excerpts from transcripts accompany interpretative analysis to provide "grounding in examples" (Elliott, Fischer, & Rennie, 1999, p. 222), allowing the reader to make their own judgements regarding the interpretation of accounts.

Thematic analysis was undertaken with reference to Smith, Jarman and Osborn (1999), who adapted traditional IPA for use with a larger sample of participants. Transcripts were printed with large left and right margins. The first transcript was read several times, with key or

repeated thoughts and feelings, apparent points of conflict and other interesting or important points noted in the left margin. Emerging themes or "concise phrases which aim to capture the essential quality of what was found in the text" (Smith & Osborn, 2003, p. 68) were then noted in the right hand margin. Participants' own words were used as theme headings in situations where their own phrases provided succinct or powerful descriptors. A table of themes was produced by interpreting the meaning of themes and clustering them, with ongoing reference to the original transcript data. Each transcript was then analysed in turn, with consideration to previous emerging themes, in an attempt to identify shared themes early in the analysis. In an iterative process, the researcher often returned to earlier transcripts to examine them in light of themes which had emerged in subsequent interviews. Digital recordings were also reviewed at times, to check for clear understanding of the participant's original emphasis. Once initial tables of themes for all twenty interviews had been produced, shared themes, clusters and interrelationships between themes were explored. A new word-processed data file of super-ordinate themes and associated excerpts was created using Microsoft Word, as "patterns, connections and tensions" were identified (Smith et al., 1999, p. 232).

#### **Researcher Reflexivity**

When Quint published her book "The Nurse and the dying patient" she was criticised for mixing her own opinions and interpretations indistinguishably with observational study data (Craytor, 1968). Throughout this project I have strived to represent my data authentically, and have provided frequent quotes from the original data in my results, and used illustrative summary examples in my discussion. Although I have sought to make the journey from raw data to conclusions as transparent as possible, my personal beliefs and experiences will have influenced many aspects of this project. Throughout the design, recruitment, collection and analysis phases, I was aware of the need to acknowledge and incorporate my own nursing experience, with my appreciation of the principles of scientific research. As an experienced nurse I have come to trust my own instincts and be guided by 'intuitive' decision making which merges my clinical knowledge with my experience. The sometimes subconscious nature of intuitive decision to this deconstruction and questioning of my way of seeing the world.

Reflexivity has been defined as "a self-conscious awareness and analysis of ways in which the assumptions, activities and interests of the researcher are likely to have influenced the process and findings of the research" (Marks & Yardley, 2004, p. 221). By including this section in my thesis I hope to shed light on some of my personal influences, using writing as a method of facilitating insight into my perspective, both personally, and for the reader. Representative of the iterative 'dance' (Finlay, 2008) of reflexivity, the following account has evolved and been revised throughout the course of writing my thesis. The ongoing process of assessing and re-examining the potential influences on my perspective has been a crucial and often challenging part of my interpretative journey as a novice qualitative researcher.

Before my nursing training even began, I had already encountered death and dying on a number of occasions, working part-time as a rest-home assistant. My memories of the first time I cared for a dying resident, and subsequently assisted with her post-mortem care, are remarkably vivid. I can also recall the reassurance and guidance I received from the Registered Nurse with whom I was working. When I was 19, I cared for my grandmother in her last few days of life, after she had a catastrophic stroke. The local hospice expertly facilitated her transfer home, allowing her to die peacefully, in her own bed, and surrounded by family. A few years later, as a volunteer ambulance officer, I learnt that death was not always the quiet relinquishing of an age-worn body. I witnessed death by SIDS, suicide, accidental and sudden unexpected medical causes. On reflection, I realise I was extremely well supported and feel grateful to the staff at Howick Baptist Home and St John Ambulance, who provided wonderful and influential support and mentorship in care of the dying and their families, when I was so young and impressionable.

By comparison, my nursing training provided little clinical experience of patient death or dying, and, on occasion, I felt that involvement in the care of the dying by student nurses was even discouraged - somehow regarded as too much responsibility, or perhaps, too distressing for a student. On reflection, I have been motivated throughout this research project by a nagging sense that I was so fortunate in my own preparation and support through early experiences with death and dying, and that, perhaps, much more could be done for other novice nurses.

## RESULTS

### **Overview**

This purpose of this chapter is to outline the findings from the semi-structured interviews carried out in Study Two. As discussed in the method section, participants who had completed the questionnaire in Study One were offered the opportunity to volunteer for participation in a further, interview study. The first twenty volunteers were included in Study Two, which provided more detailed, qualitative data exploring the nature of nurses' earliest memorable experiences with patient death (EMPD). Study Two participants included males and females from a range of ethnic backgrounds, currently employed in a variety of clinical and non-clinical nursing roles. New-to-nursing perspectives were provided by eight New Graduate nurses. Initially, a descriptive overview of the interviews, including some clinical details, is given. The seven emergent themes are summarised in Figure 11, then presented in more detail. Illustrative excerpts are provided to demonstrate clear articulation of emergent themes and grounding in the original data. Patient names, dates, clinical settings and other potentially identifying or sensitive details have been omitted or altered where necessary with pseudonyms used for all participants.

## **Participants**

Over fifty participants from Study One also volunteered to participate in Study Two and be interviewed regarding their EMPD. After 20 participants were interviewed, data saturation was reached, and no further interviews were undertaken. Interview participants were currently employed in a range of settings. A large proportion of New Graduate and Senior nurses were included in the sample, reflecting the groups who are most likely to be undertaking postgraduate study in the present nursing environment.

Age	n	Ethnicity	n	Gender	n
21-30	8	NZ European	11	Female	17
31-40	9	Other European	4		
41-50	3	NZ Maori	2	Male	3
		Other	3		
Training institution	n	Current Nursing Status*	n	Years since EMPD	n
NZ Uni/Tech	13	New Graduate	8	<2	5
NZ Hospital	2	Competent	3	2-10	7
Other Uni /Tech	2	Proficient	3	11-20	4
Other Hospital	3	Expert / Senior	6	21-30	2
				>30	2

**Table 8: Interview Participants' Demographics** 

\*Self-reported nursing status, adapted from National Professional Development & Recognition Programmes Working Party (2004)

## **Description of Earliest Memorable Patient Death (EMPD) Accounts**

Interview duration ranged from 20-50 minutes. Although probes were prepared (see Appendix G) they were rarely needed, as the nurses typically provided a rich and detailed narrative which spontaneously addressed many of the key research questions without further prompting. The clinical circumstances of patient deaths varied widely and included sudden unexpected deaths of young people, neonatal deaths and expected deaths following long or critical illness. Most (n = 17) nurses revealed that the experience described was their very first encounter with patient death. Three nurses alluded to earlier encounters with patient death, but did not choose them as EMPDs, apparently because they had very little or no nursing involvement. At the time of their EMPD, many had had no prior exposure to death or dying in their family lives. Most participants experienced their EMPD during their undergraduate nursing training (n = 14) or as newly-graduated Registered Nurses (n = 5). EMPDs most commonly took place in medical

wards (n = 12) or other specialised acute settings (n = 7) which included emergency departments and intensive care units. Only one EMPD occurred in a specialised palliative care setting. The time that had elapsed since EMPD varied from only a few weeks to over 35 years.

The nature and extent of the interview participants' nursing care during the death experience varied. Seven participants were involved with post mortem care, and for three nurses, this was their only contact with the patient. Other reported nursing care included attempting resuscitation, providing symptom-relieving medication, explaining brain-death testing to family members, notifying family members of a patient death, and facilitating a family 'shin-dig' complete with beer, KFC and guitars, the night before a patient died. Many of the accounts were extremely poignant, and recall of the experience was often so vivid that participants appeared to be re-living the encounter, complete with the emotions they experienced at the time.

IPA, which was used to analyse these accounts, acknowledges that the account provided by participants is a reflection of the way they have made sense of that experience. The initial part of each interview, where participants would 'tell the story' of their EMPD without interruption was therefore considered to be particularly meaningful, signalling themes which the participants considered most salient or noteworthy. The structure of these initial accounts was remarkably common across all participants. Typically, participants began by 'setting the scene', describing the clinical setting in which the event occurred, and defining their nursing role at the time. This was often followed by details of the patient's clinical presentation. This case-study presentation style and inclusion of detailed clinical factors was particularly characteristic of descriptions provided by more recently graduated nurses.

## **Key Themes**

Seven key themes were identified (see Figure 11). These themes do not always represent frequently repeated ideas, common across participants. Key or central themes characterising individual accounts and important comparisons and contrasting perspectives are also included. The presentation of discrete thematic categories is used to facilitate the meaningful and ordered

communication of results, but does not discount the interplay, elaborated on in the discussion chapter, that exists between many themes.

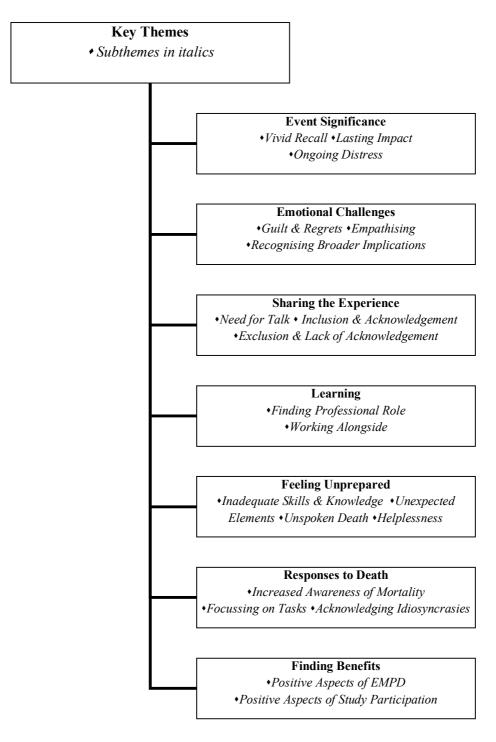


Figure 11: Key Themes from Interview Data

#### **Event Significance**

One of the key aims of this research was to determine if nurses' early experiences with patient death were salient events which had the potential to have an impact on their professional and personal lives. For participants in this study, there was considerable evidence that their earliest memorable death was a significant event. A challenging combination of clinical and personal factors appeared to have contributed to particularly demanding or distressing EMPDs for a few participants. It should be noted, however, that most participants provided an account of more common clinical circumstances, which were representative of the larger sample from Study One. Although most participants' experiences were characterised by emphatic or poignant description, there was most often a balance of challenges and rewards.

One of the most striking features of EMPD accounts was the *Vivid Recall* of details provided by participants. In addition to readily providing details of their own thoughts, actions and feelings at the time, most participants recalled the name and age of the patient who had died, pertinent information about family members and, in some cases, highly specific clinical details. Many reported that they had thought about the experience numerous times since it had occurred, and for some such recall was intrusive. Yasmin and Anna were amongst those who remarked on the vividness of their EMPD memories:

Yeah, well I can remember it vividly. . . . I can remember the people that were around that we were trying to get rid of, as well. And the doctors and everything. . . I can just sort of play through it in my mind. (Yasmin, Proficient nurse)

I can vividly remember, now, when I thought about it afterwards I can remember being in the room and the nurse going out. . . I, like, stopped and I froze because I suddenly thought shit I'm in a room with a dead person, and I'd never seen anyone dead before, I've never - hadn't at that time - lost anybody in my family, I'd never seen anybody die. . . I can remember I was bending down when I realised. (Anna, Senior nurse)

Elizabeth vividly recalled many details, including the intimate and disturbing experience of looking into her patient's eyes as he lay "powerless" and dying. Although Elizabeth returned

# recently to complete her training, this experience occurred early in her nursing career, several decades prior to the interview:

I was seventeen - no, I might have been just turned eighteen - and my job - I was put at the head of the bed with the bag. . . the oxygen mask to put on his face. And he - he just - he didn't make it. But he never took his eyes off me. He just looked at me and I looked at him. And - it was like, he was just powerless - powerless. . . And it's something that I'll never forget. . . I still remember his name. His age. All his circumstances. (Elizabeth, New Graduate nurse)

During their interviews, some participants appeared to be re-experiencing aspects of their EMPDs. Although this was emotional and at times even distressing for some, participants also seemed to enjoy the opportunity to recall meaningful or satisfying aspects of their EMPD. Whilst giving a particularly touching, detailed description of the post-mortem care she provided some decades ago, Olivia appeared to be acting out or re-living her nursing care, vividly recalling the manicured appearance of the patient's hands, and the way she had connected this to the woman's life.

I brushed her hair, very, very gently, and I took my time. I made sure I rolled a towel and put it underneath her neck. Because I had been told by the enrolled nurse, the best way of doing things. I - her eyes were already closed, but they were slightly open but I could always remember [re-enacting on her own eyes whilst describing] touching her eyelids and making sure that they were down, so that I couldn't see her eyes. And to me that was sort of - a way of being humble, of being respectful of her. [Continuing to re-enact nursing care whilst sitting talking to me] And I laid her flat, making sure that her feet touched. And I put another pillow underneath her feet, even though I really didn't need to, but so that her feet would stand upright. And her hands I crossed over. But I was told afterwards that hands are better left down the side. And I actually took a little flower from the vase, and just placed it on her chest. And - so she looked really good. And I said 'you look wonderful'. I can remember saying something like 'you look really lovely'.... For me, looking at her hands when I was massaging them with hand lotion, [re-enacting holding patient's hand in hers] I kept thinking I wonder what these hands have done. She had lovely knobs on the tips of her fingers. And she had long fingers, and they were delicate and lovely nails that were manicured. So I thought somebody's taking care of her. (Olivia, Senior nurse)

The second subtheme within Event Significance was the *Lasting Impact* that many nurses felt their EMPD had, both personally and professionally. Sometimes the overall impact was very positive, inspiring future involvement with end-of-life care. Other participants had avoided contact with death and dying, particularly clinical situations which reminded them of their EMPD. Several nurses felt that their EMPD may have impacted on subsequent career choices they had made. For some, an admired role-model or rewarding experience stirred subsequent interest in palliative, hospice or bereavement care. This was reflected in Tracey's account in which she spoke enthusiastically of the admiration she had for her preceptor ('Jo') and the positive experience she had helping her to provide end-of-life care. Many years later, Tracey still considers Jo an important role-model.

