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**DYING TO KNOW:
A Qualitative Study Exploring Nurses' Education in Caring for the Dying**

A Thesis presented in partial fulfilment
of the requirements for the degree of

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ABSTRACT

This qualitative study explored how Registered Nurses with experience of caring for the dying share their knowledge and skills with new graduate nurses in the clinical setting.

The Research Questions were: What clinical knowledge/skills do 'expert' Registered Nurses possess that allow them to care competently and confidently for patients in their final forty-eight hours of life? How might these experienced nurses most effectively share their knowledge/skills with new graduate nurses in the clinical setting? The aims of the study were, firstly to describe the clinical experiences of Registered Nurses with expertise in care of the dying in a variety of practice settings. Secondly, to develop a written document whereby experienced nurses can share their knowledge/skills of care of the dying with new graduate nurses (as a supplement to the findings of this study).

The data was collected in terms of demographic information, and a single semi-structured interview was conducted with each participant. Each participant was also asked to complete a written clinical narrative. The data was analysed using Luborsky's method of thematic analysis. The interview transcripts were read and reread and similar topics were grouped as phrases and coded as themes. The major themes were described in detail using excerpts from the interviews and narratives of the participants. Clinical stories of practice shared by the participants in their interviews are included with the clinical narratives in the Resource Document.

There was a strong emphasis in the findings of this study on one-to-one sharing between the experienced and new graduate nurse throughout the dying process. The sharing was in the hands-on care provided, stories of experience and reflection on the care given. The concept of 'care pairs', the use of resource nurses and the resource document discussed in the recommendations could be used in a variety of clinical settings.

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CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND TO THE STUDY

My interest in this study has evolved over a number of years of nursing practice in the cancer setting, working with and observing nurses at work in this clinical area. This specialty has been my area of clinical practice as a Comprehensive Registered Nurse since 1986, working with cancer patients from diagnosis, through treatments such as chemotherapy, radiotherapy and symptom control, palliative and terminal care through to death. I have worked in both outpatient and inpatient settings.

On a more personal level, I cared for my mother during Alzheimers disease, diagnosed when she was in her mid fifties. At the tender age of 63 years (in 1997) she passed away during a bout of pneumonia. By this time though, she was completely bedridden with no apparent means of verbal communication and no ability to care for herself. In contrast my father passed away in May 2002 during his first and only major cardiac event. I only now appreciate the great contrast between a gradual decline and a very sudden death.

On a professional level, I completed a Bachelor of Arts degree in 1993 in which I majored in Nursing Studies and Religious Studies. It was during this time that I developed an interest in Spirituality in Nursing. As I proceeded to complete a Master of Nursing degree I extended my ongoing study of spirituality, particularly within the Oncology practice setting. Within the research component of the degree I explored the spiritual needs of patients with Leukaemia. The patients described how they had to face thoughts of their own mortality, in some instances many years before they thought they would have to face this aspect of their lives. In terms of who/what had assisted them to meet their spiritual needs, fellow patients clearly assisted them, in their eyes. It was the old saying, 'have been there and done that'. The degree was completed in 1998. That research has led me to exploring the area of spirituality in nursing with nursing students at a local nurses' training institution.

In the year 2000 I took over the facilitation of an in-service workshop 'Care of the Dying', at MidCentral Health. I believed that this workshop fitted well with my growing and developing interest in spirituality in nursing. The workshop was one day in duration initially, but I have now developed it into a two-day event. It is multi-disciplinary in nature, allowing me to tap into the expertise of local resource persons. Those involved include a pharmacist, Complementary Therapist, Hospital Chaplain, Funeral Director, the Hospice team, the Maori Health team and Registered Nurses from different clinical settings.

The participants at the workshop are largely Registered Nurses but the workshop is open to any employees of MidCentral Health. It is one of 'my dreams' that any employees attend, be they clerical, cleaners, orderlies, nursing staff at any level, as we are all affected by death in some way at some time. The number of participants is kept at a manageable level to allow those participating to feel safe and comfortable in terms of sharing and discussion, and to acknowledge the sensitive nature of some of that discussion. The aim of the workshop is that those participating may extend their learning and be able to discuss issues related to their particular clinical areas. It is also hoped that those attending will take their learning back to their clinical areas for further discussion and debate.

My facilitation of this workshop has led me to sharing a teaching session with the hospital chaplain, in which we explore clinical issues in relation to care of the dying. The participants in these sessions are nursing employees new to MidCentral Health, who may be new graduate nurses or nurses returning after a period of time away from the profession.

More recently my interest in quality of care for the dying has been rekindled by the 'Death With Dignity' Bill before the New Zealand Parliament. I wonder, how can we even think of relieving a person's suffering by deliberate euthanasia? As professionals, in health and other areas, we are required to think carefully and deeply about how we might improve the quality of life for people at the end of their life. Quality of life often depends on adequate and effective pain control, control of nausea, agitation, confusion, on emphasising peace, comfort and support at the end of life – for the patient, family, the carers. I

believe it is often the difficult cases, the cases where the end of life has not been peaceful and comfortable, that are emphasised in the media. What about the cases where the death is peaceful and calm, where symptoms are well controlled? We probably never hear about such cases that are managed effectively and in the way we, the professionals, would dearly like every one to be cared for.

One answer to improved quality of care for the dying is education, for the carers, the professionals, so that they may feel confident, competent and supported whilst caring for these people. So, I ask: how much time do nurses within their initial education spend on care of the dying? How much time do they spend on this important area of care in relation to the time spent on obstetrics, or care at the beginning of life? I have questioned nursing students working in my area of practice and it appears that in fact very little time is spent in the curriculum on care of the dying.

Patients die in all areas of nursing, but do they receive quality in their care at the end of their life? Nurses may learn in the classroom theoretically how to care for a patient who is dying but it is much less clear how that learning is transferred to the clinical setting, or indeed whether that learning is able to be transferred, easily or at all. It appears from my observations that the new graduate nurse gains his/her clinical knowledge of care of the dying in an 'ad hoc' and often 'hit and miss' way. I believe that the new graduate nurse is most often plunged in to the care of a dying patient without receiving any effective immediate and ongoing support or guidance. This is an area of nursing I am passionate about, in terms of quality of care – care of both the patient and the new graduate nurse.

The nursing and education literature clearly states that care of the dying is an area in which nurses often feel inadequately prepared, both educationally and clinically. It appears that educators are uncertain how to include the subject in the nursing curriculum. It is also not clear whether care of the dying as a subject should be integrated throughout the basic nursing curriculum or be included as a specific course. There is little guidance on how classroom and clinical learning might be integrated so that the new graduate nurse can care for these patients

(and their families) with confidence and competence. This, then, is the background to the study.

1.2 JUSTIFICATION/SIGNIFICANCE OF THE STUDY

I believe that 'on the job' learning associated with care of the dying is often piecemeal, to the detriment of both the nurse and the patient. In completing this study I plan to add to the body of knowledge and assist with improving nursing practice related to care of the dying. Some nursing subjects are dealt a tremendous disservice when it is thought that classroom teaching is enough to equip the new graduate nurse for work in the clinical setting. Care of the dying is one such subject. Some knowledge taught in the classroom is not easily transferred into the clinical setting. It may also be that the sort of knowledge taught in the classroom does not adequately or effectively equip the new graduate nurses for the 'reality' found in the clinical setting.

I wonder, how might care of the dying be effectively taught/learned in the clinical setting? As part of this study I plan to develop a written document through which experienced nurses might share, with new graduate nurses, stories of care and their clinical knowledge/skills of care of the dying. I plan that such a document as this might be available as a resource in clinical settings (such as inpatient units, hospice, resthomes) for new graduate nurses. I wish to explore how 'on the job' teaching/learning might be effectively achieved in this area of care.

Thus **The Research Questions** are:

What clinical knowledge/skills do 'expert' Registered Nurses possess that allow them to care competently and confidently for patients in their final forty-eight hours of life?

How might these experienced nurses most effectively share their knowledge/skills with new graduate nurses in the clinical setting?

The Aims of the Study:

Firstly, to describe the clinical experiences of Registered Nurses with expertise in care of the dying in a variety of practice settings.

Secondly, to develop a written document whereby experienced nurses are able to share their knowledge/skills of care of the dying with new graduate nurses (as a supplement to the findings of this study).

The Objectives of this Study:

Firstly, to describe the transition from being terminally ill to entering the active dying process in the clinical setting.

Secondly, to explore with experienced Registered Nurses how they learned the clinical skills inherent in care of the dying.

Thirdly, to explore with those nurses how they might most effectively share their knowledge/skills of care of the dying with new graduate nurses (in their opinion).

1.3 OVERVIEW OF THE THESIS

This research report is structured as follows. Chapter two of the study describes a critical review of the literature undertaken by the researcher. In chapter three the methodology and method in terms of the planning and implementation phases of the study are explained in detail. Chapter four describes analysis of the data using Thematic Analysis. This chapter is divided into four major sections according to the major themes found in the data. In chapter five the researcher discusses the findings from the data analysis in conjunction with the literature and the implications and recommendations for nursing practice and education. Chapter six provides an overall summary of the study including final reflections and recommendations.

Appendix A contains the written resource document (stories of practice and the written clinical narratives provided by the research participants) for the clinical areas. Appendix B contains the documentation used during the study, for example the information sheet and consent form. Appendix C contains one sample page of a colour coded interview transcript.

CHAPTER TWO

A CRITICAL REVIEW OF THE LITERATURE

2.1 INTRODUCTION

A critical review of the literature regarding nursing education and care of the dying was undertaken following exploration of the following data bases: ERIC, CINAHL, Medline, Professional Development, Health Source: Nursing/Academic Edition. The years spanning the literature considered were: 1993-2003. This period of time was chosen for convenience and practicality. Much of the literature was medically oriented rather than nursing. The subjects used to identify the literature were: care of the dying, diagnosing dying, the physical stages of dying, care in the last forty-eight hours of life, end-of-life care; palliative care/nursing, nursing education, terminal care, death studies. Subjects also considered in the literature search were: clinical education, learner-oriented education, ethics/sociology, attitudes to death (societal/nursing), informal learning in the workplace and communities of practice.