So that was my first experience. And I think that's why, ever since that time - so I was eighteen and a half - I said, I think I want to be like Jo [senior nurse working with participant], I think I want to look after cancer patients. If that's what - if that's the sort of experience I can get out of it. And what the patient can get out of it. You know, he died very peacefully, there was nothing what's the word - there were no machines. There was nothing high-tech about it, that's what I'm trying to say. There was just, the patient, Jo and me. And I thought, you know, this sounds a really nice way of being able to care for people. So after my training, that's what I wanted to do. (Tracey, Senior nurse)

# Anna also felt that she really 'made a difference' to her dying patient, and that she found rewards in this experience that encouraged her to pursue a career in palliative care.

And I remember looking after her and I remember how I would feel looking after her. . . I wanted to look after her, you know because I thought I was doing something. And I thought we had a good - we were comfortable with each other and we would just sit and talk, talk with her, and she definitely is where my interest in palliative care would have come from, because she was the first patient I can really remember. (Anna, Senior nurse)

Brenda's participation in the study prompted her reflection on the possible impact that her EMPD had had on her professional development. She admitted that she had not made a conscious connection, but that it was possible that her largely positive EMPD had influenced her subsequent career choices, at least providing her with a "good background". It [reflecting on EMPD] did make me think 'goodness that obviously did have quite an impact on me'. And I'm quite surprised at the impact it did have. I can't say that 'it's had a direct impact because of blah, blah, blah', but the fact that I can remember it, twelve years later, and particularly the fact that I can't remember a lot of intervening deaths as well. That's made me think 'oh' that obviously did have quite an impact on me. . . . Whilst I couldn't say that that specific event pushed me in that direction, I think it probably has influenced it, and was a good beginning and a sort of good background to go from. (Brenda, Senior nurse)

In contrast, three participants who had more negative EMPD experiences subsequently avoided clinical settings where patient deaths were more likely to occur. Sarah had not experienced any other patient deaths in the decades that had elapsed since her EMPD, and confessed that this initial experience had an ongoing influence on her career choices.

I've always felt like I didn't look after that man very well. And I guess where I - it's coloured my practice, because where I chose to work - it's where, hopefully people aren't dying. . . . I mean, it's not like first up in my head when I apply for a job or anything, but, yeah, it is there. (Sarah, Competent nurse)

# Later in the interview, Sarah elaborated on this, specifying that her aversion to death was strongest where characteristics of her EMPD were manifest.

I certainly don't ever want to work in medical - adults. People gasping for breath just doesn't work for me at all [laughing]. So, yeah. It is - not right at the top of my list when I'm making job decisions - about new careers, new pathways. But that whole breathing thing. Adult medical. Men, particularly. They cough and splutter and spit and – [voice trailing off] it's yucky. (Sarah, Competent nurse)

Although many nurses became emotional during interviews, a few nurses described more severe *Ongoing Distress* including disruptive or intrusive thoughts, feelings and behaviours associated with a post-traumatic stress response. Several nurses experienced sleeplessness, re-experiencing the event through dreams, feared encountering similar clinical situations, or had serious concerns about the ongoing impact of their EMPD on future nursing practice. Several nurses took time off work after the event, two took extended leave and one never returned to the clinical setting of the EMPD.

Mark's recollections summed up the distress that his EMPD caused, as he described his ongoing symptoms, which included intrusive flashbacks and bad dreams, and a pervasive fear that his anxieties would interfere with his nursing care, should he be required to nurse another patient with the same condition.

Actually, I couldn't sleep for two days. At all. And my [partner] was very worried about me. I couldn't come back the next day, because I was - sort of - traumatised, myself. And that was my first day, and I thought I might not be able to go back, I might have to ask my tutor to change the placement. And I didn't go back for two days. . . . I do have a lot of memories about the first patient. And it just keeps coming back to me. And as a Registered Nurse, now, I've seen some [other patients similar to that of EMPD]. And every time I see those patients, I don't feel good, because I know the patient might die. And - just memories just keep coming back, and I have to work and I go home and go to sleep - and in my dreams, it keeps coming back. . . . It's happened a couple of times since. (Mark, New Graduate nurse)

#### **Emotional Challenges**

When reflecting on their EMPDs, a number of nurses felt that there were things that they would do or have done differently in subsequent encounters with patient death and dying. The majority of nurses viewed this in a positive light, as is covered in the Learning theme, however a few nurses found themselves burdened with ongoing *Guilt & Regrets* about their EMPDs. Sarah, who had avoided any encounters with patient death following her EMPD, appeared to be experiencing ongoing distress related to her unresolved guilt.

Interviewer: Can you tell me a bit more about - you say it's a very vivid memory - what do you think it is about this patient death that makes it so memorable?

[resolutely] Guilt. Guilt because I didn't recognise what was going on and I should have. I don't know how I should have [laughs]. But that's the... [voice trailing off] the thing.... (Sarah, Competent nurse)

Reflecting on her EMPD many years after it occurred, it seemed that she was trying to acknowledge that her age and inexperience contributed significantly to her thoughts, feelings and behaviour at the time, but she still seemed unable to 'forgive' herself.

I think the whole experience took me by surprise. And yes, no – we weren't prepared. We'd laid out a manikin - sort of thing. We had a little card, a little book with pages on everything from taking a temperature to laying out. So I knew the theory but I certainly wasn't prepared for - they weren't big on buddy systems. There wasn't somebody I could really speak to, about it. And then the kind of guilt that I felt. That I should have done something different, or better. Which, as an adult I think is unrealistic, you know. But - yeah. It has had an impact, certainly. (Sarah, Competent nurse)

Alistar mentioned feeling worried about the contribution his inexperience may have played in the unexpected death of his patient. Alistar seemed reluctant to elaborate on this, and became visibly anxious and uncomfortable when asked to discuss his feelings around the death.

*Oh. I thought, if it was from my side – I was quite worried because - maybe from my, because of my fault, or my inexperience, it happened. Because I am not sure, it worried me. (Alistar, Competent nurse)* 

Nurses often found themselves *Empathising* with dying patients and their families, and for some this was their first real exposure to grief and loss, the implications for loved ones, and the behaviour of grieving relatives. The impact that death and dying had on their patients' family members seemed to be both thought-provoking and emotionally challenging, often featuring prominently in the initial spontaneous accounts provided by interview participants. Participants commonly referred to parallels and comparisons they had made with themselves or their own families. An example of this was Janelle, who found herself imagining what it would be like to lose a grandparent.

From when they died there was a granddaughter in the hospital at the time, and she was also a nurse. Not a nurse at that hospital. She came down. She'd been up at the café or something. That was actually the hardest part. Dealing with her. Being that someone special had died for this person, that was the only time like - awwww [brow furrowed, gesturing with hands clasped to chest]. My grandmothers were alive at that stage so you're kind of like – aww, I'd feel like that too. (Janelle, New Graduate nurse)

# Rose empathised with the children of her dying patient, but differentiated between feeling sad herself and sad 'for' others.

I remember I was very sad. I don't know if I cried with the family. I think I just felt - I didn't feel sad myself, but I felt sad seeing the children, especially since they weren't much younger than I was. (Rose, Competent nurse)

# Patricia was struck by the significant impact that her patient's sudden unexpected death would have on his family, whilst her own day would 'go back to normal'.

And to see the family, to see everybody around. . . . I remember the daughter, the daughter didn't make it on time. Before the father took his last breath. So when she came in we were preparing the body. She said 'can I have a minute alone' and she just cried. [emotional] She went over to kiss her father and she just cried. And I think that was the most difficult part. . .I'm going to go home, I'm going to go home to my father, but these people aren't. I had, I had a lot of mixed feelings. A lot. (Patricia, New Graduate nurse)

Although empathy is integral to a nurse's caring role, some participants found themselves overwhelmed by a more personal emotional connection to both the dying patient and their family members. Participants often recognised a need to distance themselves or protect themselves from potential emotional distress but were not always able to control or restrict their emotional involvement. Mark commented that he didn't know 'how not to care', as captured in the next example:

I mean it was the hardest emotion that I've had. So I don't know how not to care. I always do it – put myself in that situation all the time. What if I was him? How about my family? How would my wife, my children, cope with that? What if I was the child of this patient, how could I cope with that - what could I do for them? I still think of myself, because my parents are getting older, and I don't know, in ten years or something like that I might experience something like this. I don't know, you never know. So I don't know how I can cope with that. . . . I feel - sort of depressed whenever I think of this. As a nurse it was hard, but as a, just as a person it always affects me. (Mark, New Graduate nurse)

#### Claire's personal link to her patient's tragic situation also made her unable to "put up a wall".

It's what I said before – about the putting up of this wall and doing what you need to do to get people through the department. There's completely no wall. If I remembered what he looked like, and saw him in the street, I would want to talk to him. I'd want to say 'how are you doing'? I think, have come with being a mum myself and being a family and thinking about losing people, thinking about losing your own family and a child. That, it just - I couldn't imagine it. I couldn't imagine it for myself. . . Just makes you really - as much as you put up a wall for other things, there's no wall for this. No wall. It was just horrible. (Claire, Proficient nurse)

Participants found themselves thinking not only about their patient, but also *Recognising Broader Implications* that death could have on others. Interview participants were typically very young at the time of their EMPD (Range 18-32 years, M = 22 years) and most reported having little exposure to grief, loss, death and dying in their personal and family lives (although there were some exceptions). It is perhaps not surprising, then, that so many nurses seemed unprepared for the impact that patient death could have on family members, apparently having given this little consideration prior to their EMPD. Rose and Yasmin both thought that age was a factor in this:

I think age is a big one. Because I think if you're too young you might not realise the impact that death has on the family that are left behind and if you're older you might appreciate it more. Or you might be able to give better support to the people around you, or the students, or whatever. (Rose, Competent nurse)

I didn't really think about how the other people on the phone would feel about having somebody ring them and tell them their family member had passed away. But, I think because I'd been asked to do it, I just did it. I didn't really take into account what the people would have felt like. I mean, I think because I was young, as well, I didn't really think through that kind of thing. I think, if had been me now, there would have - it would have been different. If it was someone I didn't know very well, then I'd be saying to someone else 'no, I think you should be doing it, because you know the person' or whatever, you know. But I think as a student, I just did it because they said 'oh, can you ring the family'. And so I just did it. And didn't think about it. (Yasmin, Proficient nurse)

Anna found dealing with families and relatives to be the most challenging part of her EMPD, and thought that family-centred end-of-life care should have been given more attention in nursing training:

I really don't recall when we had our training, when we talked about people dying, we talked about the person themselves dying maybe - or maybe we talked about death in a medical sense, in that kind of sense, but we never really - in terms of the impact on the people they leave behind and things...That was the hardest thing... that is something that should be looked at in more detail, actually... having somebody like one of the counsellors coming in and talking about, you know, having some appreciation for - it's not just the person you're looking after, it's everybody else. That's maybe something that was lacking. [long pause] Yeah that would be the biggest thing. And also when you're nursing a patient who's dying, you're not just nursing that person. You are looking after their whole family and everything. And I don't think I ever - I don't recall having an appreciation of that. Or being prepared for that. (Anna, Senior nurse)

#### Sharing the Experience

The most frequently occurring key theme was Sharing the Experience. Those who felt that they were part of a team at the time of the event, or discussed the experience with empathetic friends, family or colleagues afterwards, appeared to experience considerable benefits from this. Nurses who felt unable to share their experience, or that the emotional impact of the EMPD was not acknowledged by others, appeared to experience more ongoing emotional distress. It is perhaps unsurprising, therefore, that amongst a sample of nurses who have volunteered to discuss their EMPD, so many referred to the importance of *Need For Talk*. Many participants felt that informal debriefing with colleagues was important, and several referred specifically to 'cup-oftea' or 'tearoom' debriefs, highlighting the way that nurses gather together in communal areas to support each other after challenging events. Janelle felt it was important for colleagues to get together for a few minutes after any challenging event.

Debriefing after the death has always been a good thing. Everybody talks openly, it's nobody's fault. It's – these things happen. Those kind of talks afterwards, I've always found to be a good thing. Which we don't really seem to have in [my current workplace] actually.

#### Interviewer: And is that a formalised thing..?

Nah, just a sit-down in the tea-room, take ten, have a coffee. There's always something funny – nurses can make anything funny. [laughing] 'Haha – you got tangled up in the oxygen tubing'. Kinda thing. I think that's something that really helps. Yeah. I don't know how many places do do it. I've been in places that do and places that don't and I think it's far more effective than just, you know, 'alright - everybody back to your jobs'. Yeah. I found that to be a fantastic thing. After any incident, it doesn't need to be a death. Yeah. . . .Being up-front and talking about it and making people aware that there always is someone you can talk to. (Janelle, New Graduate nurse)

# Sarah felt that nurses were not supporting each other as well as they could, and also mentioned the therapeutic potential of talking with colleagues over a cup of tea.

I don't believe we're particularly good at sitting down and just saying 'ok, we're going to sit down for five minutes, have a cup of tea, and just talk about it. What we could have done better, what did we do right'. I don't think that, as a professional group, we actually handle death very well. . . .I think for young nurses - as in their length of nursing not their age – they need, some sort of awhi<sup>2</sup> around it, some support. (Sarah, Competent nurse)

# In addition to sharing their stories with other nurses or student nurses, several participants, including Ella and Alistar, talked to friends and family members who were also health professionals.

I talked to a lot of people actually about it. I had a friend who was in the same class as me, so we used to sit and have lots of coffees and [laughs] a few cocktails after work. You know, have a chat about how our days had been and blah, blah, blah. And that definitely helped, just talking about it. Yeah. And I talked to my mum, because she's a nurse, like 'I'm quite upset

<sup>&</sup>lt;sup>2</sup> Awhi (n.d.): From Maori, meaning to embrace, foster, cherish, brood, draw near, hug, incubate

today because this happened' and she said 'that's ok, this does happen, it's part of life and -' Yeah. And I think she just talked about her first experience as well. It's part of something that you need to go through to appreciate all the times you've had prior. (Ella, Proficient nurse)

Oh I talked to my relatives – an aunty and, yeah - parents. Because a few of my relatives are working in the same field - health professionals. So they told me it's like anything, it will happen everyday, so it's not a big deal. . . . The senior staff, they told me 'it's alright, blah blah blah'. Then they told me 'it's nothing, it happens daily here' – or - they were most supportive. They said 'they will come and go, we've had experiences like this before, we were upset but now [laughing] it's like a daily routine' they told me. (Alistar, Competent nurse)

# Debbie clearly articulated that talking about her EMPD with family members provided a sense of resolution, and helped her to "see she had done ok".

My Mum's a [health professional] and my brother's a [training health professional]. So it was really nice to be able to talk to people that understand - the clinical situation. And - of course, no names - but talking about how I was feeling and how it felt. And colleagues, as well. Talked to colleagues about it. . . But also going through, talking about what I did do - to try and justify. It took me a while to see that I had done ok. I had to go through, you know - reflection on what I had done. Because initially I felt really bad that bereavement care, that I hadn't done what I should have done. But reflecting on it, I realised I couldn't have known. So, by the end of talking to people and everything I felt really good about it. (Debbie, New Graduate nurse)

# Living with other student nurses in a small town meant that student colleagues and tutors were accessible and approachable for a chat, something which Karen found helpful.

At the time, because it was a placement out of the city that I trained in, I was living in a hostel. So there were other nursing students living there. So I just talked to one of my friends - but we always, [laughing] everyday we talked after work about what happened at work, so -yeah, I just talked to her about it. And also, our clinical tutor, we saw her – she worked at the hospital as well, so the next time I saw her I talked to her about it as well, and just told her – well, she, because it was such a small hospital, she knew what had happened. So she came to me and asked me if there was anything I wanted to talk about or anything like that. (Karen, New Graduate nurse)

Later in the interview, when Karen was asked what might help nurses better to prepare for and cope with their first patient deaths, she suggested that hearing other nurses' stories could be a helpful tool for preparing novice nurses.

I found that in my training that pairing nurses' experiences, no matter what they were, whether they were just talking about their, when they worked on a surgical ward or - it kind-of helped you to get an understanding of what that kind of work is like. So I guess like if nurses were willing to share their stories with students, and just so that we got the sort of - that every nurse deals with it in a different way, and every death is different. So they understand that it'll be their own personal experience. So possibly just some, yeah, other nurses sharing their experiences with students. (Karen, New Graduate nurse)

Although talking about the experience was an important coping mechanism for many, the nature of this talk appears to be important. Claire found her colleagues' desire to hear all the 'gory' clinical details of her patient's tragic death was unhelpful and even problematic for her when she attempted (unsuccessfully) to return to work after her EMPD.

And the thing was, working with so many people and some on days on and some on days off and the people on days off come on - and they're like 'oh, we've heard about this terrible thing and did you see it?' Reliving it. Reliving it and reliving it for however long, I was there. I think it was only three – maybe four shifts. And everyone had heard about it. . . . It was hospital-wide spread knowledge and you couldn't get away from it - you just couldn't get away from it. And talking about it to people - I wasn't actually talking about it - 'well, I'm actually not doing so well. . . . ' It was more like 'oh, did you hear about' - 'yeah, I did. . . and she died, and. . . ' and just relaying the story back, and not actually discussing - to help deal with it. It was just more 'ohhh - that was exciting' And it was exciting. I mean, you don't see that. And I might, hopefully, cross my fingers never, ever see it again. And they were all inquiring – 'what's it like?' and sort of stuff like that, and it wasn't helpful. At all. By any means. (Claire, Proficient nurse) Facing their EMPDs as novice health professionals, keen to be socialised into their new professional and social role, the theme of *Inclusion & Acknowledgement* seemed important to many participants. Nurses appeared to cope most easily with EMPDs when they felt that they had been part of a team, or other colleagues acknowledged their emotional responses, effectively normalising them. Rose recalled that she felt like a valued member of the nursing team, and was included in pre- and post-mortem care of the dying patient, and the sort of informal collegial debriefing previously described.

Because the team support was there, and everyone was feeling it and they were quite open about it. . . I think the team helped and. . . afterwards we all sort of came to a halt, and went into the tea room and sat around a table. No-one necessarily had to speak or anything. We just, we sort of sat together and - if someone wanted to say something, they could have. If they wanted to say 'oh it's really sad' or they wanted to swear, that was all alright. But it was just the fact, you know, all experiencing something together, individually, if you like. (Rose, Competent nurse)

Conversely, some nurses struggled with *Exclusion & Lack of Acknowledgement*. Some felt unsure of their role as students or inexperienced nurses, whilst others felt their more experienced colleagues failed to acknowledge the emotional impact early experiences with death can have. Patricia was involved in the care of a patient who died suddenly, and felt pressured to carry on with her work afterwards, but would have appreciated an opportunity to talk about her feelings:

So it was hard, because no-one actually asked after that 'are you alright' or 'how do you feel?' Because they all knew it was my first death, but I didn't hear much about it. (Patricia, New Graduate nurse)

# Natasha was aware that her preceptor was caring for a dying patient, but was excluded from any involvement with her care until after the patient had died:

I knew that there was a patient in a private room down the end of the corridor that this nurse, my preceptor, had been caring for as well as having a, sort of, six-bedded room of patients to care for as well. And so I'd been involved with the patients in the six-bedded room, but my preceptor would sort of - disappear off from time to time to go and care for this mysterious patient down the end of the corridor in the private room. And so I knew that the patient was quite sick, because she had told me that she didn't think it was appropriate for me to come and care for this patient. And this went on for sort of - a couple of weeks. And in about the third week, my preceptor came to me and said 'oh, can you come and help me lay this patient out, she's died'. [laughs] (Natasha, Senior nurse)

Natasha was subsequently asked to assist with post-mortem care but she felt she was just an extra pair of hands, and little consideration was given to how she might respond to this, her first encounter with a dead body. Natasha reported that this was the most challenging or difficult aspect of her EMPD experience:

I think the sort of the hierarchical nature of the hospital system, as well - as a student nurse you don't feel, or I didn't feel involved or - kind of respected in that situation. I think that was probably the hardest thing, not feeling included or involved. I mean, I guess maybe my preceptor was trying to aid my learning by calling me in and helping with this patient. But I think I was just an extra hand. . . . Just not feeling respected in the situation. (Natasha, Senior nurse)

# Monique found that her EMPD was not acknowledged as significant by colleagues who frequently encountered such situations:

Because it's so normal up there for it to happen - they don't think anything of it. But it was my first time and I was actually quite upset about it, and I drove all the way home trying not to cry. . . . I did mention to the charge nurse that new people on to the ward need to have a support afterwards - just someone to talk to. Not so much counselling, but – like a debrief. Just to – um - I don't know. Say that everything was normal and learn from your experience. As I say, the nurses up there didn't think anything of it because it's happened so many times. So me being a newbie – I knew nothing. (Monique, New Graduate)

#### Learning

Participants frequently identified learning opportunities provided by their EMPD. *Finding* their *Professional Role* seemed important, when faced with the unique demands presented by patient death, grief and loss. Participants often regarded their EMPD as a necessary experience, a hurdle or a even a rite of passage as a nurse. Debbie was grateful for a "nice" EMPD experience:

It made me feel, not scared of it anymore. Not worried. Because, as a student nurse and as a nurse I was always worried about that first death. Worried how I was going to react and whether I'd know what to do and things. But when it came time, I was very calm. I just went and got - and did what I needed to do without actually freaking out at all. So it gave me - I guess I feel a lot better about my practice around people that are dying. And not scared - or it's very natural for people to die. So, nursing someone who is dead is not a problem to me anymore. Not scary. It was actually extremely rewarding to sort of - conclude that. To know that he had been in a lot of pain, a lot of suffering. To make - I felt really - I don't know. Really happy that I was the person who could do that for him, could help him finish that. It was a really nice experience. Even though it was very strange, I was really glad to have had it. Especially that first one. . . . Feeling - just really- it felt really rewarding. Really good that I can now do - that's another thing, another piece of experience, you know. (Debbie, New Graduate nurse)

# For Wendy, her EMPD seemed to represent a defining moment in the development of her professional identity:

I think, it must because it made an impact on me, really. Because it was the first time I'd sort of, you think 'this is my profession' and you go in there and you know it's not obviously a relative or anything. But it just, sort of, stirred emotion that I probably don't feel so much now. It's not because I've lost any sense of caring. It's just because you know what to expect and maybe because I'm not so young any more. It's just become something that - I don't know. I just remember, probably, because I was young, maybe. It upset me momentarily. (Wendy, Senior nurse)

Nurses who were assigned to a preceptor when encountering death for the first time clearly benefited from *Working Alongside* a more experienced nurse. As simple as this may sound, not all of the nurses interviewed had this fundamental support. Nurses who were very new students often had particularly positive EMPDs, as they felt that the responsibility for nursing care lay primarily with their preceptor at the time. Those who had EMPDs after graduating typically did not have the benefit of formal supervision. Ella's preceptor helped her to feel prepared and supported, by talking her through the likely trajectory of the patient's death and outlining her nursing role and responsibilities:

And I had a really great preceptor who said 'this is what happens, and this is what to expect next - and when it [the patient's death] actually does happen, this is what we'll do' - and actually talked me through the process and what was going to happen. (Ella, Proficient nurse)

Some nurses provided glowing accounts of the practical and emotional support provided by their preceptors. Janelle described her preceptor as the key to her positive EMPD experience. As Janelle was a very new and inexperienced student nurse at the time, she followed around 'on the heels' of her preceptor, benefitting from his sensitive approach as well as his modelling of nursing care:

I was put with a fantastic nurse. . . everything that he did that day was just fantastic. . . . Once she did die, he explained everything - what we had to carry along and do, you know like giving her a wash and laying her out properly and calling the family. . . He made sure – first and foremost – that I was fine with what was going, he was aware that he had a student nurse with him and it could have been something that was a real shock for me. (Janelle, New Graduate nurse)

Just as feeling helpless and out-of-control characterised negative experiences, nurses seemed to benefit from feeling in-control, particularly where a preceptor allowed them to 'choose' their level of involvement in care of the dying or deceased patient, as was Karen's experience:

But the whole experience, I felt quite supported by my preceptor and she said that I could be involved if I wanted to be, or I didn't have to be if I didn't want to. (Karen, New Graduate nurse)

#### Feeling Unprepared

The majority of participants (n = 16) felt they had been inadequately prepared for their EMPD, and all participants offered suggestions to improve preparation for novice nurses encountering EMPD. Most participants had thought about encountering death, and considered it an inevitable part of their nursing training, and some felt adequately prepared to cope with the emotional demands presented by their EMPD. A more prevalent theme, however, was an overarching frustration with basic knowledge about death and dying, *Inadequate Skills*, and a lack of

confidence in their professional role. When Debbie came on to a morning shift and discovered a patient who had died overnight, she found the patient's altered appearance 'weird' and 'creepy'. Debbie expressed low death anxiety and denied finding the experience upsetting, but did experience considerable doubt about her professional role in the situation and felt it was inappropriate even to touch the patient, although she was a Registered Nurse, responsible for care of the patient at the time:

Yeah, I never expected - because when I saw him, his face was on the side and he had dribbled huge amounts of saliva. And I never expected that. And I'll never forget that – you know - the blue colour – because his lips and tongue were hanging out, and I never expected it to look like that. . . . Touching him was weird because I felt -I don't know - When I was alone with him, I felt very strange – almost like, you know, like it's 'tapu' – I didn't feel like it's allowed, to touch him. Especially when someone wasn't with me. More for the fact, I felt - I wasn't allowed to, and shouldn't be. But when I was told I was meant to and it was my job, then I felt alright. (Debbie, New Graduate nurse)

Tony regretted failing to recognise the signs of imminent death as his terminally-ill patient deteriorated. An experienced nurse handing care of the patient over to Tony appeared to make the assumption that Tony would adapt his care to meet the needs of the dying patient and their family members, but Tony had no experience in assessing or meeting these unique end-of-life needs. Even as the patient lay unconscious, and with an abnormally low body temperature and blood pressure, Tony continued to provide the only nursing care he knew how to provide – including attempting to give the patient oral medications:

The change in the way she was in the last couple of hours. The way she went from being quite alert and - you know - awake, to being so - getting quite agitated and not being able to talk. And yeah, just not verbalising properly. That huge change and the way she'd gone suddenly – or what seemed to me so suddenly downhill. That was [appears distressed, speaking softly] what was quite scary. . . . Because I'd never seen anything like that before. So, it was really bad. And that was a kind of a big wake up call to tell me – yeah she's about to die. It was pretty scary.

Interviewer: So what do you think could be done to better prepare nurses and help them to cope with this kind of situation, with patient death?