This review will show that health professionals are under-prepared educationally to effectively care for the dying. There is a variety of literature that describes how care for the dying may be taught in the classroom. There is a dearth of literature that describes and discusses how the nurse may share his/her *clinical* knowledge and skills related to such care. In other words there is a lack of literature describing how the nurse may share his/her skills with other nurses, whilst working in the clinical setting. Murphy (2003) has this to say in regard to classroom and clinical teaching/learning:

Education is often delivered away from the clinical arena and context of care and thus away from real life experience of caring for the dying patient and his or her family. This may act as a barrier for the translation of theory into practice in the clinical area (p.106).

I begin by setting the scene in terms of attitudes to death – the attitudes within society and within nursing.

2.2 SETTING THE SCENE

2.2.1 The Attitudes of Western Society to Death

The anxiety and fear associated with thoughts of our limited lifespan and our own mortality prevent us from discussing death – our own death and the death of others. This in turn, impacts on how we care for those who recently bereaved and grieving, be it in a professional or a personal sense.

It is a common remark in the literature that, in Western society particularly, today people are sheltered from death. In the past most people died at home, whereas today death has been removed from the home to institutions (Robbins, 1989). In this way death has been removed from being seen as a natural part of everyday life. Children may grow to maturity having never been associated with death other than that seen in the entertainment sense. The modes of entertainment such as radio, television, Internet news, (Morrall, 2001) may communicate in an impersonal way, high profile deaths and perhaps more bizarre deaths, thus again removing death as a natural part of life. Morrall (2001) sees that death today is presented to society through motion pictures and literature in a ‘virtual’ sense. At the less public end of the spectrum, death is still not often discussed openly in any kind of personal and individual way.

In Western society there is difficulty accepting death as it is rarely seen (Kubler-Ross, 1995) There is often no set period of mourning and often no specific rituals associated with mourning, that is there are no specific outward signs that a person is in mourning. In other societies death is not welcomed but it is viewed as part of everyday life. I believe we have much to learn from other cultures in the way they deal with death.

A variety of professionals have studied and indeed are still studying dying and death. Aspects of death have been, and continue to be discussed, debated and defined. Thanatology is the interdisciplinary study of death and dying (Straub, 2002).

2.2.2 The Attitudes of Nurses to Death

In health care today, with increased sophistication of techniques and advancement in technology, there is more emphasis on prevention of, and cure of disease. It appears that when cure is no longer possible some health professionals may feel a real sense of failure.

Samarel (1995) says health professionals “must understand their own attitudes toward dying in general and their own death in particular” (p.103) before they can relate to another who is dying. Prior to caring for patients at the end-of-life nurses are required to evaluate their own feelings about death and dying (Meraviglia, McGuire & Chesley, 2003). Rooda, Clements & Jordan (1999) make the following remark in the discussion of their study that “nurses should be aware that their attitudes toward caring for dying patients may be affected by the extent of their contact with dying patients and by their own attitudes toward death” (p.1687). The past experiences, thoughts and feelings, positive or negative, of the nurse will play a large part in how she cares for dying patients (Landry & Landry, 2001). Particularly if the nurse has had negative experiences perhaps within her own family there may be serious difficulties for her in caring for patients who are dying.

I believe self-evaluation exercises that allow the nurse to reflect on his/her own death experiences are useful whilst learning about care of dying patients. Firth (2001) makes several important comments in relation to care of the dying in a multi-cultural context. She says “students have to be aware of and sensitive to their own culture, attitudes, and values, as well as the cultural milieu of the nursing environment. This includes being willing to recognise and challenge the dominance of the prevailing bio-medical models of health and a recognition of the validity of other models” (p.85).

A young person may well enter nursing having never seen or been involved with death and dying. A nurse may also graduate from her initial nursing programme still having never cared for a dying patient. Ideally we would hope this is not so.

Bisset, Robinson and George (2001) say that care of the dying “has always been a part of nursing... and should not be seen a specialist art but a skill everyone should possess” (p.40). Wong, Lee and Mok (2001) say that caring for dying patients is “an essential and major aspect of nursing care” (p.112).

Lev (1986) says “there is almost no formal curriculum to prepare them [nurses] for the special demands of such work [caring for the terminally ill]” (p.241). She goes on to say about the courses available to nurses regarding care of the dying that, “the few courses that are available are described as didactic rather than clinical experiences” (p.241). I wonder, at this time, 2003, has nursing, or have nurses come any further in their education of care of the dying than Lev could see in 1986? I am not sure that any real progress has been made, in New Zealand anyway.

2.3 THE NURSE AS NOVICE, THE NURSE AS EXPERT

2.3.1 Novices and Experts

Today, as in the past, much of nursing, particularly that inherent in the nurse-patient relationship, remains tacit and unarticulated. Certainly there is much in the expertise of nurses and nursing that remains invisible and unacknowledged. The novice nurse initially learns the ‘know that’ or the theoretical knowledge. As Benner (1984) describes “Nursing students enter a new clinical area as novices; they have little understanding of the contextual meaning of the recently learned textbook terms” (p.21).

Delaney (2003) conducted a phenomenological study investigating the transition experiences of graduate nurses during orientation. She interviewed ten graduate nurses. In relation to caring for the dying several of the participants in this study felt that “coping with death and dying was an emotionally difficult experience for which they felt unprepared” (p.437). The participants felt they were not ready for such end-of-life experiences. In the nursing implications Delaney says that “ways to cope with death and dying issues must be built into curricula” (ibid, p.442). It is not clear what part the clinical setting rather than the classroom setting, should play in this professional development and learning process.

The expert nurse, on the other hand, has the 'know how' or the more intuitive knowledge. Within her experience the expert nurse has an intuitive grasp and a deep understanding of the total situation (Hanson, 1995). Similarly, Benner (1984) says "the expert nurse, with an enormous background of experience, now has an intuitive grasp of each situation..." (p.32). Benner and Tanner (1987) define intuition as "understanding without a rationale" (p.23). He/she is able to grasp the total situation, to recognise recurring patterns and similarities particularly from dealing with similar patients in the past in knowing both the disease process and the intricacies of the illness. The expert nurse is able to differentiate between the very important, the important, and the unimportant in the context of the total situation (the physical, psychological, social and spiritual components).

Benner and Tanner (1987) ask: "can we teach intuition?" (p.30). Intuition comes in to the 'art' of nursing. The scientific component of nursing may be taught successfully in the classroom setting. The 'art' of nursing allows the expert nurse to be creative and innovative in his/her care. Benner and Tanner (1987) say that pattern recognition that goes along with the development of the intuitive "can be developed through case studies, enriched feedback, by precepting, and by the validation of expert nurses" (p.31).

2.3.2 Articulating the Theoretical and the Practical Knowledge

It is often the seemingly small acts of bedside care that make all the difference to the patient and family. I wonder: how might the novice nurse learn about such acts of care? How might the 'expert' nurse effectively articulate such acts of care so that the novice may provide competent and confident care in the clinical setting? This is indeed a challenge for the novice and the 'expert' nurse.

Rittman, Paige, Rivera, Sutphin and Godwin (1997) in their study describe the (shared) practices of oncology nurses caring for dying patients. The authors asked nurses on an oncology unit who were regarded by their peers to have a high degree of expertise, to describe an experience of caring for a patient who was dying. In the background to their study Rittman et al (1997) importantly differentiate between practical and theoretical knowledge. They say "practical

knowledge, the “knowing how” gained from experience, differs from theoretical knowledge taught as formal knowledge in educational programs. Skills and shared practices of a discipline constitute practical knowledge” (p.116). This is indeed an important differentiation. The novice nurse has the theoretical knowledge provided for in her training but the practical knowledge comes from the clinical setting. The two, though, may be, and often are, very different.

Rittman (1997) go on to say that it is this degree of expertise in caring for dying patients that allows these nurses to “establish different levels of involvement in different situations. At times, they become very involved and experience a closeness that has great meaning...at other times, their relationships with the patients may not include an engagement of this intensity” (p.119). The establishment of such a relationship between the nurse and the patient does not occur through acquiring theoretical knowledge alone. I believe it is also established through the practical knowledge learned in the clinical setting.

2.4 WHEN AND WHERE DYING OCCURS

2.4.1 When Does a Person Cross the Boundary from being Terminally Ill to Entering the Active Dying Phase?

Pitorak (2003) in her paper ‘Care at the Time of Death’ correctly points out that “active dying is the process of total body system failure” and that “each patient’s death takes a different course” (p.44). As with most aspects of nursing care, each individual case is different. This adds to the difficulties experienced in transferring classroom teaching into learning in the clinical setting. There can be no set pattern, no set expectations. Pitorak (2003) explains the active dying phase by discussing each body system and the changes that may occur as that system shuts down.

Ellershaw and Ward (2003) talk about “diagnosing dying”. Although their clinical review article appeared in the British Medical Journal I believe it contains much information of use to nurses and to nursing. The authors cite Higgs (1999) who says that “in order to care for dying patients it is essential to diagnose dying” (p.30). Ellershaw and Ward (2003) recognise that such diagnosis is complex and difficult particularly in a culture where cure rather

than care is emphasised, midst the available technology. They go on to remark that being able to recognise “the key signs and symptoms is an important clinical skill in diagnosing dying” (p.30).

Ellershaw and Ward (2003) then use the dying phase for cancer patients as an example, recognising though that no two situations are the same. They say: in cancer patients, the following signs are often associated with the dying phase: the patient becomes bedbound, is comatose, is able to take only sips of fluid, is no longer able to take oral drugs” (p.31). Whilst this may seem to greatly simplify the situation, these signs and symptoms may be a useful guide for the new graduate nurse who may be unfamiliar with care of such patients.

Ellershaw and Ward (2003) in the article clearly describe the multi professional team approach to care of the dying patient. The authors also recognise the “hospice model of intensive palliative care...providing physical, psychological, social, spiritual care for the patient and the relatives” (p.32). I believe this is a very useful article for the new graduate nurse who may have little experience of care in this area. The article would be particularly useful as the novice nurse attempts to determine whether a patient has entered the actively dying phase of illness. Clues and cues associated with the dying phase are identified and described by the authors.