I think perhaps some sort of teaching about the whole process of when someone is dying like that would be helpful. So that they perhaps know what to expect. I think that might be appropriate for people. Some people might already understand all that stuff, but I definitely didn't and I'm sure I'm not alone. So I think that would be quite useful, so that they're prepared better. To know what to expect when they walk into a room and see a person who's dying, so they know what they're seeing at each stage. I think that'd be quite useful. (Tony, New Graduate nurse)

For some nurses it was not just the fact that a patient had died which seemed to have caused distress, but the *Unexpected Elements* surrounding that death. Natasha was shocked by changes occurring in the human body after death:

And that was obviously the first time I'd ever seen a dead person. So, yeah - it was interesting to, sort of, have the experience of laying the patient out. But obviously, as a student nurse you have all these, sort of, things going through your head at the time. And I wasn't quite prepared for, sort of, a few things that happened. Like, when we rolled her over all the [laughs] gas came out of her body. Which is a bit shocking for a young student nurse! (Natasha, Senior nurse)

Natasha felt that teaching about death and dying was more emotion-focussed, and more practical knowledge about physical changes after death, how to perform post-mortem care, and 'what to do when someone dies' would have been helpful:

*I think it's quite focussed on the emotional side, but for me it was just the shock of the physical.* 

#### Interviewer: And what do you think might have helped you to prepare better for that?

Just... being told about it. This is what happens, this is what they look like... you know, [laughing] they might have flatulence when you turn them over. This is - even just how to lay a patient out. I mean, I had no idea that that's what you do with a patient when a patient dies. And what happens to the body afterwards. (Natasha, Senior nurse)

Claire had previously associated death and dying with the elderly and chronically ill, and felt utterly unprepared for her EMPD, which involved the sudden death of a younger person:

There's nothing, nothing at all prepares you for that. Nothing in life, nothing in training, university, nothing. You cover patient death at university and you know that it's coming, you know that it's going to be part of your job. And you know that it's going to be older people, having a stroke, having a - MI - and they're going to slip away, they're going to go. Not a thirty-three year-old. It's not discussed at university. It's not discussed. You're sort-of taught aging population, CVAs, MIs, you know, triple-A's - .people just die it's a natural part of life. Nothing prepares you for that. (Claire, Proficient nurse)

# Yasmin felt inadequately prepared for many aspects of her EMPD including walking in on her dying patient and participating in a resuscitation attempt which failed to revive her patient:

I think - probably the most memorable - I think, actually, walking in on someone that was dying - was quite a - was a bit of a fright. And then I think - trying to get the guy to come back to life - was, you know, was, really quite hard, I think. Just, you know, I think - everything that you can possibly think of and they teach you and that you know, in trying to resuscitate someone, and you think it would work. But it doesn't. So I think that was quite - quite a bit of a shock.... I think just the fact that you walk in on somebody that's kind of like - dying. And you try everything you can and you can't get them to come back to life.... I think I was dumbfounded by the situation. And knowing that we'd done everything that we could kind of - that we were supposed to do. And the guy still didn't live. And I think - because it was quite chaotic, I think, as well, it made it something that kept going through my mind the whole time. (Yasmin, Proficient nurse)

The extent to which death was openly discussed varied enormously. Where there was free discussion of death and dying, this was often a feature of the family and personal background of the participant. All too often, nurses' education was characterised by *Unspoken Death*. Ella's early nursing training left her with the strong impression that death was 'taboo' and something which could not be discussed. When asked what she thought could be done better to prepare nurses for their first deaths, Ella recalled the unfortunate approach a nursing lecturer had had to death education:

*Ummm. What... what our lecturer said in our first year in our human development paper was 'I did used to show a video of someone dying, that was in one of those documentary things, but I* 

found too many students got upset, so I don't show it anymore.' So even that. Getting upset and being able to talk about it. That would have made a difference. Saying it is ok to talk about it and it is ok to get upset. That probably would have helped. Because I remember thinking back when this woman died, if I had seen someone actually die. Even if it was a video or something. It still would have made me feel a little bit more prepared, or it would have allayed some of the fears I had about someone actually passing away. Hmmmn. (Ella, Proficient nurse)

Ella completed her New Zealand-based nursing training only a few years ago, making the lecturer's obvious discomfort with, and avoidance of death and dying education, a particularly disturbing finding. Her perception as a novice nurse - that it was unacceptable to discuss death and dying - was a recurring theme in her interview:

It's sort of been a covert thing. Even with the whole growth and development paper. Even skipping that bit at the end because too many people got upset by the video. It set a precedent that it's not that ok to talk about it. You skip that bit because that bit doesn't really matter and it's a bit morbid to talk about those sort of things. And it's tricky because you don't want to upset the boat as a student and say 'hey I'm really upset and not coping' because you just want to do your best and say 'yeah I'm a really keen student and I want to learn'. But at the same time you think, I just have to suck this up. Everyone else seems to be coping. (Ella, Proficient nurse)

Participants who voiced feelings of *Helplessness* and chaos at the time of the event often also described ongoing symptoms of distress associated with exposure to a traumatic event. This provides a contrast to the apparent protective function of focussing on nursing tasks and the satisfaction gained from confidence in the nursing role, which feature in later themes. Throughout his interview, Tony described feeling inadequately prepared to anticipate or meet the needs of his dying patient and their family members:

I was feeling quite... superfluous and, like - useless. And I just, wanted to get out of there really because I hung around much longer I was probably going to lose my composure and I didn't want to do that, especially in front of the woman's family. So I left and a little while later the consultant had charted a graesby, for her, with some antiemetics and stuff - so - kind of keep her settled during her final hours, and I was getting quite upset because I didn't want to go into the room because I didn't want to start crying [nervous laugh] in front of the family. But I didn't know how to put a graesby together, I'd never done that before [nervous laugh]. So I felt really useless, because I couldn't help the family and I couldn't do this either. . . . (Tony, New Graduate nurse)

When Tony was asked how he felt at the time and immediately after his EMPD, he described feeling helpless, frustrated with his lack of skills and knowledge, and unable to do anything because of his underlying fear of losing his composure:

Yeah, I felt, I felt really - sort of helpless. That there wasn't anything I could do. . . . I didn't know how to put together a graesby, I'd never done that before, and I felt if I was there then I was going to lose my composure, and I didn't want to do that. So, I really feel as if - I really felt quite helpless, and unable to do anything, unable to help because of that. . . . I felt unable to give this patient and their family the kind of care and attention that they probably needed at the time. (Tony, New Graduate nurse)

#### **Responding to Death**

Although participants had typically anticipated that they would encounter death and dying in their nursing role, many came away from their EMPD with an *Increased Awareness of Mortality*. Nurses' EMPDs sometimes prompted thoughts or anxieties around their own mortality, or the mortality of their loved ones. Immediately following her experience, one nurse scheduled a medical check-up for a parent, another wrote a will and a third nurse reported discussing advanced directives with family members. Wendy gained a new appreciation for the good health of her family members:

I think, just that it, sort of, reminded me of someone that was close to me, so it made me feel a little bit upset that this was - could have been - my relative, or - It makes you quite aware of death. Of your own, maybe, family. Yeah. So I remember feeling like that. (Wendy, Senior nurse)

Patricia found herself thinking about her parents' mortality, after the sudden unexpected death of her patient:

I was shocked. Again, I think it was mostly because he was so close to my Mum's age, and so close to my Dad's age. And it really gets you thinking about a lot of things. Things you normally don't want to think about, though you know exist. (Patricia, New Graduate nurse)

Nurses sometimes shifted uneasily between descriptions of task-orientated nursing care and more emotionally-laden aspects of their EMPD. *Focussing on Tasks* – the technical aspects of their nursing care seemed to have a protective function both at the time of the event, and during the interview. Olivia appeared comfortable detailing the careful post-mortem care she provided her patient, but admitted that focussing on these nursing cares helped to distract her from unwelcome doubts or anxious thoughts:

And I was there for a good hour. And I was wondering 'where on earth is this enrolled nurse that was meant to be helping me?' And I thought I've got to keep those thoughts at the back on my head. And I just sort of went into automatic overdrive and I knew - fold up her gear, have it ready in the bag. place the seat - there were two seats there - close to her. (Olivia, Senior nurse)

# Wendy found the appearance of the patient's body upsetting, but getting on with the tasks involved in post-mortem care "wasn't really an issue":

I remember going in there, it was an elderly lady, and the first time I saw her it reminded me straight away of like, my grandmother. And that was kind of - sort of freaked me out and made me feel quite upset. But it didn't really stop me doing the job. But I remember, when I'd finished, feeling quite sad. Like we had to remove her jewellery, and... So the process of doing it wasn't really an issue, you know like wrapping the body up and washing it. It was more about what it looked like, I think. (Wendy, Senior nurse)

# Many nurses who were involved in post-mortem care were struck by the careful, prescribed way this was conducted. Brenda felt that she was learning a ritual:

And the thing that stuck with me, as well, the whole - it was almost like a ritual. Almost a bit like a dance going on, with how you washed him, and how you laid him out - very specifically, how you wrapped the body and that sort of thing. And it did seem like a real - yeah, a ritual.

There were certain ways of doing things, which stuck with me and [giggling] I still remember now, how you were supposed to do it, how this nurse taught me to do it. (Brenda, Senior nurse)

Participants were often keen to acknowledge that every death was unique, and that different nurses employed distinctive strategies for coping with difficult situations. Many stated that it was difficult to prepare nurses for their early encounters with death because of the unpredictable nature of that encounter. Whatever preparation and support was provided, it seemed important that no 'blanket rules' were applied, and efforts were made at *Acknowledging Idiosyncrasies*. When asked how best to prepare and support nurses through their EMPDs, Rose highlighted the importance of helping nurses to recognise their own, individual coping styles:

Don't try and put a set strategy in place, I think. Try and help them find a way to cope with it. Or point out to them say, if you know that they went for a run yesterday, point out to them. . . do you think that was something that maybe helped you cope with it better. So they're maybe more aware of how they cope with it themselves. . . I think it's a very individual thing, how people cope with death. It's difficult. (Rose, Competent nurse)

# For Rose, enforced participation in debriefing following her EMPD was an unwanted and unhelpful intervention:

I think the whole debriefing thing is a waste of space. Like they do here, or after a code or anything like that. You have to come in and you have to sit down and you have to go [voice trailing off] I remember that. That was a lot worse. Because I really just didn't want to be there. And that made me all tense and I just wanted to - carry on and work through it myself. (Rose, Competent nurse)

The extent to which nurses could be 'prepared' for their first encounters with death was questioned by several participants, who emphasised the unpredictable nature of both encounters with death and dying, and responses to those encounters:

*Every single death is different. Well, that's what I feel. And you can't really be told how you'll react. And you might react one way to one patient's death, but then the next patient's death you experience is completely different and you react a different way. (Karen, New Graduate nurse)* 

I don't think you can ever, really be prepared, per se, until it happens. You don't know how you're going to react until it happens . . I think it's maybe a difficult subject, because everybody's got their own feelings on it, different experiences, their different points of view. (Janelle, New Graduate nurse)

#### Finding Benefits

Although participants' EMPD typically presented numerous challenges, several nurses were also keen to point out that they had benefited from the experience. Several of the *Positive Aspects of EMPD* described by participants have been covered in previous themes, including the conquering of a 'first death hurdle', reduced death anxiety and increased self-efficacy, an opportunity for learning, mentorship and role-modelling, feeling included in a team and being well supported. It is important to acknowledge that, where participants did not offer any spontaneous examples, the interviewer made a direct enquiry as to whether there were any positive, rewarding or satisfying aspects of their EMPD. Several participants did not describe any positive aspects, even when specifically questioned, however some participants appeared to spend some time 'searching' for positive or rewarding aspects when questioned to this effect, apparently feeling obliged to find an example. When asked if she could recall any positive or rewarding aspects of her EMPD, Monique's answer was less than emphatic.

I don't - no [pause] Well, I mean, you've always got to learn to handle these situations. Not harden yourself to them, but handle them. And being with the nurse I was with really opened my eyes up to what could be done, for the family. So, yeah. That was rewarding. Hmmn. (Monique, New Graduate nurse)

#### Yasmin took a full thirty seconds before providing her answer to the same question:

*Umm* [very long pause, seems to be trying to find an example]

*I think probably the most - I don't know - it's quite difficult to think about something that would be positive. But I think probably just having the experience. (Yasmin, Proficient nurse)* 

Given this approach to responding to probes relating to benefit-finding, emphasis has been placed on positive aspects which were spontaneously or emphatically articulated by participants. Inherently rewarding aspects of EMPD centred around facilitating peaceful death, giving good care to patients and family members, and showing respect for the deceased. Some nurses also described a sense of personal pride, satisfaction, or pleasure when others expressed approval or gratitude. These positive, rewarding and satisfying aspects of EMPDs echo those which emerged in Study One. Ella benefited from involvement with carefully planned, family and patient-centred palliative care:

And when she actually did die, all her family came in and gave me a big hug and said 'thank you so much. . . we thought it was going to be just horrible and you just made it so much easier because we had a really great night the night before'. . . . In your training there's not a lot of stuff like that. And providing hope for families, as well. Not hope that they're going to get better, and a miracle's going to occur. Just hope that the way they are going to pass away is going to be pleasant for everybody. Because it's going to be something that they remember for the rest of their lives, too. (Ella, Proficient nurse)

Olivia remembered felt satisfied and 'therapeutic' when she had completed her patient's postmortem care, and recalled receiving praise from a nursing colleague and her patient's family member:

The enrolled nurse came and she said 'oh she looks wonderful, you've done a really good job'. And so I said 'can we call the family down now?' Because what I really wanted was them to see her... And they came down and, naturally, they cried because they were close to her, and - but I can remember, and it must have been her son, and he said 'she's at peace now, she looks really good, I like her looking like this, now'. As if to say, well, she's no longer in pain... For myself, I felt really satisfied. I felt therapeutic. (Olivia, Senior Nurse)

An extremely rewarding aspect of this study was the spontaneous, heart-felt reporting of *Positive Aspects of Study Participation* from many participants. Recruiting participants who are willing to volunteer their time for research projects is often challenging, particularly where there is no incentive or compensation for time offered. All nurses involved in this research project were undertaking postgraduate study in addition to employment (typically full-time shift-work).

It is therefore a significant finding in itself that nearly 50 nurses volunteered to participate in the interview study. As well as being generous with their time, participants were also very generous with their accounts, providing richly detailed recall and insightful reflection on their EMPD experiences. Several participants who were in their first year of nursing appeared self-conscious or initially unsure, sometimes describing very 'fresh' experiences which had occurred only weeks or months prior. Even for those who had first encountered patient death some decades ago, some appeared to vividly re-live the experience as they described it, and strong emotional responses were often evident. Despite these apparent challenges, all interviews were completed in full, no-one withdrew from the study, and a majority of participants described their participation in the interview study as a positive, beneficial, or even therapeutic experience. Patricia was pleased to have an opportunity to discuss her experience with another health professional, in a non-clinical environment where she did not have to think about nursing demands:

Talking about it - [I feel] a lot better. Because I've had this opened up and - talking to anyone who isn't a medical or health professional - it's hard for them to understand that a stranger can actually affect you. Even though that person was unconscious, from the time you met him. And it's a very hard thing to want to say that he did affect me, because you can't explain how. That's what my boyfriend asked me. 'How'd it affect you? He was unconscious.' It's like - well, there's something there, you weren't there to see it. I think talking to you, now - someone who's also a nurse, especially in ICU - it does help. I don't have patient obs to worry about here, I don't have patients waiting for me, I don't have antibiotics due. (Patricia, New Graduate nurse)

# Natasha felt she had benefited from reflection on her EMPD and the opportunity to talk about such experiences had therapeutic potential:

So it's actually been really positive to do your questionnaire and then go away and think about it and then be interviewed - just going back to your previous question about what sort of support services, or what could be improved around the hospital for dealing with patient death - maybe a session like this interview situation. Amongst health professionals, or something. I think it's really good. To think about it - the processes you went through. (Natasha, Senior nurse)

# Mark expressed his gratitude for the opportunity to talk about his challenging EMPD and described a physical sense of relief at the end of his interview.

I feel a bit less emotion in there [gestures pressing down on stomach]. Like there was a pressure, like - pressing me. Whenever I feel – like - think about it, I feel choked. I feel nervous still - sweating in my hands. It's better when I only think about it, but now I spoke it out so I feel less pressure in there. Probably to keep doing this – a regular, like, debriefing sort of session – would be very beneficial I think. Just now I did this, that helped me I think. That's what I wanted. Yeah. . . .One of the reasons why I volunteered for this is, probably there are student nurses who don't have any experience of death. And I know it's very hard, I know it affected abilities and their experience in being a nurse. So I hope you make a good report. By reading that they might have a chance to, sort of - think about the experience, be prepared and have a better, sort of, experience when they have this. Hopefully it can just help others as well. (Mark, New Graduate nurse)

#### **Summary**

This idiographic, semi-structured interview study explored the earliest memorable experiences with patient death (EMPDs) of 20 currently practicing New Zealand Registered Nurses. Interpretative Phenomenological Analysis (IPA) revealed seven key themes: Event Significance; Emotional Challenges; Sharing the Experience; Learning; Feeling Unprepared; Responses to Death and Finding Benefits. The possible meanings and implications of these themes are explored with reference to existing literature, integrated with Study One findings, and critiqued, in the following discussion chapter.

### **DISCUSSION**

This research project utilised two studies to explore the clinical circumstances and nature of nurses' earliest memorable patient death (EMPD) experiences. This chapter provides an integrated discussion of the meaning and implications of findings from both Studies One and Two. Rather than seeking to prove or disprove any hypotheses, the key research aims were to discover:

- at what point in their professional development, and under what clinical circumstances, nurses' EMPDs occurred;
- whether nurses' EMPDs had an impact on them personally or professionally;
- whether nurses felt that their undergraduate training prepared them adequately for early nursing encounters with death and dying;
- what cognitive, emotional and clinical challenges nurses faced during their EMPDs and how they coped with these challenges; and
- whether nurses recalled positive, rewarding or satisfying aspects to their EMPDs and what factors were associated with these aspects.

The EMPD experiences reported by participants in this research were very diverse. Just as there is no typical patient death or family grief experience, there appears to be no typical EMPD or nurse response. Each EMPD was unique, and summary statements are made to facilitate discussion, without discounting the idiosyncratic nature of each experience.

This chapter begins with a discussion of key findings regarding the clinical circumstances and impact of EMPDs. Findings related to the nature of EMPDs are then considered. Early attempts to structure a comprehensive discussion of the nature of EMPDs in a linear fashion proved to be very challenging, as it was difficult to adequately address the interconnectedness of factors which emerged in the integrated data. This section of the discussion is prefaced with a diagram (Figure 12) to provide a more visual overview of factors. The key research findings are explored and related to previous literature, theory and practice, and the potential implications are examined. Consideration of the strengths and limitations of this research is followed by conclusions and recommendations.

#### **Clinical Circumstances**

Eighty-five percent of EMPDs occurred during participants' nursing training or whilst they were New Graduates. Accordingly, more than half of participants were under 21 years at the time of their EMPD. Participants were most commonly involved in the provision of comfort cares or post-mortem care and most frequently reported EMPDs involving older patients whose deaths were expected or somewhat expected. It is noteworthy that a significant number of EMPDs involved neonatal and paediatric deaths, and/or sudden unexpected or traumatic deaths. Previous research has suggested that nurses can find unexpected patient deaths or those involving children to be the most acutely stressful (O'Connor & Jeavons, 2003). It is also an important finding that such a high proportion of EMPDs occurred in acute care settings. Many New Zealanders die in their own homes or in rest homes and geriatric hospitals, but results suggest that novice nurses may get little exposure to patient death prior to commencing their nursing education, instead experiencing EMPDs in medical, surgical or specialised acute care wards in public hospitals. Novice nurses spend a lot of time in these clinical environments, so it isn't surprising that this is where they are often encountering death, but although there is vigorous discussion of the inherent challenges of caring for the dying in high-tech cure-focussed environments (e.g. Seymour, 2000; Walker, 2008), implications of this early exposure to death in the acute setting do not seem to have received attention in the literature. The likelihood of first encountering death in the acute setting, and the inclusion of sudden and paediatric deaths amongst EMPDs have implications for preparation and support, discussed in later sections of this chapter.

### **Impact: Contrasting Factors**

"I've always felt like I didn't look after that man very well. And I guess where I - it's coloured my practice, because where I chose to work - it's where, hopefully people aren't dying." (Sarah, Competent nurse)

"And I remember looking after her and I remember how I would feel looking after her. . . and she definitely is where my interest in palliative care would have come from, because she was the first patient I can really remember." (Anna, Senior nurse) The enthusiastic responses, detailed accounts, high Patient Death Impact Scale scores, and vivid recall of information, evident in both questionnaire and interview data, suggest that EMPDs were salient events for most participants. It is acknowledged that, by asking participants to report on the earliest memorable occasion when a patient died, participants may have been influenced to select a noteworthy early patient death, rather than reporting on the earliest one that they could remember. It should be noted, however, that 17 of the 20 interview participants reported that their EMPD was also their first ever patient death. A number of comments included in the questionnaire data also indicated that participants were frequently reporting on their very first encounters with patient death, and often this was their first encounter with death and dying of any person. In a study where medical students were asked to report on their 'most memorable patient death', over two-thirds of participants described their very first patient death (Rhodes-Kropf et al., 2005). Other published research and numerous poignantly written exemplars (e.g. Barker, 1991; Devcich, 2000) also suggest that the first encounter with patient death is particularly salient for many nurses.

Around three-quarters of questionnaire participants somewhat or strongly agreed that their EMPD memories were very vivid and that they spent a lot of time thinking about their EMPDs in the days and weeks after they occurred. Although results from this research indicate that EMPDs had a significant impact on participants, the event was not necessarily upsetting, often including a mixture of negative and positive elements. High Patient Death Impact Scale (PDIS) scores gave a measure of impact, but not the underlying contributors to the salience of the event. A high PDIS score could indicate a particularly challenging, distressing, unique or rewarding event. Accordingly, scores from the PDIS scale and the finding of a weak correlation between PDIS and Patient Death Preparation Scale (PDPS) scores should be interpreted with caution. Contrasting elements were also evident in the interview data, which revealed EMPDs were sometimes associated with ongoing distress, exclusion, helplessness or guilt but could also be characterised by reward, inclusion, support and learning. It was evident that challenges presented by EMPDs were not inherently 'good' or 'bad' but there did appear to be some factors which were associated with adaptive coping and positive outcomes, whilst others were associated with distress and a more negative lasting impact. A summary of these factors is presented in Figure 12.

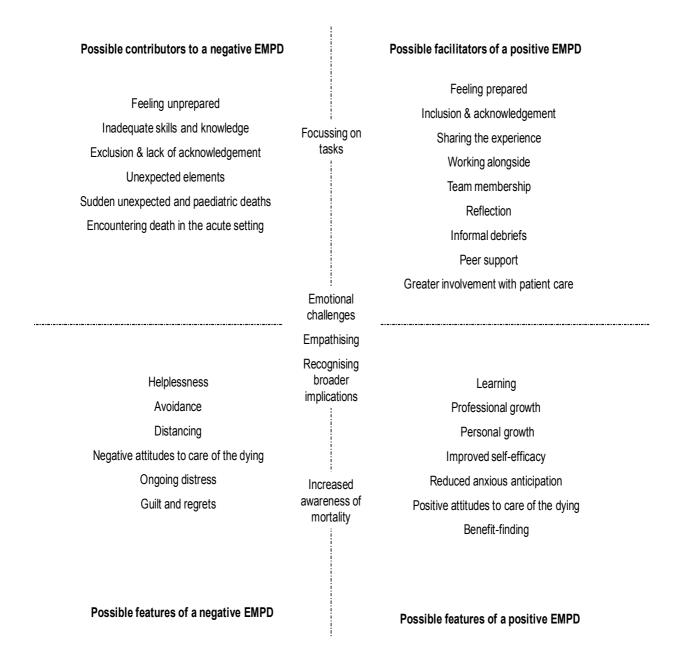


Figure 12: Influential Factors in Participants' EMPDs

#### **Inadequate Preparation and Unexpected Elements**

"I really felt quite helpless. . . . I felt unable to give this patient and their family the kind of care and attention that they probably needed at the time." (Tony, New Graduate nurse)

Previous research indicated that nurses' early encounters with patient death can be highly anticipated, stressful or dreaded events (Cooper & Barnett, 2005; Delaney, 2003). Although no specific effort was made to assess death anxiety, fear of death itself did not emerge as a theme in interview participants' early death experiences. Most interview participants predicted some contact with death and dying as an inevitable part of their job, and although they sometimes responded with shock at the physical aspects of death, or reported an increased awareness of their own mortality, there was little evidence that a fear of death was an important factor in EMPDs. Anxious anticipation of EMPDs seemed to be focussed around the desire to meet perceived professional expectations – particularly to remain competent and composed. What appeared to be most distressing to nurses was: the unexpected elements of death; feeling helpless during or after the experience; and feeling inadequately prepared. Information gained from the interviews indicated that participants often felt unsure of their role as nurses and had few practical skills and little knowledge about death and dying. These results resonate with the findings of decades of nurse researchers and educators suggesting that novice nurses are most anxious about the performance of their caring role as nurses, rather than being fearful of death itself (Beck, 1997; Cooper & Barnett, 2005).

Evidence that so few participants felt their undergraduate training had prepared them well for encounters with death and dying is dishearteningly congruent with many years of international research findings (Birzholz et al., 2004; Hopkinson et al., 2005). Patient Death Preparation Scale (PDPS) scores were variable, but a large cluster of nurses indicated that they strongly disagreed that their undergraduate education had prepared them well for any of the listed death and dying related items. By comparison, very few participants indicated that they felt very well prepared on the PDPS items. Specific areas where participants expressed frustration with a lack of nursing knowledge and skills included: awareness of bodily changes after death; recognising signs of imminent death; the role of the nurse when a patient is dying; the role of the nurse when a patient is found deceased; the role of the nurse after a patient has died; resuscitation survival rates; causes of sudden death; awareness of neonatal death and miscarriage; and the limitations of responsibility for student nurses when caring for the dying patient and family. It would appear that most of these practical knowledge and skill deficits could easily be addressed in a classroom setting.

#### **Experiential Learning**

"I don't think you can ever really be prepared, per se, until it happens. You don't know how you're going to react until it happens" (Janelle, New Graduate nurse)

Although many participants were quick to criticise the short-fallings of their education in this area, there was also scepticism regarding the extent to which nurses can be prepared for some aspects of patient death. Questionnaire participants reported feeling particularly poorly prepared for 'what death would be like' but several interview participants pointed out that every death was different, and it was difficult to anticipate what any one nurse might face and how they might respond. Many interview participants indicated that classroom learning had limited relevance to this area, and experiential learning was essential. Undergraduate death education learning objectives appear focussed on increasing knowledge about symptom management, ethical issues and interpersonal communication. Integrated death education delivered in brief, chiefly didactic modules may be convenient for educators, but does not provide students with the interaction, application and reflection which has been recommended by so many death education researchers (Allchin, 2006; Barrere et al., 2008; Mallory & Allen, 2006; Wass, 2004). Previously conducted studies indicate that more positive attitudes towards care of the dying can be fostered, where death education allows students sufficient time, opportunity and support to identify and reflect on their personal beliefs, fears and responses to death (Degner & Gow, 1988; Mooney, 2005). Previously conducted end-of-life educational courses which encourage participants to reflect on their thoughts and feelings have been well received. Innovative opportunities for reflection include the use of journaling and internet discussion boards (Thompson, 2005). Reflecting on the narratives of others involved in care of the dying also allows student health professionals to gain insights into the challenges involved (Wittenberg-Lyles, Greene, & Sanchez-Reilly, 2007).

Timing of components of nursing education can be difficult to get right, but results from this and other studies suggest death education isn't well integrated with clinical experience (Downe-Wamboldt & Tamlyn, 1997). Over a third of questionnaire participants reported EMPDs after qualification, indicating that their undergraduate death education came with no opportunity to apply their learning in the clinical environment, experience or reflect on patient death whilst in the role of the student. Conversely, one New Graduate stated that she could recall no didactic death education during her undergraduate training, and had already encountered several deaths in her current (high patient mortality) area of employment. She reported that she was aware of an upcoming 'study-day' which was going to cover death and dying related issues and that, for her, this formal teaching was somewhat overdue.

#### **Unexpected Elements**

"You cover patient death at university and you know that it's coming, you know that it's going to be part of your job. And you know that it's going to be older people, having a stroke, having an MI, and they're going to slip away, they're going to go. Not a thirty-three year-old." (Claire, Proficient nurse)

Data from the questionnaire revealed that 22.4% of participants' EMPDs involved the unexpected, sudden or traumatic death of a patient and 8.8% of EMPDS involved neonatal or paediatric deaths. With health education often focussing on the aging population and chronic illness, it appears that some participants had not anticipated encountering and dealing with sudden death from unexpected causes, paediatric and infant death, or death of young or previously-well patients. When reviewing research into undergraduate nursing education, the researcher noted that palliative care education, death education and end-of-life care education were regarded as synonymous by most authors. Although the content of death education is not well researched, it appears that there is an almost exclusive focus on terminal and chronic illness, provision of palliative care, and effective communication with dying patients and families (Dickinson et al., 2008; Downe-Wamboldt & Tamlyn, 1997). Although skills and knowledge around palliative care and communicating with the dying and their families are important for novice nurses, these teachings and ideals may not easily be applied to the reality of their early encounters with patient death. Only around one third of questionnaire participants were involved in giving symptom-relieving medications and less than half were involved in

comforting grieving families or breaking bad news. As over 80% of participants experienced their EMPD in acute care settings including medical and surgical wards, intensive care units and emergency departments, it cannot be assumed that these lessons transfer readily to deaths encountered in these cure-focussed environments. Nurses anticipating that the clinical circumstances of their early encounters with patient death will allow for the careful assessment and delivery of holistic, patient-centred care, may find it crushing if they cannot live up to such ideals. Awareness of the importance of patient autonomy, family presence, psychosocial care and symptom management at the end of life may cause feelings of conflict or inadequacy if, in an acute setting, a patient succumbs rapidly, dies alone, or is suffering distressing symptoms or receiving aggressive curative treatment at the time of death.