2.4.2 The Clinical Settings in which Care of the Dying takes place

As palliative care has developed as a specialty the gaps between theory, research practice have widened. (Dowell, 2002) This is a very important point. Patients in any clinical setting die. Nurses caring for dying patients and their families may be found in any clinical setting. Lev (1986) recognises the diversity of clinical settings in which care of the dying may take place. Dying does not just take place at a hospice. In fact, as Meraviglia et al (2003) rightly point out in their introduction, “in the past 20 years, much of the care for the terminally ill has shifted from acute care hospitals to their homes or extended care facilities” (p.122). I believe that as society as a whole becomes more aged that shift, particularly toward extended care facilities, will become even more marked.

Nurses, in whatever setting they work, will inevitably have to care for patients who are dying. But not only that, nurses will also have to assist the patient/family to decide where the dying family member wishes to die. The nurse will have to facilitate, to make it possible, for that person to fulfil their wish to die where they wish to – be it at home, the hospice, the hospital, long term care facility or indeed a combination of these places in terms of support.

Today it appears that more patients wish to live out their final days in their own home. Therefore, community, rural or district nurses may be involved in the care. Such patients may be in a surgical or medical ward in a public hospital. As people live longer today than ever before, rest homes may more often care for these patients. Ferrell, Grant and Virani (1999) in their study make an important comment by saying that “palliative care, which has traditionally been limited to hospice programs, must extend to other settings and be incorporated into the trajectory of care” (p.256). Aranda (2001) makes a comment similar when she says there is a need to move away “from what have been identified as ideological perceptions of hospice care, to consideration of contemporary models of palliative care delivery as part of the mainstream health care” (p.764).

2.5 NURSES’ EDUCATIONAL PREPARATION FOR CARE OF THE DYING

2.5.1 The Adequacy of the Educational Preparation of Health

Professionals to Care for the Dying

It has long been cited in the literature that health professionals, medical and nursing, feel inadequately prepared, educationally, to care for dying patients and their families (Wong et al, 2001). Nurses find themselves particularly inadequately prepared in this aspect of care, in terms of communicating with dying patients and their families (Wong et al, 2001). Nurses have reported that the reality of practice is very different to theory they have received (Brisley and Wood, 2004). Nurses commonly state that their basic nursing education left them less than adequately prepared for end-of-life care (Ferrell, Virani, Grant, Coyne, Uman, 2000; Manias, Kristjanson, Bush, 1997). Training has been described as lacking and ineffective (Ferrell, Grant and Virani, 1999; Farrell,

1998). This lack of preparation is in relation to what is taught as well as how and where it is taught.

Downe-Wamboldt and Tamblin (1997) undertook "An International Survey of Death Education Trends in Faculties of Nursing and Medicine". The researchers state that their descriptive, exploratory study had the following purpose:

...to identify and describe the current availability of death education, including teaching and evaluation methods, specific content areas, and the professional background of faculty members involved in teaching death and dying content in university programs of nursing, medicine and social work in Canada and the United Kingdom, and to identify priorities for future education planning (p.179).

A seven page questionnaire was developed based on relevant literature and mailed to the professional or national academic associations of university based programs for nursing (80), social work (65) and medicine (36). Sixty-three percent of the questionnaire responses were received from nursing programs; the response rate from Canadian programs was 93 percent nursing, the rate was forty-five percent nursing from the United Kingdom.

Death education content was included in all of the Canadian nursing programs who responded, and 96 percent of those in the United Kingdom. The nursing programs allocated a greater number of classroom and clinical practice hours than did the medical programs. It was reported that "sixty-six percent Canadian and fifty-seven percent United Kingdom nursing programs reported that most or several students had the opportunity to work with dying patients" (p.181).

The methods used to evaluate the affective domain of learning and the students' knowledge and attitudes within the nursing programs included observation during clinical practice and discussion. Written tests and case studies were the most common methods used to evaluate the cognitive domain of learning.

Downe-Wamboldt and Tamlyn (1997) discuss whether the most 'appropriate' teachers are those within the same discipline or whether a multi-disciplinary

approach may be more effective. Most frequently the nursing programs used members within their own discipline to teach death and dying content. The medical programs used a multi-disciplinary approach to the teaching of such subjects. The benefits and limitations of each approach were outlined.

The authors made several useful comments in the conclusion and discussion of their study. They remark that although research points to the superiority of experientially based learning over didactic approaches, in this study lectures were the most common teaching approach used in the programs. A priority area for future curriculum planning was the need to provide focussed clinical experiences. The authors say “this finding is consistent with the finding that a structured clinical experience with dying individuals and their family members was provided in few programs” (p.186). I believe that this remains an important area to be addressed today. More research is required to address the area of the interdisciplinary approach to teaching death education according to the authors of this study.

White, Coyne and Patel (2001) surveyed 56 registered nurses, and asked, “What do you wish you had been taught in nursing school about caring for dying patients or terminally ill patients and families?” Themes were identified and the literature searched for the construction of twelve areas representing issues in end-of-life care. A mailed survey was formed from the themes identified in the first phase of the study. The survey questionnaire was mailed to 2334 nurses (Oncology Nursing Society members, across four states in the U.S.A) and 760 responded (33%).

In the part of the study that related to end-of-life continuing education, 26 percent said “they had an excellent level of preparation to effectively care for a patient and family during the end-of-life period; 54 percent reported a good level of preparation, 17 percent indicated a fair level of preparation, and 4 percent reported little preparation” (White et al, 2001, p.149). 74 percent of the participants reported that they had received continuing education related to end-of-life care in the last two years and of those, 55 percent had received over four

hours in continuing education. Most who had received continuing education found it to be useful and current, that is, they were able to use it in their practice.

2.5.2 The Place of Continuing Education

In a study undertaken by the Nursing Times and The Nuffield Trust (2001), United Kingdom, where 300 readers completed a questionnaire survey 'How do you deal with death', Addington-Hall (2001) reported that "only 64 percent of respondents had received pre registration training [to care for dying patients]" (p.24). On a more positive note it was found that the younger nurses were more likely to have received such training.

The participants in the study by White et al (2001) were asked to rank in order "12 topics that comprise EOL (End of Life) care competency that they wish they had learned in nursing school" (p.149). The results: "Almost two-thirds of the respondents ranked one of three competencies highest: how to talk to patients and families about dying (30%); pain control techniques (28%); and comfort care nursing interventions (9%)" (p.149).

In the discussion section of the study White et al (2001) make five major concluding remarks. Firstly, that one third of the nurses in their study received less than two hours' continuing education in end-of-life care during 1997-1999. Secondly, the core competencies and educational needs (for example how to talk to patients and their families about dying) were ranked by the respondents according to their age. But the top rated competencies (for example recognising impending death, comfort care interventions, cultural perspectives of care) were consistently ranked despite age, state where working, educational level, practice setting. Fourthly those nurses who reported receiving little or no continuing education worked in outpatient setting or physicians' offices. Finally, the researchers cited that organisational values "might help administrators determine budget priorities related to providing palliative care services and continuing education" (p.151).

Quite a different focus is provided in a study by Ferrell, Grant and Virani (1999) who describe a project funded by the Robert Wood Johnson Foundation:

“Strengthening Nursing Education to Improve End of Life Care” (p.252). Interestingly the stated overall purpose of the project is to strengthen nursing education to improve EOL care by accomplishing three goals: “goal 1 is to improve the content regarding EOL care that is included in major textbooks used in nursing education. Goal 2 is to ensure the adequacy of content in EOL care as tested by the national nursing examination. Goal 3 is to support the 3 key nursing organizations in their efforts to promote nursing education and practice in EOL care” (p.252). I wonder, how do these goals relate to the classroom learning and clinical competency of nurses towards care of the dying in their practice setting?

The resources rated as being the most helpful to assist faculty in improving EOL content in nursing education were named as being: “case studies, access to clinical sites, internet resources, audiovisuals, access to speakers, lecture guides/outlines, computer assisted instruction, textbooks, and standardised curriculum” (p.254).

2.6 THE CURRICULUM RELATED TO CLASSROOM LEARNING

2.6.1 An Integrated Approach Throughout the Curriculum or an Elected Course?

Tanner (2004) says “The Meaning of Curriculum: Content to be Covered or Stories to be Heard”:

...changing the way we teach is a journey, one of our own learning, reflection, and growth. When we begin to see ourselves as mentors and guides, rather than experts, when we become committed to hearing the students’ interpretation of their experiences over our “points to make”, and when we understand that to nurse well takes tending to the body, mind, and spirit, we commit to creating places for that growth to occur. And then our discussion about curriculum will shift from what content is covered, when, and at what level, to ones about our broad learning goals and way we engage students in authentic learning (p.4).

There is an abundance of exploration within the available literature of the merits of an integrated approach throughout the curriculum. There is ongoing

discussion and debate in the literature regarding whether a topic such as care of the dying is most effectively taught/learned when integrated throughout the nursing curriculum or offered as an elective course (Wong et al, 2001; Degner and Gow, 1988). Should the learning of such a subject be compulsory or offered as an elective? I believe that this, and the response to this question, are key factors in the effectiveness and appropriateness of teaching/learning such a subject.

Lev (1986) describes an elective course designed at the College of New Rochelle, using a hospice program of care as the framework. The course included both a didactic approach and a clinical component. Lev says the course is based on the belief that “a long-term guided experience with dying patients and their families helps students deal with grief and the grieving process” (p.242). The course assists nursing students to explore their reactions to working with patients who are dying and helps them to develop their communication skills. There is an associated belief that by assisting the students to examine, and so reduce, their fears they will in turn be able to provide more humane care to these patients. The didactic component required two hours a week and the clinical component required three hours a week. The students made a weekly visit to a patient at home or in a variety of health settings.

The students recognised and described strengths of the course as: “the long-term relationship with the patient and family; the ability to schedule visits at mutually convenient times rather than being assigned to a specific time to visit; and interacting with hospice team members in the agency to which they were assigned” (ibid, p.243). The overall finding: “The elective course in hospice nursing demonstrated that students’ knowledge, attitudes, and behaviours toward death and dying patients can be changed” (ibid, p.243).

Degner and Gow (1988) critically reviewed fifteen evaluations of death education in nursing. The most frequent approach to death education has been to integrate the subject in to the curriculum (in the United States of America). Such integration included teaching/learning methods such as lectures, seminars, specified readings as well as, Degner and Gow (1988) say “exposure to care of

the dying and their families in clinical practice” (p.152). But clinical experiences varied from student to student and there was little indication of assigned clinical experience with dying patients. Exposure to care of the dying in clinical practice does not necessarily mean a ‘hands on’ clinical experience.