Uncontrollable events, dealing with the unexpected and feelings of helplessness have long been associated with the experience of stress (Taylor, 1995). Research suggests that hospital-based nurses feel a need to exert control over the trajectory of a patient's death, and that a well controlled death is a 'good' death (Costello, 2006). This underlying desire for control was also evident in the interview data gathered in this study, as participants reported frustration with failing to anticipate events, being caught off-guard by their own emotional responses as well as those of patients and family, and feeling unable to act due to a lack of skills and knowledge. Although control is not necessarily desirable or achievable, preparing nurses to cope with uncontrollable aspects of death and dying may, in itself, be a worthwhile goal. Many deaths in the acute setting are unanticipated, unpredictable or uncontrolled, but data from this research suggests novices failed to anticipate this.

These findings, and those of other researchers (Burney-Banfield, 1994; Williams, Wilson, & Olsen, 2005) support the use of problem-solving approaches to death education, which don't just seek to arm nurses with knowledge and clinical skills to provide end-of-life care to dying patients, but also encourage thinking about how death and dying might affect the patient, the family, and themselves in a variety of situations (e.g. Kenny, 2003; Mok, Lee, & Wong, 2002). Several nurses commented that it was difficult to truly prepare a novice nurse for his or her first encounter with death. There may, however, be some advantage in encouraging novices to expect the unexpected – in other words, to consider a broad range of clinical circumstances, and emotional, ethical, interpersonal and clinical challenges. Interventions which seek better to

prepare nurses for their early encounters with death should acknowledge that every EMPD is unique, and give novice nurses the chance to consider, in advance, the range of possible encounters which they may face and how patients and family members might be affected. These results also suggest that novice nurses may benefit from the opportunity to consider, in advance, how *they* might respond to encounters with a range of patient death and dying scenarios - what they might find upsetting, ethically challenging or rewarding, how others deal with death and dying, and what coping strategies they themselves could utilise.

#### **Empathising and Recognising the Broader Implications**

"... I'm going to go home, I'm going to go home to my father, but these people aren't" (Patricia, New Graduate nurse)

Even the most experienced nurses can find dealing with patient death and dying emotionally demanding, and interview participants described a number of emotional challenges associated with their EMPDs. As novice nurses are often younger, it is possible that the combination of a lack of life experience and professional experience contributes to making EMPDs particularly challenging. Some interviewees explicitly mentioned age as a factor which made them less able to anticipate the needs and responses of dying patients and their families, but the influence this immaturity may have had on their own coping responses was not discussed, and perhaps warrants further investigation.

The emotive nature of many EMPDs appeared to serve as powerful demonstrations of the patient as person. Participants often reported empathising with the patient or grieving family members, and could not help but see that the patient they were caring for was, for example someone's child, a parent, a brother or a partner. Novice nurses can be focussed on learning and performance of tasks, but the often emotive and final nature of EMPDs appeared to stimulate thought about the greater implications that death and dying can have on a patient and family. Realisation of the broader implications of a patient's death was quite overwhelming for some, and exposure to death and bereavement also appeared to trigger increased awareness of their own or family members' mortality. For some, the EMPD was a critical moment in their early

career when they realised that nursing was a 'bigger' role than just looking after an assigned patient. Nurses are introduced to patient care philosophies including cultural, spiritual and psychosocial awareness and family-centred care in contemporary undergraduate training, but a patient death can be the most demanding test of these models of care.

### Making a Connection vs. Risking Distress

"I mean it was the hardest emotion that I've had. So I don't know how not to care. . . . As a nurse it was hard, but as a, just as a person it always affects me" (Mark, New Graduate nurse)

Empathising with patients and families facing death and dying presented emotional challenges including sadness, death anxiety and frustration - emotions which have been associated with early death experiences in previous research (e.g. Beck, 1997). However, emotional engagement with those involved also appeared to facilitate the provision of meaningful and rewarding care. Making a difference was the most frequently reported positive aspect in the questionnaire study, and examples of this often featured special attention to, and understanding of, the needs of patients and family members. The emotional investment made by participants during their EMPDs also appeared to 'pay off' when they received thanks or praise from patients, families and colleagues. As pointed out by one palliative care expert: "Care can begin when one individual enters into the life world of another person and attempts to understand what it is like to be that person" (MacLeod, 2001, p. 1720). It is possible that EMPD experiences represent potentially polarising caring experiences for novice nurses, offering substantial potential reward, but also carrying the risk of distress, including grief, helplessness or increased death anxiety. Other researchers have noted distinctive nursing behaviours and coping responses associated with stressful death and dying encounters (Kent, 2004; Marjanovic et al., 2007; Terry & Carroll, 2008). It is therefore possible that particularly distressing or rewarding EMPDs could have the potential to influence whether nurses 'dare to care' in future encounters with death and dying, or in their nursing practice in general, and further research in this area is warranted.

Focussing on tasks appeared to serve a protective function for many participants. The performance of post-mortem care, for example, was almost exclusively reported in a positive light. Nursing often is a very hands-on job. Although nursing education is becoming more

knowledge and theory based, nurses who trained under the old 'hospital' system can be quick to criticise this contemporary 'thinking' approach to nursing, and so the nursing environment can quickly socialise New Graduates to become 'doers' (Chang & Daly, 2001). The ability to perform practical skills in a competent and timely fashion is highly prized in the busy ward environments where many New Graduate nurses are first employed, and this may have contributed to the finding that nurses often focussed on tasks during their EMPDs. Nursing care of the dying has long been characterised by measures of detachment and use of rituals. Reflecting on her nurse training in late 70s America, Couden (2002) recalled that expression of emotion was inappropriate, and she should always be cheerful and task-oriented: "I learned how to prepare a body for the morgue, to give the family time alone with the deceased, and to encourage them to express their feelings. I don't recall learning what to do with myself when patients died" (p. 37). Today, nurses continue to refer to patients by their diagnosis or bed in the ward, move dying patients to side-rooms and avoid contact with them by focussing on 'nursing tasks' and leaving family or assigning healthcare assistants to presencing<sup>3</sup> (J. M. Badger, 2005; Copp, 1999; Hopkinson et al., 2005).

### **Sharing the Experience**

#### Inclusion and Working Alongside vs. Exclusion and Lack of Acknowledgement

" I felt quite supported by my preceptor and she said that I could be involved if I wanted to be, or I didn't have to be if I didn't want to." (Karen, New Graduate nurse)

Results from this study suggest that participants benefited from the opportunity to share their EMPD in a number of ways: by working alongside others at the time of the event; by discussing it with them afterwards; and by reflecting on their EMPD as study participants. As is well recognised by nursing theorists including Benner (1984), novice nurses have insufficient experience of their own to draw on, and need rules and role models to guide their behaviour. Working with a more experienced nurse appeared to reduce anxieties associated with

<sup>&</sup>lt;sup>3</sup> Just being there, attending, staying close (Benner, 1984; Zerwekh, 1997)

professional performance and responsibility for care. Where interview participants faced EMPDs as very new student nurses, their role often seemed more clearly defined – it was one of observer, learner, and assistant. Participants reported benefiting from the reassurance, presence, guidance and practical and emotional support offered by more experienced staff.

"I think that was probably the hardest thing, not feeling included or involved" (Natasha, Senior nurse)

Ideally, novice nurses should always face new and demanding clinical situations with a suitably experienced, supportive and approachable nurse providing mentorship (Benner, 1984). In reality, the data from this study indicates that this is not always the case. It was an interesting finding that all three male interviewees appeared to take on a lot of personal responsibility for care of their patients, and received only limited or delayed assistance from senior colleagues. Each of these male nurses' EMPDs seemed to demonstrate failed acknowledgement or recognition of the need for support. Whether this was due to the attitudes and behaviours of participants, senior staff, or both, is more speculative.

### Peer debriefing

Even where novice nurses did not have the opportunity to work alongside another nurse during their EMPD, they appeared to benefit from inclusion and acknowledgement by peers afterwards. It is possible that opportunities to reflect following an event, and have behaviour, thoughts and emotions normalised, may facilitate personal and professional development, including role development. Research with medical interns conducted by Levine and colleagues (2006) identified supportive relationships and reflection as important facilitators of personal growth when faced with challenging early clinical experiences and concluded it was important for interns to have the time and access to someone who could discuss challenging events with them in a supportive and understanding way. The value of peer support has been widely recognised by nursing researchers, who have long advocated getting nurses together to share experiences and provide peer teaching and support (Beck, 1993; Clarke & Feltham, 1990). In the past, informal debriefing with fellow students was likely facilitated by the increased social contact and common communal living of hospital-trained student nurses. It is unclear how many

opportunities today's undergraduate student nurses have to meet with each other and share their experiences. In today's hospital nursing environment of staff shortages, high workloads, and younger, less experienced staff nurses, it is also possible that senior staff nurses have less of the time and confidence needed to talk with novice nurses about their early experiences with patient death.

"New people on to the ward need to have a support afterwards - just someone to talk to. Not so much counselling, but – like a debrief. Just to. . . say that everything was normal and learn from your experience" (Monique, New Graduate nurse)

It appears that relatively few educational or employment organisations actively facilitate peer support, although pilot studies have shown promising results (Halfer, 2007; Mangone, King, Croft, & Church, 2005). The nature of talk appears to be important – participants found it valuable to have their personal responses, thoughts and feelings acknowledged by an empathetic audience of peers. One participant reported that the process of recounting clinical details of her EMPD to curious colleagues only made her feel more upset. Results from a small Australian study by Lowery and Stokes (2005) suggested that student paramedics found social support most protective when discussion of traumatic events was reciprocal – in other words, students were able to 'share' their experiences, confide in each other and demonstrate a mutual understanding.

Although only a few participants mentioned formalised 'debriefs', these appeared to offer little benefit, and two nurses expressed resentment that they were forced to participate. Although there was some awareness that formalised counselling was available in their current work environment, interview participants were largely dismissive of utilising this to cope with any patient death encounter. The New Zealand Nurses' Organisation (2005) Incident Debriefing Position Statement describes formal debriefing as 'essential', and New Zealand nurses are sometimes required to attend compulsory formal debriefing, typically facilitated by external providers, following 'critical incidents' in the workplace. The use of formal debriefing is not, however, well supported by evidence. The latest Cochrane review (Rose, Bisson, Churchill, & Wessely, 2008) found no evidence supporting the use of single session debriefing following traumatic incidents and recommends that compulsory debriefing should not be used.

The need for talk is interwoven through many of the findings discussed here. It is acknowledged that the interview participants were, by nature, all people who wanted to talk about their EMPDs. Accordingly, the apparent need for talk, inclusion, acknowledgement and benefits of sharing the experience with others could have been particularly prominent in this group of self-selected 'talkers'. The questionnaire data revealed that, although almost half of participants were unsure where to get help if they were upset about their EMPDs, 83% of participants had discussed their EMPD with at least one, and often several, other people. Not all participants had previously had opportunities to share their experience and some reported that they had never, or rarely, discussed it.

### Death denial

It's sort of been a covert thing. . .it set a precedent that it's not that ok to talk about it. . . You skip that bit because that bit doesn't really matter and it's a bit morbid to talk about those sort of things" (Ella, Proficient nurse)

It is an unfortunate finding that many participants felt there was a continued 'taboo' surrounding the discussion of death and dying, particularly whist they were novices, which appeared to have contributed to both a lack of preparation and support. There did not appear to be evidence that contemporary nursing education was addressing this, as a lack of open discussion about death and dying was reported by recently-graduated participants as well as those who had trained some decades ago. Eager to learn professional norms, novice nurses can easily be influenced by the attitudes and behaviours of nursing educators and role models. Anecdotal evidence from interview participants suggests that nurses are being socialised to use avoidance and distancing when considering death and dying, even before they have clinical exposure to patient death and dying.

### Personal and Professional Growth and Finding Benefits

"It took me a while to see that I had done ok. I had to go through, you know - reflection on what I had done. Because initially I felt really bad. . . that I hadn't done what I should have done. But reflecting on it, I realised I couldn't have known. So, by the end of talking to people and everything I felt really good about it." (Debbie, New Graduate nurse)

Just over half of questionnaire participants were able to recall positive, satisfying or rewarding aspects of their EMPDs. When describing the benefits of these experiences, participants most frequently mentioned that they offered an opportunity for learning. Other researchers have also found that nurses often identify professional and personal benefits when reflecting on their early encounters with patient death (e.g. Allchin, 2006).

The fact that nearly half of participants did not report benefit-finding, also needs to be acknowledged. As all participants were currently practicing nurses, it is not clear how their EMPDs impacted on subsequent experiences with patient death, and it would be interesting to explore whether benefit-finding in EMPD was predictive of later involvement and satisfaction in care of the dying, or nursing in general. Emotionally powerful early nursing experiences are opportunities for both professional development and personal growth. Research suggests that positive attitudes towards specialised nursing roles (such as care of the dying patient) can be fostered through good preparation and support and positive early experiences (Degner & Gow, 1988). Facilitators for growth include reflection, supportive relationships and self-knowledge including an awareness of values and beliefs (Levine et al., 2006). If improved preparation and support for critical incidents (such as patient death) can facilitate benefit-finding, this may also have significant implications for the reduction of chronic secondary stress. Emerging research proposes that fostering so-called compassion satisfaction could help to counterbalance the negative impact of compassion fatigue in vulnerable individuals and occupational groups (Conrad & Kella-Guenther, 2006).

### **Strengths and Limitations**

Rather than critiquing and defending this research using social science's 'holy trinity' of objectivity, reliability and statistical generalisability (Kvale, 1996), a recently proposed framework for critically appraising qualitative and mixed methods research (Kuper, Lingard, & Levinson, 2008; Lingard, Albert, & Levinson, 2008) has been adapted to structure discussion of the strengths and limitations of these studies. This framework addresses: the justification for use of mixed methods and clarity of approach; sample appropriateness and transferability of results; appropriateness of data collection; appropriateness of data analysis; and the adequacy with which researcher reflexivity and ethical issues were addressed.

### Justification for mixed methods and clarity of approach

This mixed-methods design was selected to provide new insights and information through a rigorous methodology which emphasised completeness, trustworthiness and authenticity (Kearney, 2001). In this relatively unexplored area, existing measures addressing research aims have not been tested, and quantitative data alone would have limited scope. The use of qualitative methods allowed participants to be captured in their own terms and describe their experiences using their own categories (Lofland, 1971). As qualitative research allows for the contribution of many different perspectives, multiple sources of data have been used in this study, to improve comprehensiveness and allow method and data triangulation (Mays & Pope, 2000). By gathering both interview and questionnaire data, it has been possible to gain greater insight into this common but emotionally challenging aspect of nursing.

### Sample appropriateness and transferability of results:

It is acknowledged that the measures of sample appropriateness and adequacy for quantitative and qualitative research are significantly different. Ideally, a questionnaire sample should be randomly selected and of an adequate size to detect differences, with the chief goal of representativeness of the target population. A qualitative interview sample needs to contain insightful, willing individuals who are able to articulate their experiences (Barbour, 2001; Coyne, 1997; Morse, 1991). The nature of phenomenological research, and practical and ethical considerations, made the risk of sample biases an inevitable feature of this research. Therefore, it cannot be assumed that the retrospective accounts provided by nurses in this study reflect the EMPD experiences of New Zealand Registered Nurses as a population.

Non-random, self-selected convenience samples were used in both studies and this is likely to have resulted in a sample which is not representative of New Zealand Registered Nurses in general. The purposeful sampling technique may have selected participants who are particularly well-adjusted, having adopted effective coping strategies in their day-to-day lives and nursing practice. All participants were practicing nurses, undertaking further study in nursing. It is possible that nurses who are electing to take on the additional burden of postgraduate study are typically coping well with, and motivated to further, their nursing skills and knowledge. Nurses who had unbearably stressful or difficult experiences early in their training or careers may have left the profession, may not feel motivated or able to take on postgraduate study, and may have been less likely to volunteer for this study. New Graduate participants may have represented a contrasting group, in this regard. Fresh from completion of their training, still adjusting to the role of nurse, and enrolled in compulsory papers as a component of their Nurse Entry to Practice program, this group was potentially more representative of contemporary New Graduate nurses in New Zealand.

This potentially concentrated convenience sample of well-adjusted nurses may be further distilled by volunteer bias. A large longitudinal study of medical students and graduates showed that volunteers tended to achieve more highly both during and after medical school than non-volunteers and non-respondents (Callahan, Hojat, & Gonnella, 2007). Response biases may have contributed to the findings of this study, but it is difficult to determine the nature of non-responders. Those who elected not to participate may not have been able to report on an EMPD, perhaps because they had not yet encountered patient death, because no event came to mind, or because they were reluctant to recall an unpleasant or distressing EMPD. Although demographic data for the recruitment sample were not available, it appears that there may have been an under-representation of males in the participant sample, and the reasons for this may be significant and worth exploring in themselves. Notably, of the five men who took part in the questionnaire, four volunteered to be interviewed, and three were included in Study Two. It is pleasing that both study samples were diverse, with good representation from a range of ages, ethnicities, training backgrounds and current employment settings. The reported EMPD

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experiences were also varied, with participants giving a mix of accounts which included very distressing, very rewarding and more balanced experiences.

### Appropriateness of data collection

As pointed out by van Manen (2006), recollective reflection is one of the only ways to access the lived experience of another person. Although it is possible that the accounts that are given are not historically accurate recollections of events, the researcher is interested in the experience of the individual, rather than the events themselves. What is remembered and how it is described is a reflection of the individual's subjective experience and may be psychologically revealing in itself (Giorgi & Giorgi, 2003). Vivid recall was a feature of both studies; detailed factual recall of, for example, the exact age of the patient, was evident in the questionnaire study, whilst interview data yielded rich and carefully detailed descriptions of many aspects of EMPDs. Interviewer effects, social desirability responding and other factors may have influenced interview data, but all interviews were conducted in private, nonclinical areas in an attempt to minimise this.

Time and logistical constraints necessitated concurrent participant recruitment and data collection in both the questionnaire and interview studies. Although data from incoming questionnaires and completed interviews were used to develop future interviews, opportunities for this iterative process were limited by the scope of the original research proposal. Had time and recruitment opportunities allowed, a sequential, two-phase, or even three-phase design with adequate opportunity for data analysis between phases could have been used (Cresswell et al., 2003). Proposed alternative or future study designs to further explore nurses' early patient death experiences could use:

- A qual→QUANT two-phase design, where an initial, qualitative study (involving focus groups or interviews) was used to inform the development of a more comprehensive, reliable and valid questionnaire addressing emerging issues.
- A quant→QUAL two-phase design, where initially a larger survey study measured EMPD-related preparedness, impact, distress and benefit-finding, as well as present attitudes to caring for dying patients, then results were used to create a stratified sample

for the follow-up study (again, focus groups or interviews) ensuring that participants with a range of EMPD experiences, death attitudes etc were represented.

### Appropriateness of data analysis

As the research aims were exploratory and the questionnaire measure tested only on a pilot sample, data analysis was focussed on description of the sample, with judicious inclusion of inferential testing. Interview data were analysed using Interpretative Phenomenological Analysis (IPA), an iterative approach outlined in the method. One of IPA's assumptions is that the participant is competent to accurately and fully articulate the nature of their own experiences. As this study aimed to explore the cognitive, emotional and behavioural aspects of nurses' early experiences with patient death, this was quite a high expectation. As purposive sampling was used, analysis of the data included consideration of details of the participant sample. Logistical restraints may have precluded a more in-depth analysis and integrated presentation of the large amount of data collected for this study.

### Adequacy with which researcher reflexivity and ethical issues were addressed

These studies were designed in consultation with members of the population of interest, under the supervision of experienced researchers, and with ethics approval from the appropriate ethics committee. Participation in this study appeared to facilitate reflection and emotional expression, the benefits of which are supported by research and the anecdotal reports of participants themselves. Although a few participants showed signs of some mild distress during their interviews, every attempt was made to be sensitive to these responses. It was made clear that participants could stop the interview or withdraw from the study, and contact details for professional counselling support were also made available.

There is no doubt that the researcher's dual background in psychology and nursing influenced all aspects of this study, from inception to design, data collection and analysis. It is possible that preconceptions and biases influenced the way data were collected and analysed, particularly during interviews. Participants would sometimes explicitly appeal to the researcher's own nursing background, apparently seeking evidence of empathy or understanding, and when

participants finished statements with ". . . you know?" it was sometimes challenging finding a balance between facilitating rapport by acknowledging comradery, and probing for more detail. The assumption of a shared understanding between researcher and participant, as nursing peers, may, at times, have restricted the explicit revelation of the true nature of experiences. On the other hand, results from this research and numerous other studies suggest that nurses prefer to talk about sensitive work-related issues with other nurses, so it is likely that the researcher's nursing background facilitated participation, rapport and the candid, detailed and apparently uncensored nature of accounts provided.

### **Conclusions and Recommendations**

It is clear from reviewing the literature that relatively little has previously been published about nurses' early experiences with patient death, and the exploratory, inductive methodology underlying this research allowed the nature of these experiences to emerge.

Results suggest that EMPDs are often salient events which can have a significant impact on novice nurses. There was evidence that participants had thought about encountering patient death and dying prior to their EMPDs, but few had given consideration to challenging situations such as sudden unexpected or paediatric deaths. Where EMPDs were characterised by unexpected elements, lack of preparation and helplessness, participants were more likely to report distress both at the time of the event, and ongoing negative emotions, such as guilt and regrets, during the interview. It appears that the majority of the EMPDs occurred in acute care settings such as medical and surgical wards. Although research has not specifically explored the implications of this, it may be that novice nurses find it difficult to apply palliative care teachings to the deaths that occur in curative clinical environments, and undergraduate education should better prepare them for the range of deaths which can occur in acute settings.

Sharing the experience with others was important to participants. Working alongside a more experienced nurse appeared to provide emotional and practical support, and the apparent

reduction in responsibility helped to allay fears of inadequacy. The most positive EMPD experiences were characterised by the supportive influence of a positive nursing role model.

Most participants had confided in others regarding their EMPDs, and reciprocal sharing of patient death experiences with other nurses appeared to be particularly helpful. Opportunities for reflection with peers may assist nurses to cope with the challenges of their EMPDs by normalising the experience and facilitating emotional disclosure, finding benefits, and personal and professional growth.

Little can be done to control the clinical circumstances of nurses' early death encounters – novice nurses may face extremely challenging situations, including sudden unexpected and paediatric deaths. However, by better preparing and supporting novice nurses it may be possible to minimise more negative factors such as unexpected elements, feelings of inadequacy, exclusion and role conflicts and facilitate coping, sharing the experience, personal and professional growth, and other positive outcomes.

Nurses supported this project enthusiastically, and many of those who shared their EMPD experiences reported that their participation was, in itself, a beneficial experience. The potential benefits of facilitated reflective practice following early encounters with death merit further investigation.

In the foreword to The Nurse and the Dying Patient, Helen Nahm wrote:

Quint's timely book brings to the reader both a sense of shock and a sense of revelation. .

. . that so little attention has been given in years past to preparing nurses to cope

effectively with problems associated with dying. . . .that so much can be done, not only to enable nurses to provide the care and comfort that is so much needed by patients and their families during periods of extreme stress, but also to achieve the sense of personal worthwhileness and fulfilment which comes from the knowledge of work well done (Quint, 1967, p. vii).

Forty years later, despite being conducted in a different cultural, educational and medicaltechnological context, the findings from this study resonate remarkably with many of Quint's original observations and recommendations. Although educators are attempting innovative new approaches to address the broader implications of nurses' early death experiences, more systematic research is needed to evaluate the effectiveness of these interventions. Results from this study suggest that nurses' early encounters with patient death are salient events which can offer challenges and rewards to the novice nurse. Interventions which seek better to prepare and support nurses facing patient death for the first time should be well informed regarding the important factors involved in these experiences. This study was preliminary and exploratory in nature, and more research in this important area is needed.

## **APPENDICES**

# **APPENDIX A: Ethics Approval Confirmation Letter**



## **APPENDIX B: Participant Information and Invitation for Study One**

[Reproduction of email]

### **RESEARCH INVITATION:** Nurses' early experiences with patient death

Hi there! My name is Natalie Spackman and I am a Registered Nurse studying towards a Master of Science in Health Psychology at The University of Auckland, under the supervision of Professor Glynn Owens and Associate Professor Bridie Kent. For my thesis research project I am exploring New Zealand nurses' early experiences with patient death by gathering data through an anonymous online questionnaire, and face-to-face interviews. It is hoped that results from this research will help to guide preparation and support for tomorrow's nursing students and New Graduates who are faced with the personal and professional challenges of patient death.

### The questionnaire should take less than 10 minutes to complete.

Your participation is entirely voluntary. This email was sent on my behalf, by a third party, to ensure the privacy of your contact information. Please take the time to read the following information carefully so that you can decide whether or not you wish to take part. You are welcome to discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please do not hesitate to contact me.

The data gathered from this questionnaire will be kept secure using password-protected data files, which will be accessible only to the researcher (Natalie Spackman), and will be kept for a period of six years and then destroyed. The anonymity of your answers will be secured by SSL encryption technology provided by the SurveyMonkey website.

For the purposes of this questionnaire, I would like you to bring to mind the earliest memorable occasion in your nursing training or career, when you experienced a patient death. It does not matter whether or not you were assigned to be the primary nurse for that patient, only that you were involved in their care in the role of student nurse, enrolled nurse or Registered Nurse. It does not matter if you are unsure if it was the very first time you encountered a patient who died or was dying – only that it is the earliest experience which comes to mind, and which you are willing to share with me to assist me in my research. If you cannot think of any occasion when you have experienced a patient death, I would still appreciate you answering a (shortened version) of my questionnaire.

To begin the questionnaire, please just click on the blue, underlined link below. (Or, if your email provider doesn't show this as a link, just cut and paste it into your web browser address bar, and hit 'go')

https://www.surveymonkey.com/s.aspx?sm=n8yX67PtV5r9tN1J4w4Bvg\_3d\_3d

Your participation is greatly appreciated. Thank you for your time and help in making this study possible. If you have any queries or suggestions, or if you are happy to be interviewed I can be contacted on (021) 656 497 or email: <u>NatalieSpackman@gmail.com</u>

Alternatively you can contact either of my supervisors:

Prof. Glynn Owens, Psychology Department, University of Auckland, Private Bag 92019, Auckland, Tel. (09) 373 7599 ext. 86864

Assoc. Prof. Bridie Kent, School of Nursing, University of Auckland, Private Bag 92019, Auckland, Tel: (09) 373 7599 ext. 86460

Head of Department: Assoc. Prof. Fred Seymour, Psychology Department, University of Auckland, Private Bag 92019, Auckland, Tel. (09) 373 7599 ext. 88414

For any queries regarding ethical concerns please contact:

The Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Research Office – Office of the Vice Chancellor, Private Bag 92019, Auckland. Tel (09) 373-7999 ext 87830

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 16th April, 2008 for 3 years from 16/04/08 to 16/04/11 Reference Number 2008/087

## **APPENDIX C: Study Two Questionnaire**

[Reproduction of online questionnaire]

### Nurses' early experiences with patient death

### Welcome !!

Thank you for agreeing to complete this brief questionnaire. Your answers will remain anonymous, and the questionnaire should take less than 10 minutes to complete. This questionnaire is part of my Master's thesis research project exploring New Zealand nurses' early experiences with patient death. It is hoped results will help to guide preparation and support for nursing students and new graduates who are faced with the personal and professional challenges of patient death.