The second most popular approach to providing this education to nurses was by means of an elective course with specific objectives and including role plays. Despite the popularity of these two methods of teaching/learning care of the dying there was little evidence of supervised clinical practice inherent in them.

Degner and Gow (1988) conducted a study in which the experimental group were third year undergraduate nursing students who received a required course in palliative care; a nursing control group received an integrated approach to death education throughout their four-year undergraduate program and a non-nursing control group received no death education as part of their four year program. The groups sat pre-tests and post-tests at set times. 330 students took part. The independent variable was an eight credit hour undergraduate course. The dependent variables were death anxiety, and attitudes to care of the dying. The two central questions for this study were: firstly, do all nursing students need to receive death education. The second question being: should death education include supervised clinical practice? I believe the second question is vitally important, especially today.

Degner and Gow (1988) found that “the inclusion of a required course appeared to stimulate death anxiety and improve attitudes *even prior* to its being taught. In the integrated program, death anxiety gradually was reduced and attitudes to the care of the dying gradually were improved over time” (p.166). The students who received a required course judged their program as being more adequate in preparing them for care of the dying than the students who received an integrated approach.

The students revealed their perceptions about the most effective way to teach care of the dying (revealed during the qualitative interviews and analysis). The students would firstly analyse their feelings and attitudes to death in lectures and

seminars and follow on to form a framework by which they might assist patients and their families in care of the dying. Secondly the students would be assigned to a dying patient, following him/her through to death and maintaining contact with the family after the death. It would be hoped that the student would have experiences in at least two different settings, for example in hospital and in the community. But this is the ideal. As Degner and Gow (1988) say “few existing educational programs would meet these requirements, even those offering elective or required courses.

This study provides much useful insight for nursing care of the dying in the curriculum today. With regard to the second question in the study, should death education include supervised clinical practice, the answer from the students as new graduates in this study was “an unequivocal “yes!” ” (p.168). This is an important finding, for then, and for the present.

2.6.2 The Focus of Teaching

The focus is primarily on the acquisition of knowledge rather than exploring values, attitudes and skills (Wong et al, 2001). I believe that establishing the effectiveness and appropriateness of teaching and learning about care of the dying, lies not only in the acquisition of knowledge and/or exploration of attitudes and values. It also lies in establishing how the [classroom] knowledge might best be transferred by the nurse learner to the clinical setting.

Degner, Gow and Thompson (1991) completed a qualitative study in which they asked ten experienced palliative care nurses and ten nurse educators to describe situations in which a student or graduate nurse had displayed very positive or very negative attitudes to care for the dying. Seven critical nursing behaviours were identified in the study, these were: “responding during the death scene, providing comfort, responding to anger, enhancing personal growth, responding to colleagues, enhancing the quality of life during dying and responding to the family” (p.248).

Degner et al (1991) focus on the acquisition of knowledge and behaviours in relation to the nurses caring for patients who are dying. The authors say in their

discussion that “the seven critical nursing behaviours identified in this study could serve as a beginning guide for structuring nursing education programs about care for the dying.... Subsequent projects in this research program will use the beginning list of critical behaviours to define a model of expert nursing practice by studying comparative samples of nurses from a variety of clinical settings: (p.252-253). There is little mention of how the knowledge and behaviours are linked to or learned in the clinical setting.

Ellershaw (2001) says the health professionals’ emphasis on cure means that they are unable to respond to the needs of dying patients and their families. He follows on by saying that “ if best practice is to be achieved in the care of the dying, it is not just the acquisition of knowledge and skills, which is required, but also a change in attitude, especially in the hospital setting” (p.3).

2.6.3 The Educational Format – Active (Experiential) or Passive (Didactic) Participants?

Where care of the dying is included in the curriculum it appears that the lecture style of teaching/learning is used. The lecture style does not encourage the learner to take an active part.

The didactic approach to learning primarily by lecturing, is not appropriate to effective and efficient teaching and learning in the clinical setting. An emphasis on developing a learning curriculum is required. Inherent in such a curriculum is informal learning in the workplace, or on-the-job learning.

Sellick, Charles, Dagvik, Kelley (1996) completed a study that described the education needs of non-physician service providers of palliative care. The data was collected using a survey and a two-hour in depth focus group. 146 surveys were distributed and 135 were returned. Sellick et al (1996) reported that “fifty-nine percent of the respondents categorised their palliative care involvement as hands-on, direct care” (p.36). Thirty-two percent felt their formal education had adequately prepared them for delivery of palliative care. Although they felt prepared due to their educational background, they did not necessarily feel confident. Sellick et al (1996) make the following important statement “Instead,

confidence in delivering palliative care was strongly related to actual, hands-on experience as reflected in total time spent in direct care” (p.36). But despite this it is interesting to note that the preferred learning format was the lecture mode. Formats considered desirable were “small-group problem based learning, practicum opportunities, and rounds” (p.37). So despite recognition of the importance of hands-on experience, the preferred mode of learning was still the lecture method. Why might this attitude prevail? How do we move away from a sometimes inappropriate emphasis on learning by lecture? There is a need to move outside the classroom to learning in the clinical setting.

It appears that students are not often encouraged to examine their personal reactions to experiences of caring for patients who are dying (Wong et al, 2001). The personal experiences of the nurse play a large part in the nurse-patient relationship. Often the nurse will deal with particular situations well or badly depending on her/his own personal experiences with death and dying. What comes first for nurses, confronting their own reactions to death, or gaining experience caring for patients who are dying?

Hurtig and Stewin (1990) in their study asked the following question: How can nurse educators help students to face death-related fears before they come to the bedside of the dying patient? They saw death education as one possible means, but stated that there was no conclusive evidence as to its effectiveness. The subjects for their study were a first level class of 106 diploma nursing student with no clinical experience. They were randomly assigned to one of three groups: experiential, didactic and control.

The didactic approach consisted of lectures, films, group discussion to present topics such as: death in society, a developmental view of death, the process of dying, tasks of the dying and the value of death. The experiential approach consisted of a personal focus using death awareness exercises, music, drawing, dyadic encounters between students. The control was a simulation game. The authors reported that “an experiential programme was more effective than a didactic approach in helping students without a personal death experience to confront their thoughts and feelings concerning death” (p.32). Students who

were 'death experienced', in terms of their own life experiences found both the didactic and experiential approaches beneficial.

Hurtig and Stewin (1990) ask if it would be useful to divide a group of students according to whether they were death experienced. That is, those students who have little or no experience with death prior could benefit more from an experiential approach. Those students experienced with death could benefit more from a didactic approach in their learning.

The authors make the comment that "such a division may also facilitate the dynamics within the learning groups, as students may be more able and willing to share reactions to death with others having similar experiences" (p.33). These authors do make some valid points but once again there is no clear link between classroom learning and transfer of that learning to the clinical setting.

Wong et al (2001) discuss the effectiveness of a problem based learning approach to caring for dying patients. The participants were a group of 72 registered nurses who were enrolled in the fourth year of their degree studies. The students were divided into three large groups and each group focussed on a problem. The large groups were further divided into four groups of six. Each problem had three scenarios and these were ongoing. The group would discuss the scenario, identify cues, inferences, and problems. They decided on aspects that required further clarification and how they would obtain that. Wong et al (2001) says the members of the groups shared what they had learned and critiqued each other's view points" (p.114). Each student kept a journal containing the process and learning gained from exploration of the problem and scenarios.

Through this process the students examined their own attitudes, their fears of death and brought unconscious thoughts to their conscious awareness. They specified areas for further development. Wong et al (2001) say in the discussion of their study that "with the support of their peers, nurses in this study gradually changed their attitude from avoiding to confronting the issue, and eventually gained confidence in dealing with the dying and their families" (p.118).

Wong et al (2001) ask the following in their conclusion: “What are the key features of problem-based learning that contribute to such learning effects?” (p.120) Segmented scenarios establish a context for learning, the students have to explore to find possible answers, the situations are practice related and so can add to their knowledge base. The approach involves brainstorming in group work, thus the students can challenge each other and share their thoughts.

2.6.4 Care of the Dying in the Clinical Area

There is an abundance of literature that discusses and describes teaching and learning in the classroom that is related to learning to care for the dying. However there appears to be much less study of how nurses might best learn about such care in the clinical setting. Robbins (1989) makes the following comment identifying how important a combination of modes of learning is in effective care of the dying:

...by learning from observing more experienced colleagues, by reading from the considerable literature now available, and by overcoming the tendency to avoid dying patients because of painful and inadequate feelings in ourselves, we can demonstrate a more confident attitude to the dying patient in our efforts to make his or her dying comfortable in body, mind and spirit (p.10).

Beck (1997) conducted a study to “explore the meaning of 26 undergraduate nursing students’ experiences in caring for dying patients” (p.408). The students completed written accounts of their experiences. Six themes emerged: the students experienced a gamut of emotions while caring for these patients; as they cared for these patients the students contemplated the patient’s life and death; supporting the family of the dying patient became an integral part of the student’s care; helplessness was experienced by the students in their role as advocate; their nursing care included providing physical, mental and spiritual comfort; and while caring for these patients the students’ learning flourished.

Beck identifies and recognises that nursing students need assistance to manage the ethical challenges that they encounter as they care for dying patients. The author sees a role for discussion in small group to enable students to argue for

and against specific positions. Beck (1997) says such an “educational strategy can be used to help prepare nursing students to deal with ethical dilemmas they will be confronted with in caring for dying patients” (p.414). Beck goes on to say that “time needs to be designated in nursing curricula to allow students the opportunity to grapple with these difficult issues before they encounter them on the clinical unit” (p.414). I believe it is very important that such issues are dealt with at least in part in the classroom before the students are working with these patients in the clinical area.

Later Beck (1997) talks about the use of role models, in terms of less experienced nurses observing and carefully imitating expert nurses. Here Beck, I believe, makes several important points about how nursing students may learn in the clinical area. She says “Expert nurses are the role models who act as mentors or instructors to the less experienced nurse or nursing student. Perhaps when nursing students begin caring for dying patients they can be linked up with expert nurses on the unit where novice students are assigned” (p.414).

Beck (1997) suggests that when the student nurse is assigned to a dying patient for the first time she could be an observer, working with an expert nurse as her mentor. Beck (1997) goes on to point out the advantage of such a situation, “once the primary responsibility for providing care to the dying patient is removed from novice students, their anxiety level decreases and allows the students to observe and study the performance of their mentors before they are required to care for a patient on their own” (p.414). Dunlop and Hockley (1998) also recognise the value of the novice-expert interaction. They say “Role-modelling is one of the most useful informal methods of teaching-having the learner come in to see how the expert interacts with the patient or family” (p.112). Dunlop and Hockley go a step further in saying that such teaching “can be carried out across disciplines” (p.112).

Hoban (2004) recognises and describes differences between traditional role models and the models described in today’s nursing climate. She says:

...traditional role models include ward sisters, ward managers, and mentors but nurses are now looking for inspiration from less traditional

areas: junior colleagues, nurse consultants, modern matrons, doctors, and allied professionals....

Rather than heroes on pedestals, role models should be human beings who people can turn to for advice (pp.22-24).

Thus nurses may well look outside of their own profession for role models.

I believe that there is a lot of merit in this teaching/learning situation in the clinical area. This way the novice nurse feels, and indeed is, supported in a situation that she is initially unfamiliar with and probably anxious about. This way much expertise that is 'invisible' can be shared as the novice and the expert nurse share in the patient care and the clinical situation. Not only are the knowledge and skills of the 'expert' nurse invisible but I believe that the process where the knowledge might be/is shared is also invisible to others. Beck (1997) says in her concluding remark: "Nursing students should be encouraged to share with each other their stories regarding the rewarding aspects of caring for the dying" (p.414). Indeed all nurses, novice to expert, should encourage each other to share such stories, as this is how 'invisible' knowledge and expertise becomes visible. Beck's (1997) study is a valuable one.

Kenny (2003) investigated the effectiveness of palliative care education and the difference it may make to practice introduces the concept of "clinical facilitation". She introduces this concept as an addition to the well-known methods of facilitation such as mentoring, clinical teaching and preceptorship. Kenny says clinical facilitation is being used "to describe the process of working with students in a clinical setting" (p.192). In other words once the student has completed the course the teacher works alongside that student in the clinical setting to see how they apply the new learning to their daily practice. Such facilitation allows the teacher to note how the new learning is integrated in to practice and whether that integration is sustained over time. Kenny (2003) goes on to say that clinical facilitation "acts as a reminder to students when the enthusiasm about the course may have waned and they are back in to the responsibilities of their own workplace" (p.192).

I believe that there is much merit in the concept of clinical facilitation. It assists the student to continue to integrate the theory and practice inherent in attending a course and then continuing to apply that learned in their own workplace. It also means the student is able to integrate the theory with the practical in a positive and supportive environment.

Pitorak (2003) recognises the importance of nurses “seeking the assistance of the interdisciplinary team” (p. 50) in order that they do not feel they are caring for the dying patient on their own. The author also rightly recognises the role of debriefing or “professional review” (p. 50) after a patient’s death. This allows the staff to review the events around the death and to enable both professional and personal learning. This review also allows concerns and questions to be dealt with. I believe that such debriefing, particularly in clinical areas where a number of deaths occur, assists with the prevention of ‘burnout’ in nurses.

2.7 THE NEW ZEALAND SCENE

2.7.1 Care of the Dying in Nursing Education in New Zealand

Manias et al (1997) make a vital point as they describe the challenges for Australia and Canada (and indeed for New Zealand) in palliative care nursing education. They say “An essential element of palliative care nursing education is a strong research base. As palliative care nurses undertake research that better articulates their practice and examines clinically relevant research questions, this knowledge should be integrated into undergraduate and postgraduate nursing curricula” (p.96).

Aranda (2001) expresses the following concern:

The role of specialist palliative care nurses in providing direct “hands on” care to the dying is perceived to be under threat in Australia and New Zealand as a result of government imperatives that empathize the role of all health practitioners in providing appropriately for the need of people dying in their care (p.757).

Much of the knowledge and many of the skills inherent in the care provided by ‘expert’ nurses to patients who are dying lie in the heads of those nurses. It is imperative that such knowledge is articulated if it is to have any effective chance

of being shared with new graduate nurses. Once such knowledge is articulated, clinically relevant questions can be formed, thus there is a link between the theory learned and the clinical aspects of care. Only then can the next step be successfully implemented; integrating the knowledge and skills of those 'expert' nurses in to the under-post graduate nursing curricula.

With the introduction of the Health Practitioners Competency Assurance Act (2003) and along with that, competency based practising certificates for nurses, much that lies 'hidden' in the heart and head of nurses will be uncovered. In other words making the tacit explicit. As nurses work toward the presentation of their professional portfolios the stories of nursing will be articulated and shared at a new level. As the stories are shared by nurses there will be an ongoing identification of educational and research opportunities in areas of nursing that have been less explored in the past.

2.7.2 Possibilities for the Future

Owens (2003) says "...as nurses we all teach, both informally and formally, everyday to patients, families, and professional colleagues" (p.184). One aspect of palliative or end-of-life care that is clear in the literature is that such care is of a team, multi/trans-disciplinary (Doyle, 1996; Kristjanson & Balneaves, 1995; James, 1993) and multi-professional nature (James, 1993). As such the educational program should be of a multi-disciplinary nature also (Dowell, 2002; Kristjanson & Balneaves, 1995). Kristjanson & Balneaves (1995) do recognise though that there must be a "blend and balance" between the interdisciplinary care team and "discipline specific care associations" (p. 8). In this way the standards and educational requirements of each professional group are identified and addressed. Interestingly though, Loftus and Thompson (2002) say "there are good reasons for offering uni-disciplinary courses for generic nurses ... confidence, knowledge level of nurses, educational background, availability of practice placements on pre-registration nursing courses and the number of patients who currently die without specialist placements" (p.354).

Within the multi-disciplinary and multi-professional approach to care James (1993) uses the terms "sharing knowledge in the care setting... sharing of

understanding” (p.7). Thus, I believe, it is important that any ongoing education in the clinical setting regarding care of the dying be of a multi disciplinary nature. It is the wide variety of individuals who make up the palliative care team that sets it aside from other medical specialties (James, 1993). James sees that the task of palliative care education is not to merely teach those who do not know, it is to “articulate to others, their theories and bases for action and to develop in other caregivers a framework for the understanding of practice” (p.8). In other words, it is for those with expertise in end-of-life care to be able to articulate ‘why they do what they do’, to be able to effectively communicate how they have acquired their expertise. Didactic approaches to education will not achieve this aim.

So, I wonder, how do we get a multi-disciplinary, multi-professional group together, all of whom have a passionate interest in firstly, improving the quality of life for patients facing the end of their life, and secondly, clinical education for all professionals but in particular, nurses involved in the care of such patients? What ideas was I able to glean from the available literature?

Etienne Wenger and various colleagues introduce, or perhaps rather, reintroduce me to the idea of communities of practice. Wenger, McDermott & Snyder (2002) define communities of practice as “groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis” (p.4). Groups such as these are not new or at all uncommon, in fact they exist everywhere. Wenger & Snyder (2000), in a very useful and informative paper, briefly describe communities of practice as “groups of people informally bound together by shared expertise and passion for a joint enterprise” (p.139). Wenger et al (2002) go on to describe the characteristics of such groups and their members, they say

These people don’t necessarily work together everyday, but they meet because they find value in their interactions. As they spend time together they typically share information, insight, and advice. They help each other solve problems. They discuss their situations, their aspirations, and their needs. They ponder common issues, explore ideas, and act as sounding

boards. They may create tools, standards, generic designs, manuals, and other documents-or they may simply develop a tacit that they share....

Over time, they develop a unique perspective on their topic as well as a body of common knowledge, practices, and approaches (p.4-5).

These groups are informal, may be spontaneous, members generally organise themselves (that is, in terms of leadership and setting agendas) and may share their experiences and knowledge in ways that are very creative. Such groups, due to their energy and passion, may foster best practice, solve problems efficiently and develop professional skills toward mentoring as a means to share knowledge and skills.

I believe communities of practice may be one way that professionals (multi) with a passionate interest in care of the dying can join together to discuss how clinical care occurs, how it may be best learned in an effective and supported way. Professionals within the group may be able to provide support in the clinical areas in terms of mentoring, preceptoring, buddying, supervising and guiding less experienced staff as together they care for patients who are dying. Wood (2003) describes a “care pairs program [that] takes care of new RNs” (p.1). This is one way in which experienced and new graduate nurses may be buddied in clinical practice. Following the death of a patient, members of the group may spend time with less experienced staff discussing the care, debriefing, reflecting on the experience. Communities of practice ‘set themselves up’, membership is self-selected, the groups are self organised and set their own things to be completed as they see fit.

2.8 SUMMARY

Many of the studies I have reviewed above concerning care of the dying emphasise the classroom curriculum. There appears to be very little evidence of how classroom learning is linked to clinical practice, and indeed whether it is able to be linked. I wonder: what about the *clinical* teaching and learning between the experienced and novice nurse in the workplace? I believe there is a very large gap in the literature here. How do nurses make the important transition from classroom learning to the clinical setting in terms of caring for

the dying? Who really teaches nurses to care for the dying? Does it occur in an adhoc and 'hit and miss' or piecemeal way? As nurses how can we improve both the education and clinical practice in end-of-life care?

CHAPTER THREE

METHODOLOGY AND METHOD

3.1 INTRODUCTION

Methodology refers to the overall approach used in this study. The method concerns the details of how that approach is planned and implemented.

The research questions for this study are:

What clinical knowledge/skills do 'expert' Registered Nurses possess that allows them to care competently and confidently for patients in their final forty-eight hours of life?

How might these experienced nurses most effectively share their knowledge/skills with new graduate nurses in the clinical setting?

In order to answer the research questions I believed it was necessary that I gather detailed information from nurses with expertise in care of the dying. The information would include stories of their nursing practice in the clinical setting. Secondly I sought to ascertain from these nurses how they saw they could most effectively share their knowledge and skills with novice nurses. Thus I chose a qualitative methodology for this study. The methodology is described in detail in the following section (3.2).