For the purposes of this questionnaire, I would like you to bring to mind the EARLIEST memorable occasion in your nursing training or career, when you experienced a patient death. It does not matter whether or not you were assigned to be the primary nurse for that patient, only that you were involved in their care IN THE ROLE OF STUDENT NURSE, ENROLLED NURSE OR REGISTERED NURSE. It does not matter if you are unsure if it was the very first time you encountered a patient who died or was dying – only that it is the earliest experience which comes to mind, and which you are willing to share with me to assist me in my research.

1. Can you recall an occasion in you	r nursing training or career, when you
experienced a patient death?	

O Yes

O No

urses' early experiences with	n patient death
linical circumstances of first pat	tient death
hen answering the following questions, please co RAINING OR CAREER, when you experienced a pa	nsider the EARLIEST memorable occasion in your NURSING atient death.
2. On the occasion when this patien	nt died, what was your nursing status?
Student Nurse (Early in training)	New Graduate Registered Nurse
Student Nurse (Late in training)	Registered Nurse (qualified >1 year)
Enrolled Nurse	O Do not remember
3. Which of the following best desc	ribes the extent of your care for the patient?
I had limited involvement in the care of the paties	nt prior to his/her death
I had cared for the patient on a number of occasi	ons
$igcar{}$ I had cared extensively/intensively for the patient	t
4 On the occasion when this natio	nt died, what was YOUR approximate age?
The occusion when this putter	n alea, mat has rook approximate age.
6. To what extent was the patient's <ul> <li>Expected (following a terminal illness)</li> <li>Somewhat expected (patient chronically or critically)</li> </ul>	s death expected? (select one answer only)
Sudden death (previously fit and well)	
Traumatic or accidental death	
Suicide	
Suicide	
0	
Do not remember	

rses' early experiences v	with patient death
7. In what clinical setting did th	ne patient die?
Medical ward	Hospice
ICU or NICU	Community
Emergency department	O Theatre / recovery
Maternity	Geriatric care facility / rest home
Rehabilitation	O I do not remember
Surgical ward	
) Other (please specify)	
. Did your nursing care of the nany as apply)	patient who died involve any of the following? (tick as
Providing comfort cares to the dying patien	ıt
Resuscitation efforts	
Comforting distressed family members	
Post-mortem care (e.g. 'laying-out'/washin	ng/removal of lines from the deceased)
Providing symptom-relieving medications t	o the dying patient
Breaking bad news to family	
Presence at the time of death	
Other (please specify)	

### Nurses' early experiences with patient death

### Nursing experience: preparedness, impact and support

Please indicate the extent to which you agree or disagree with the following statements relating to the earliest memorable occasion in your nursing training or career, when you experienced a patient death. If you feel any statement is irrelevant or inappropriate, please indicate "not applicable".

#### 9. To what extent do you agree or disagree with the following statements:

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	N/A or Do Not Remember
My earliest memorable patient death was more upsetting than any other event in my early nursing career	0	0	0	0	0
I was not affected much by my earliest memorable patient death	0	0	0	0	0
No subsequent patient deaths have upset me as much as my earliest memorable patient death did	0	0	0	0	0
I knew where to get support if I was upset about my earliest memorable patient death	0	0	0	0	0
In the days and weeks immediately after it happened, I spent a lot of time thinking about my earliest memorable patient death	0	0	0	0	0
My memories of my earliest memorable patient death are very vivid	0	0	0	0	0
My earliest memorable patient death has continued to have an impact on the way I've dealt with death and dying as a nurse	0	0	0	0	0
I had very little exposure to death and dying in my personal/family life prior to my earliest memorable patient death	0	0	0	0	0
If possible, I prefer not to care for dying patients and their families	0	0	0	0	0
Caring for dying patients and their families can be very rewarding	0	0	0	0	0

10. With regards to this experience with patient death, do you remember feeling that there were any positive, satisfying or rewarding aspects for you personally or professionally?

O No

Yes (please specify)

11. My undergraduate (student) nursing training prepared me well to:

\*

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	N/A or Do Not Remember
Deal with my personal reactions to patient death	0	0	0	0	0
Confidently provide end-of-life care	0	0	0	0	0
Communicate with dying patients and their families	0	0	0	0	0
Care for bereaved relatives	0	0	0	0	0
Know what patient death would be like	0	0	0	0	0

Ν	urses'	' early ex	periences	with pa	tient deat	th		
	12. Di	id you talk t	o anyone ab	out this ex	perience wit	th patient de	eath?	
	() Yes	5						
	O No							

Nurses' early experie	ences with patient death	
Support		
13. Who did you talk to	o? (Tick as many as apply)	
Charge Nurse	New Graduate Nurse	Friend (non-health professional)
Student Nurse	Parent	Counsellor
Partner	Educator/tutor	Preceptor
Senior Nurse	Friend (nurse or other health professional)	
Other (please specify)		

rses' early e>	periences with patient death
emographic De	ails
	mation is requested to help the researcher identify the nature of the sample of as a group. Individual questionnaire data remains anonymous.
14. What is your	current age?
15. With which e	thnic group(s) do you identify? (Please tick up to three)
NZ European	Fijian Chinese
Other European	Samoan Indian
Maori	Cook Island Maori Other Asian
Tongan	Other Pacific
Niuean	South East Asian
Other (please specif	
17. Where and w Country Institution	hen did you gain your first nursing qualification?
ear	

Nurses' early experiences with patient death
18. In what clinical setting(s) do you currently work? (Tick as many as apply)
Medical ward
ICU or NICU
Emergency department
Maternity
Rehabilitation
Surgical ward
Hospice
Community
Theatre / recovery
Geriatric care facility / rest home
Not currently employed in clinical work
Other (please specify)

### Nurses' early experiences with patient death

### Thanks so much for completing this questionnaire !!

Obviously, a questionnaire is limited in the extent to which it can capture an experience as complex as nursing a patient who dies. As an additional part of my thesis research, I will be conducting face-to-face interviews, to give nurses the opportunity to more fully share their first experiences of patient death.

IF YOU WOULD BE INTERESTED IN PARTICIPATING IN AN INTERVIEW, lasting approximately thirty to forty-five minutes, and at a time and location of mutual convenience, please email me: NatalieSpackman@gmail.com or phone or text message me: 021 656 497. Your questionnaire details will remain anonymous and will not be linked to your interview data.

# **APPENDIX D: Participant Information Sheet for Study Two**

DEPARTMENT **PSYCHOLOGY** 

Faculty of Science

Participant Information Sheet (Interview participants)

Nurses' early experiences with patient death

Dear [Interview participant]

My name is Natalie Spackman and I am a Registered Nurse studying towards a Master of Science in Health Psychology at The University of Auckland, under the supervision of Professor Glynn Owens and Associate Professor Bridie Kent. For my thesis research project I am exploring New Zealand nurses' early experiences with patient death, by gathering data through an anonymous online questionnaire, and face-to-face interviews. During the interview, I will ask you to describe your earliest memorable nursing experience with patient death.

Your participation is entirely voluntary. Please take the time to read the following information carefully so that you can decide whether or not you wish to take part. You are welcome to discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please do not hesitate to contact me.

If you decide to participate in this research, you will be asked to sign a consent form and fill out a short demographics form. You are still free to withdraw at any time, and without giving a reason.

It is hoped that the findings of this study will help to guide the preparation and support provided to tomorrow's nurses so that they may best meet the challenges of encountering patient death early in their careers. If information you provide is reported or published as a part of my research, this will be done in a way which protects both your identity, and any potentially identifying or sensitive patient details.

Your interview will be conducted at a time and location of mutual agreement, and will take approximately thirty to forty-five minutes. It is essential that an audio recording be made of the interview. Your interview recording will only be available to the principal investigator (Glynn Owens) and researcher (Natalie Spackman) and will be stored safely in a locked filing cabinet in the University of Auckland Department of Psychology, and transcribed by the researcher. The consent form, demographics form and interview recording will be kept, separately, for six



Room 321, Building 721 Tamaki Campus Cnr Morrin & Merton Roads Glen Innes Auckland, New Zealand Telephone 64 9 373 7599 ext.86886 years and then destroyed by the principal investigator. You have the right to withdraw your information up until the 30<sup>th</sup> October, 2008. When completing your consent form, you will also be given the opportunity of requesting a copy of your interview recording, and/or a copy of the interview summary, with an opportunity to provide feedback on the accuracy of that summary.

You may also be invited to participate in possible follow-up research in 12-18 months time; however this will also be entirely voluntary, and subject to approval of a further ethics submission. Whether a follow-up study is conducted will depend on the results obtained in this study.

I believe that taking part in this interview will be a meaningful experience, and will provide an opportunity to reflect on your personal and professional development, but if you find any topics discussed in the interview distressing in any way, you will be provided with names and contact details of suitable counselling services.

Your participation is greatly appreciated. Thank you for your time and help in making this study possible. If you have any queries or wish to know more about the research, I can be contacted on (021) 656 497 or email: NatalieSpackman@gmail.com Alternatively you can contact either of my supervisors:

Prof. Glynn Owens, Psychology Department, University of Auckland, Private Bag 92019, Auckland, Tel. (09) 373 7599 ext. 86864

Assoc. Prof. Bridie Kent, School of Nursing, University of Auckland, Private Bag 92019, Auckland, Tel: (09) 373 7599 ext. 86460

Head of Department: Assoc. Prof. Fred Seymour, Psychology Department, University of Auckland, Private Bag 92019, Auckland, Tel. (09) 373 7599 ext. 88414

For any queries regarding ethical concerns please contact:

The Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Research Office – Office of the Vice Chancellor, Private Bag 92019, Auckland. Tel (09) 373-7999 ext 87830

### APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 16<sup>th</sup> April, 2008 for 3 years from 16/04/08 to 16/04/11 Reference Number 2008/087

## **APPENDIX E: Consent Form for Interview Participants**

DEPARTMENT OF PSYCHOLOGY

Faculty of Science

satisfaction.



Consent Form (Interview Participants)

Nurses' early experiences with patient death

Room 321, Building 721

Tamaki Campus

Cnr Morrin & Merton Roads

Glen Innes

Auckland, New Zealand

Telephone 64 9 373 7599 ext.86886

- I have read the participant information sheet and have understood the nature of the research and what is required of me. I have been given the opportunity to ask any questions regarding the research and any questions I have asked have been answered to my
- I understand that participation or non-participation in this research project will not affect my course work at the University of Auckland. I am also aware that participation in this research is completely voluntary and that, even if I consent to take part, I may withdraw from this study at any time, without penalty, and without giving a reason.
- I understand that I will be asked to fill out a short demographics form and take part in an interview that will take approximately thirty to forty-five minutes. I understand that I will be asked to describe the earliest memorable occasion in my nursing training or career when a patient died.
- I am aware that an audio recording of this interview will be made and I give permission for this. I understand that I have the right to withdraw my information from this study up until the 30<sup>th</sup> October, 2008.
- I understand that my interview recording will only be available to the principal investigator (Glynn Owens) and researcher (Natalie Spackman) and will be stored safely in locked filing cabinet in the University of Auckland Department of Psychology, and transcribed by the researcher. I understand that my consent form, demographics form and recording will be kept, separately, for six years and then destroyed by the principal investigator.
- I understand that if the information I provide is reported or published as part of this research, this will be done in a way which protects both my identity, and any potentially identifying or sensitive patient details.
- I am aware that a copy of my interview recording can be made available to me upon request.

- I am aware that, if requested, I can be sent a written summary of my interview, and given an opportunity to provide feedback on the accuracy of its content.
- I understand that while it is hoped that the interview will be a meaningful opportunity for me to reflect on my personal and professional development, if I find any topics discussed in the interview distressing in any way, I will be provided with names and contact details of suitable counselling services.

If you would like to receive a copy of your interview summary, please tick the box  $\Box$ 

If you would like to receive a copy of your interview recording, please tick the box  $\Box$ 

Please provide your postal address (if you require a copy of your interview summary or recording):

I have read the above terms and agree to participate in this research project.

(Please print)

Signature of Participant.....

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 16<sup>th</sup> April, 2008 for 3 years from 16/04/08 to 16/04/11 Reference Number 2008/087 **APPENDIX F: Demographic Form for Interview Participants** 

#### Demographic Form (Interview Participants)

Name.....

Email.....

What is your current age? .....

# With which ethnic group(s) do you identify (please tick up to three)?

NZ European	Other European	🗖 Maori	Samoan
Cook Island Maori	🗖 Tongan	🗖 Niuean	🗖 Fijian
Other pacific	South east Asian	Chinese	🗖 Indian

□ Other Asian □ Other (please specify) .....

### What is your gender?

□ Male □ Female

## Where and when did gain your first nursing qualification?

Country	

Year

Institution	

#### What is your current employment status (please select as many as apply)?

Employed full-time	Employed part-time
Not currently employed	Full-time student

#### What is your current nursing status (please select one)?

Staff Nurse (New Graduate)	Staff Nurse (II / Competent)
Staff Nurse (III / Proficient)	Staff Nurse (IV / Expert)
Senior Nurse (Education)	Senior Nurse (Charge / Co-ordinator)

□ Other (please specify).....

#### What is your current area of work (e.g. medical ward, community nursing?)

.....

# **APPENDIX G: Interview Guide**

# **Interview Guide**

Could you please tell me about the earliest memorable occasion in your nursing training or career, when you experienced a patient death?

The following probes may be used, if these areas are not covered by the interviewee without prompting:

How prepared do you think you were for this patient death? What could have been done to better prepare you for this patient death?

How do you remember feeling about this patient death? What was challenging or difficult for you personally? What was rewarding or positive for you personally?

Was this patient death was a memorable or significant event? What lasting impact has this patient death had on you?

What did you do afterwards to help you cope? Who did you talk to about this patient death?

At the time, were you aware of anything (else) that you could have done if you'd been upset by, or worried about this patient death?

What do you think would help nurses to prepare for and cope with their first patient death?

How has reflecting on this experience made you feel?

What should I have asked you that I didn't think to ask?

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