The details of the method I used to answer the research question included the collection of demographic information, semi structured interviews, a written clinical narrative and thematic analysis. The collection of the demographic information provided me with information about the participants – their length of experience in nursing, how long they had been involved with care of the dying and the context in which they practiced. The semi-structured interviews allowed the participants to share the detailed information I required to answer the question. The written clinical narrative provided an added dimension to the data collection in that it allowed the participants to reflect on an incident in their clinical practice. The method is described in more detail in a later section (3.3).

3.2 THE METHODOLOGY

3.2.1 The Qualitative Approach

The approach is interpretive, exploratory and descriptive in nature. The qualitative in terms of research approach is used in an endeavour to uncover and capture the meanings and interpretations of the particular community of people being studied.

This study is *interpretive* and qualitative in terms of the researcher interpreting the experiences of those nurse-participants in their care of the dying in order that their knowledge and skills be made explicit and be able to be articulated for new graduate nurses in order that they be shared. Thus an interpretive and not a positivist paradigm is used in this study. A positivist paradigm would be too objective and scientific an approach for this work. The emphasis is on the interpretation of narratives, not numbers, and so experiences rather than statistical evidence are sought in this study.

It attempts to make implicit knowledge and skills more explicit. In this study the researcher is seeking to make explicit the 'heart' and 'head' knowledge and skills experienced nurses hold associated with care of the dying. Once this knowledge is made explicit and so is able to be articulated it can then be shared effectively and efficiently with new graduate nurses. In order that the researcher successfully accomplish this, the study is required to be exploratory, descriptive and interpretive in nature. Polit, Beck and Hungler (2001) say that "exploratory research investigates the full nature of the phenomenon and the other factors with which it is related" (p.19). The researcher *explores* with the participants their knowledge and skills, so that these are identified and then articulated and described. The *description* occurs verbally in terms of a semi-structured interview and also in written form in terms of a written clinical narrative in this study. The reason for the written part is the formation of a resource document for new graduate nurses who may be placed in the clinical setting.

3.3 THE METHOD: PLANNING THE STUDY

3.3.1 Background

My interest in how nurses care for patients who are dying was initially sparked by my long-standing practice in the Oncology field and, more recently, in nursing education. A newly graduated nurse may have completed her training and never been involved in the care of a patient who was dying. I had also seen new graduate nurses being allocated patients who were dying because it was perceived that, as these patients were no longer receiving active treatment, they did not require a lot of input from their nurse. I wondered how I could assist nurses with experience in care of the dying to share their knowledge and skills with less experienced nurses. I talked informally with new graduate nurses to ascertain what kinds of experience they had had in this area of care. It became apparent that often inexperienced nurses were plunged in to caring for patients with very little education or support. This led to negative experiences at times, and the nurse feeling very much 'out of her depth'.

My wish was to explore the knowledge and skills that nurses had, who were experienced in the care of patients who were actively dying. I sought to discover where those nurses recognised they had gained that knowledge and those skills from. I was interested in how those nurses currently shared the knowledge and skills, with less experienced nurses, in the clinical setting in which they practiced. And finally I aimed to explore with the nurses what might assist them to share their knowledge and skills more effectively (in their opinion).

3.3.2 Ethical Issues

As I prepared the ethics application for this study I became aware of the potential ethical issues. This was particularly with regard to the sensitive nature of the topic and the relationships between the nurses and patients. I recognised that there could be emotional risks for the participants in this study. I was also aware of myself, as the researcher, that I needed support too. There could also be emotional risks for myself in this study.

To minimise the emotional risk to myself, as the researcher and to the participants, I approached a senior Social Worker to be available if there were issues that required ongoing support following the interview.

I was aware that nurses with different cultural backgrounds might desire to take part in this study. I did not wish to exclude any nurse from participating on the basis of culture. The Consent Form included the request for an interpreter if required (see Appendix B).

To this end participants were offered the opportunity of having a support person present for any part, or for the duration of, their involvement in this study. Ongoing support was available to all the participants if emotional issues had been raised during the data collection. The participants were able to consult influential members (as indicated by the participant) of their affiliated group during the process of consent. As the researcher of the study, if requested by a participant, I would have consulted the influential members (as indicated by the participant) of that participant's affiliated group to discuss this study. None of the participants took up this offer.

The issue of informed consent was considered in terms of the ethics proposal. The study was advertised (see Appendix B) in the local newspaper and as a poster in clinical settings and outside the staff cafeteria within MidCentral Health (after gaining the appropriate approval to do so). Any nurses interested in participating in this study contacted me and I posted out further details such as the Information Sheet (see Appendix B). If still interested following reading the Information Sheet the nurse then contacted me, to clarify any issues or questions answered. A convenient time and venue for the interview was then arranged. The written consent form (see Appendix B) was signed immediately before the interview.

I was very aware that, as the Registered Nurse participants were being recruited from within MidCentral Health they could be, perhaps, more easily identified in the thesis report. I chose to identify the participants using short pseudonyms with no gender preference (Chris, Kim, Lou, Lyn, Mic, Pat, Phil, Rob and Sam).

For the same reason the demographic information included does not directly link any one of the participants to any particular clinical area. The more personal details of the participants have been changed in their stories and clinical narratives.

3.3.3 Approaching the Ethics Committees

An ethics proposal was submitted to the Massey University Human Committee (June 2003) and to the Manawatu-Whanganui Ethics Committee (July 2003).

The Massey University Human Ethics Committee congratulated me on a very thorough, good quality application. The proposal was approved subject to several minor modifications being made (see letter in Appendix 2). These modifications related to rewording and simplifying the Transcriber's Agreement and the Consent Form. I made the modifications and the Proposal was approved by the Committee.

Following the sending of the Ethics Proposal to the Manawatu-Whanganui Ethics Committee it was suggested by a member of the Committee that I attend the next meeting to speak to the Proposal in person. This suggestion was made as it would shorten the approval process as any questions the members had could then be answered directly. I attended the meeting held on 14 July 2003. The Manawatu-Whanganui Ethics Committee commended me on a well-designed research project. The Proposal was approved subject to two minor modifications (see letter in Appendix B). Firstly the Committee suggested a member of the Maori Health Unit, MidCentral Health as a point of contact if required. The second modification was a change of wording in the Proposal document. These modifications were made and the Proposal was approved by the Committee.

The presentation of an Ethics Proposal in person to an Ethics Committee can be a stressful encounter. I found this part of the process to be worthwhile and fruitful. It allowed me to speak to my Proposal in a clear and honest way and in a way that would not be possible by email or letter. An interesting example of this direct interaction was the discussion that took place at the meeting

concerning the definition of terminally ill. The question was: could a different term be used? The comment was made by the member, we are all terminally ill. Following an informal discussion a more appropriate term was not found!

3.4 HOW THE STUDY WAS IMPLEMENTED

3.4.1 The Selection Criteria

In order to answer the research question I needed in depth information about the daily practice of nurses with experience in caring for patients who were dying. I thought about areas of practice where nurse would care for this type of patient. To meet the requirement I chose to advertise the study in a variety of areas where I determined these experienced nurses would be practicing. In order to collect the depth of information I required I chose to collect the data by means of written demographic information (on a Response Form included in the Information Sheet – Appendix B) and a single semi-structured interview. In addition I chose to ask the participants to complete a written clinical narrative. It was my belief that this piece of work would provide the study with an added dimension, in that the participants would have time to reflect on an incident in their clinical practice that had had a major effect on them at some time.

My aim was to gather data from Registered Nurses, working in a variety of clinical settings, with expertise in the care of patients who were dying. The inclusion criteria for the participants was as follows:

- the participant would be a Registered Nurse;
- the participant would have practiced/be practicing within the MidCentral Health area;
- the participant would have experience in care of the dying (this would be determined by themselves);
- the participant would have worked or would be working in one or more of the following clinical areas: inpatient unit, hospice, Community Health/rural health setting, rest home, Nursing Agency.

3.4.2 Advertising the Study

This study was advertised (see Appendix B for the advertisement) in the free local weekly newspaper, the Guardian, on two separate occasions. This proved to be a valuable and very worthwhile exercise. Six of the participants took part in the study as a result of reading the advertisement.

A letter (see Appendix B) introducing researcher and the study was sent to the Team Leaders, Managers or Clinical Nurse Co-ordinator of these specific practice areas: medical inpatient wards, the hospice, District Nursing Service, Rural areas, Rest Homes (with hospital wings), Nursing Agencies within the MidCentral Health area. In the letter I asked permission for the study to be advertised in the staff sections of the clinical areas. Along with the letter was sent a copy of the Information Sheet and the Consent Form (see Appendix B). A few days following delivery of the letter I emailed or telephoned the Leader of the clinical area to gain permission to advertise the study by way of a poster (see Appendix B), to discuss the study further, answer any questions and offer to visit the clinical area to discuss the study with staff if required. I was aware that I might be refused access to Registered Nurses in some areas. This situation did not in fact occur.

Three of the clinical areas took up my offer to speak to them about the study. These areas were a medical ward, a rest home and the hospice.

3.4.3 Signing Up Participants for the Study

Potential participants registered their interest in taking part by emailing or telephoning me. I then contacted the person to discuss the study and answer any initial questions. Following that initial interaction I posted a copy of the Information Sheet and covering letter to the interested participant. The interested participant was invited to make contact with me or I would follow up with a telephone call two weeks later. This call would allow me to answer any further questions/concerns and ascertain whether the potential participant was still interested in taking part.

3.4.4 The Sample

A purposeful sample was selected according to the experiences, willingness and time available to the participants. The maximum number of twelve participants was selected owing to the time constraints on the study. I was aware that I might not achieve the total of twelve participants. I did state that if I received too many volunteers from one particular setting that not everyone might be accepted to take part. I would notify promptly if volunteers had been accepted or not. In fact no volunteers were not accepted.

Ten Registered Nurses registered their interest in taking part in the study. One nurse later withdrew owing to family and work commitments.

I achieved my aim of recruiting participants from a variety of clinical settings, such as inpatient wards, community, rural settings, Hospice, rest homes and nursing agencies. All of the participants had a minimum of twenty years nursing experience and more than ten years experience in care of the dying. The nine participants, one male and eight females including one Maori, came with a variety of clinical backgrounds, such as Educators, Managers, Care Co-ordinators. The participants worked with a variety of staff whilst caring for the dying – student nurses, new graduate nurses, Registered Nurses, Enrolled Nurses, Care Assistants/Caregivers.

3.4.5 Data Gathering

Triangulation is, as cited by Ellis (2002) the combination of designs, methods, and data sources in the study of the same phenomenon (Denzin, 1978), so the advantages of each complement each other, while the inadequacies of individual approaches are offset (Corner, 1991). Triangulation, in terms of this study, consisted of the demographic data collected, a semi-structured interview conducted and a written clinical narrative completed by each participant.

The demographic data was collected from the participants by use of the response form in the Information Sheet (see Appendix B). The form allowed the participants to provide information about their nursing career, the time and areas

of experience in nursing and their involvement in caring for patient who were dying.

It took six months to interview nine participants. This was primarily due to the limited availability of those taking part – time commitments and work schedules. There were several occasions when arrangements for interviewing had to be rescheduled, owing to participants being called in to work a shift in the clinical setting.

The interviews for this study took place in a variety of settings, depending on what was most convenient for the participant, for example at their home or place of work, or at my home. Each participant signed written consent immediately prior to their interview taking place. The duration of the interviews was sixty to ninety minutes. The participants were welcome to have a support person present during the interview. None did this. The interview was audio taped, following the participant's consent. Each transcript consisted of 12 to 20 pages.

One participant, whom I had spoken to by telephone at length on several occasions prior to her interview, was completely 'put off' by the presence of the audio-tape. In hindsight I should have taken written notes during that interview and not used the audio-tape.

Unfortunately one of the interview tapes was of a very poor quality. This was due to there not being a flat surface available to place the transcribing machine on during the interview.

I advertised on the hospital email system for an independent transcriber, who signed a confidentiality form (see Appendix B). The participants were sent a copy of their interview transcript. This allowed them to comment, add or delete any information. None of the participants did this.

A written clinical narrative was requested to be completed by each of the participants. These were to be completed by 31 January 2004. The reason for the narrative being written rather than given verbal was that in writing it in their

own time the participants could continue to reflect on the incident. The narratives were to be used in conjunction with the stories of patient care shared in the interviews. The guidelines for the writing of the clinical narratives are included in Appendix B.

I had completed the nine interviews by the beginning of February 2004. To that date I had only received one written clinical narrative. I extended the completion date to 30 June 2004. I sent 'friendly' reminders to the participants about every six weeks until mid June 2004. I believe that it was due to work and other pressures that these narratives never got completed. By the middle of July 2004 I had received a total of three written narratives.

3.4.6 Data Analysis/Interpretation

Themes within an interview will not necessarily 'leap out' at the researcher. Instead the researcher is required to reflect on, as he/she reads the transcript, just what the participant is trying to say, to ask, what is the participant trying to tell me? (Morse and Field, 1996)

The plan was to analyse the interview transcripts and narrative data using Luborsky's method of thematic analysis (1994). Luborsky (1994) says that themes can "provide insight into the cultural beliefs and values that instil powerful experiences and motivations and shape how individuals plan, makes sense of, and respond to events" (p.190). The identification and description of themes in this study will allow the researcher to record 'expert' nurses' stories of their care of the dying. During this process to uncover often 'hidden' knowledge and skills (including experiences, reflections, beliefs and perceptions) in the endeavour to provide information useful to new graduate nurses caring for such patients in the clinical setting.

Data collection and analysis occur simultaneously. Themes are discovered and generated as the participants converse during their interviews and reflect during the writing of their narrative. Non-verbal information is as important as the verbal information so that a complete picture emerges as the data is collected.

Initially the researcher becomes familiar with the interview and narrative transcripts by reading each one without taking any notes. He/she reflects on the interview. The transcripts are then read and the main points and topics are summarised. Similar topics are grouped as phrases and coded as themes. The themes are compared. These themes are portrayed as words or phrases. The importance and recurrence of themes is noted (both within and between interviews). The themes are described in detail using excerpts from the narratives and interviews of the participants. Any patterns identifiable by the researcher are also noted.

Luborsky (1994) says that themes may be identified in two ways: “one is to seek those statements that occur most frequently or are repeated. The other approach is to look for those statements that are marked in some way as being of great importance to a person(s)” (p.196). The first approach allows the researcher to count the statements in an endeavour to uncover those that most frequently occur. The second approach has an interpretive component in terms of how the researcher determines the statements that are of the utmost importance to the participant. One means of successfully doing this may be for the researcher to identify such statements and then return the transcript and statements to the participant for his/her perusal and verification or otherwise.

The interview tapes were transcribed by an independent person who had signed a confidentiality form. It took four months for the tapes to be transcribed. As I received each transcript I read and reread, taking note of key words and phrases. Once I had received several transcripts and read each one individually I began to note keywords and phrases across the interviews. I colour coded each word or phrase (see sample page in Appendix C).

As I sought the key words and phrases in the transcripts I took particular note of the stories of clinical practice that the participants had shared with me. I thought these stories might be useful to include in the resource document (see Appendix A) as a way of illustrating points for new graduate nurses. Many of these stories were too long to include in the data analysis section of this report. The stories

could not easily be shortened due to the risk of losing the real depth of the story as shared by the participants.

I continued to read the interviews seeking to combine similar words and phrases in order to make links and develop themes. Common themes began to develop once I had studied several interview transcripts. I colour coded the major themes (see example in Appendix C) along with the corresponding data. I typed up the themes as colour coded, along with the data. I then began the first draft of the data analysis chapter of the thesis report.

3.4.7 Issues of Reliability and Validity

Reliability, or dependability (or auditability), as it is applied in qualitative research refers to, according to Gillis and Jackson (2002) “the stability and the trackability of changes in the data over time and conditions” (p.216). An audit trail as a form of diary was used throughout this study. The trail was commenced at the beginning of the study (January 2003) and will be continued until the end of 2004). This includes the phases of review of the related literature, data collection and analysis.

Validity, or credibility (or authenticity), as it is applied in qualitative research refers to, according to Gillis and Jackson (2002) “the accuracy of the description of the phenomenon under investigation” (p.215). Triangulation of data in terms of the methods will be used. This was in the form of the demographic data collected, a semi-structured interview and written clinical narrative from each participant. This enabled the collection of a greater range of information in different ways from the participants.

The participants were each given a copy of their own interview transcript to make any comments, alterations or additions. The participants were able to comment on the accuracy in terms of their own background and experiences. Feedback was sought by the researcher regarding the accuracy of the codes and themes generated from the interview and narrative data. None of the participants provided me with comments or feedback regarding any of the above.

Transferability (or fittingness) according to Gillis and Jackson (2002) is concerned with the “generalisability of the study findings to other settings, populations, and contexts” (p.216). The inclusion of participants from a variety of clinical settings increased the transferability of the findings to other settings and contexts.

Confirmability according to Gillis and Jackson (2002) refers to the objectivity of the data. The researcher has clearly described her own biases, values and assumptions that may have impacted on this study.

3.4.8 Presentation of the Data

The written clinical document for new graduate nurses is included as Appendix A. This document includes the written clinical narratives (three) and stories of clinical practice selected from those shared in the interviews. I plan that this document will be available to new nurses in clinical settings as a resource document. The research participants will be offered a summary of the research findings at the conclusion of the study.

The research findings will be communicated to the local Universal College of Learning Nursing Department and Massey University School of Nursing in presentations and a written paper. The research findings will be communicated to MidCentral Health in terms of verbal presentations and written document. The research findings will be submitted for publication in a nursing education journal.

3.5 STRENGTHS AND LIMITATIONS OF THE STUDY

3.5.1 The Strengths

There were several strengths of this study. The Registered Nurses who responded to the advertisements for the study did indeed have a wealth of experience both in nursing generally and in relation to caring for patients who were actively dying. The respondents were from a variety of backgrounds and different clinical settings.

The study allowed the nurse participants to share their stories of clinical experience in their interviews. Thus these stories can now be shared with other nurses. The clinical narratives, although small in number, enabled the nurse participants to share their reflections on clinical incidents that had had a major impact on the care they provided.

The qualitative research approach was very appropriate for this study. It allowed the in-depth information to be shared and collected. Stories of practice are a powerful means to share information and learning. Thematic analysis, in which key themes, in terms words and phrases, allows 'hidden' knowledge and skills to be uncovered in the endeavour to share that information with less experienced nurses. This was achieved in this study.

3.5.2 The Limitations

There are several limitations of this study. The size of the study is small, the scope was very specific and the location was the MidCentral Health area. These limiting factors were deliberate owing to the time constraints of the study.

The maximum number of participants planned for the study was twelve, once again due to the time constraints on the study. Ten potential participants showed an interest in taking part in the study, and finally nine were interviewed. The tenth declined due to work pressures.

The participants consented to take part in a single semi-structured interview and all completed this. They also agreed to submit a written clinical narrative as a supplement to their interview, but only three participants completed this (as at 16 July 2004). I believe this was due to the pressures of work in their clinical areas.

The areas addressed in this study were specific that is informal aspects of learning. Other related areas were not addressed, for example more formal sessions in the clinical areas, and how care of the dying is addressed in the classroom.

3.6 FURTHER AREAS FOR RESEARCH

Now the research has been completed I believe that qualitative research is required to gain a perspective from new graduate nurses and their initial experiences of caring for patients who are dying. More information is needed regarding the competence and confidence of these nurses to care for the dying, from their own perspective. Competence and confidence may be judged from their classroom learning, their clinical skills, as well as the support they require and receive as they provide bedside care. It appears from the literature that novice nurses are not well prepared to care for patients who are dying. If the new graduate nurse's first experience is a 'negative' one, that is he/she feels ill prepared educationally and/or unsupported, the associated fear and anxiety of that time will most probably be carried with the nurse as he/she cares for such patients in the future.

The emphasis in this study has been on patients who have passed from being terminally ill to entering the active dying phase of illness. Thus these patients have reached the final stage within chronic illness. It would be useful to research nurses' experiences of sudden death in the clinical setting. When nurses think of sudden death it is often clinical areas such as the Intensive Care Unit or Emergency Department that are thought of. But sudden and unexpected death can occur in any clinical area. Qualitative study in this area would allow nurses to tell the stories of their experiences, how prepared they felt educationally, the support they received and the debriefing strategies that were helpful.

Care of the dying is an area of nursing practice that requires further research, discussion and debate if nurses are to feel competent and confident providing the care. Ongoing education (workshops and sessions in the workplace) and support (mentoring, debriefing and supervision) for all nurses, experienced and new graduate, is important in order that patients and families receive quality care and nurses feel confident and competent to provide such care.

3.7 SUMMARY

In this chapter there has been a detailed description of the sequence of the study. The methodology has been discussed. The method used, in terms of the planning

phase, the background to the study and the ethical issues have been outlined. A description of how the study evolved – the selection criteria, advertising the study, signing up participants, sampling strategies, data gathering, and analysis/interpretation, issues of reliability and validity have been provided. The presentation of the data, identified strengths and limitations of this study as well as some thoughts regarding possible areas for further research conclude the chapter.

CHAPTER FOUR

ANALYSIS OF THE DATA

4.1 INTRODUCTION

In this chapter there is an introduction to the participants in the study. Analysis of the data is presented in four major sections according to the themes identified. The themes are substantiated with excerpts from the interviews with the participants. The four parts deal with: recognising the dying stage; role models: watching, reflecting; working alongside; clinical supervision and education.

4.1.1 The Participants

The source of this information is the demographic data collected on the Response Forms (see Appendix B – Information Sheet, page 5) and the Research Questions used to guide the semi-structured interviews.

Ten potential participants responded to the advertisements for this study. Six of them responded to the newspaper advertisement. The other four responded to posters advertising the study in their staff cafeteria or work place. All ten were accepted for the study. Only one later did not take part, owing to the pressures of work.

The nine participants in this study were one male and eight females; one was Maori and the remainder were European. They had between twenty and forty-five years experience in nursing. This experience had been gained in New Zealand and overseas. The participants had ten to twenty-three years of experience caring for the dying. They came from a variety of areas of clinical practice. They were nurse managers, nurse educators, District Nurses. They practiced in acute medicine, hospice/palliative care, nursing agencies, aged care facilities, rehabilitation and education. These Registered Nurses were all involved in the education of new graduate nurses, Enrolled Nurses, student nurses in training (Universal College of Learning and Massey University), and Care Assistants/Caregivers, as well as, of course, other Registered Nurses.

The nurse participants are distinguished in this chapter by short genderless names and the page references of their own interview transcript. Further details of each nurse are not provided here, as linking them with their respective area of clinical practice may have led to them being able to be identified by a reader.

The participants described specific incidents in their clinical practice with regard to care of the dying. These stories are included in the resource document for new graduate nurses and can be found in the appendix at the end of this study.

4.2 RECOGNISING THE DYING STAGE

In response to the question: “*How would you describe the transition from being terminally ill to a patient entering the active phase of dying?*” the participants answered in one of two ways. Firstly, several of them described a *holistic* approach to care. The participants described the physical, emotional and spiritual changes that may be part of the transition phase. Secondly, the participants described how the nurse ‘*knows*’ that the patient has entered the active phase of dying. There was description of the role *intuition* in the nurse’s knowledge of the situation. The terms *holistic*, ‘*knows*’ and *intuition* are defined later in the chapter.

4.2.1 Holistic Recognition and Observation

There was a clear recognition by the participants that the transition from terminal illness to actively dying may be gradual or sudden. Along with this recognition several of the participants described overall interpretation of signs of physical deterioration that may occur at this time. Phil described the common signs including:

...somebody becoming much weaker, probably less interested in taking food and fluids, more difficult to swallow, breathing patterns change, colour and feel of skin can change quite dramatically, becoming cold and mottled, it is very difficult to swallow... it is more difficult for people to communicate (Phil, p.3).

Lyn described the patient exhibiting signs such as:

...becoming restless and agitated,... the colour of their skin, the warmth, the cold, or the clamminess of their skin... sometimes they become disorientated, they can become very listless (Lyn, p.2).

Mic described physical changes in terms of a gradual deterioration in “independence and ability to do things for themselves” (Mic, p.1).

Mic, Lou, and Sam all described the holistic approach to care in terms that the deterioration occurs simultaneously in the patient’s physical, emotional and spiritual state of health at the time they enter into the active dying phase of illness. Lyn described the decline as “a general decline, holistically, a decline in body, mind, soul and spirit” (Lyn, p.2). Such holistic recognition leads to holistic care.

The psychological aspects inherent in the transition from terminal illness to entering the active dying phase were described by the participants in terms of the grieving process. Mic described it this way, the patient:

...finding out that they are terminally ill and the grieving process that follows that... that’s the psychological bit, the grieving process, the shock, the denial and in the physical changes (Mic, p.1).

Three of the participants recognised and described the impact of the spiritual dimension at this time of life, of death. Mic described the spiritual in this way:

...it is almost as if there is a body, ...like a sphere or something is leaving the body, ...where the life force that was there, is leaving or moving away, and you are effectively just caring for a body (Mic, p.1).

Pat made a similar comment, in that she recognised that her female patient would not be alive the next evening:

...because those changes are starting [that is, the physical changes associated with active dying], that flaccidness is there, the life is leaving it [that is, leaving the physical body] and the breathing has altered (Pat, p.2).

Rob described the way the younger patients fight for life right to the end. She explained it this way:

The younger ones will fight it out until the last and quite often go in their sleep, having been up that day and it is like their little spirit just goes to sleep, the candle goes out (Rob, p.4).

There was a recognition and description by two of the participants that discomfort and distress experienced by patients at the end of life may be due to spiritual issues. Lou expressed a belief that the state of the patient's spirituality may have a bearing on whether the active dying stage progressed quickly or slowly. And that one's 'religiousness' could have a positive or negative affect on that process. She went on to say "if a patient's death is less than ideal, there could be spiritual things [issues unresolved]" (Lou, p.2). Lyn acknowledged that if a dying patient is restless, agitated and distressed that it "could be spiritual distress" (Lyn, p.2).

4.2.2 Intuition

The participants recognised and described the holistic approach to assisting the patient through the transition from being terminally ill to the active dying phase of illness. A very important part of the transition was the role of intuition in the nurse knowing that the patient had passed into that final stage of illness. The question being: how does the nurse *know* the patient has entered the final phase of the illness?

Several of the participants appeared to initially have difficulty articulating how the nurse knows. Chris explained it this way:

It's about a subtle change, [the] ability to pick up subtle changes, a whole raft of changes, it could be any one of them or all of them, any change really...part of the care is recognising the change(s) that's occurring (Chris, p.6).

Phil makes the point that if the nurse knows the patient, if she has built up a rapport with the patient, she is more easily able to pick up the subtle cues. She said:

If you have been looking after somebody for a period of several weeks, you notice those changes, even subtle changes, daily I think, and sometimes it can be quite hard to put your finger on it but you do... and you just really see that change so once things start to happen, in a way, it doesn't take you by surprise... it's nice if you can be with someone over a period of time and get to know their families and kind of recognise those changes and support the family and the patient through them... (Phil, p.3).

There was a very strong opinion amongst the participants that you just know (Lyn, Mic, Pat, Phil, Rob, Sam) intuitively, when a patient is actively dying. Sam described it very well, like this:

I've never really thought about what happens to a person when they go into the active dying phase, I just, you just know that it is there, it is an intuitive sort of thing that they are ready to go... by how their body is, how their mind is, how they have all come together and relaxed... at peace... that is how I see it but I don't know that you can describe it (Sam, p.1).

Mic explained that the nurse gets a 'sense of something', she said:

I guess a lot of it is...intuitive, you get a sense of something from someone, ...you get a sense that something is not quite right, and then something happens...condition suddenly deteriorates... a lot of talk about the intuitive feeling...we don't see it written down in any form, nurses talk about it (Mic, p.1).

Lyn described the intuitive feeling of the nurse this way:

It is just a look sometimes that the patient has... often I would say the patient knows they are dying... and you pick it up and you just know... and they suddenly go downhill... it might be things they say to you, often the patient will say something to you (Lyn, p.2).

Rob described this intuitive sense as the nurse "having a sixth sense" (Rob, p.3). By this she meant the nurse having a feeling that all was not right with the patient. She said "where she [that is, the nurse] gets an agitation when we know we can't put our finger on things and we go away not feeling happy... and then the patient deteriorates" (Rob, p.3).

Along with this intuitive or 'sixth' sense is the voice of experience. One participant called it old age and experience (Pat). It is the experience that

allows the nurse to pick up the more subtle cues to a patient entering the active dying phase of illness. Rob sums it up this way:

I have seen, and my patients have seen a lot of things, I have seen it with both my mother and my father and I try and share the positive aspects of dying because it is part of living... there are two certain things in life and that is death and taxes so I think to an experienced nurse it is obvious (Rob, p.4).

Summary

The participants described, holistically, signs and symptoms of patients entering the active dying phase of illness. The experienced nurse assessed the patients in a holistic manner to ascertain if they had reached this phase of their illness. The feelings of the participants were strong that many of the recognisable signs and symptoms associated with this stage of illness were gained intuitively by the nurse. This intuitiveness was a part of the nurse's knowledge and experiences of caring for patients at the end of life, in terms that they had 'seen it before' in other patients.

4.3 ROLE MODELS: WATCHING, REFLECTING

In response to the question: *“What factors have influenced how you have developed your own knowledge and skills related to care of the dying?”*

Firstly the participants described role models who had been influential early on in their nursing career. They also described watching other people and viewing what worked well and what did not, in terms of achieving the objective of a ‘good death’ for all involved. The participants described what the term ‘good death’ meant for them in terms of their practice.

4.3.1 The Impact of Role Models

The participants mentioned the influence of good role models, mentors, senior nurses in the process of clinical learning. These people were described in various ways. Phil explained it this way:

...in terms of knowledge and skills [I’ve gained] I’ve always remembered people I have worked with before, some of them quite pioneering in their fields when I was working overseas, in the field of palliative care, just the way they were, the way they were professionally and with others. I have tried to remember that and to hold on to that as far as developing skills goes...if you [the new graduate nurse] can work with good people, good mentors, people who don’t mind taking you along with them, it is great if you can find people like that... you just really connect with them (Phil, pp.5-6).

Sam described the value of talking to, and watching the practice of role models, people she could remember who had influenced her in the past and what they had to share. Sam said:

Role models, people in the past, I think that is how we learnt earlier in my life, you learnt by watching other people, seeing what they said when they were talking to people when they were dying, [how they] broach subjects and things like that, like talking about death itself to people, a lot of people don’t like doing that. You watch what other people have done in the past and you think, I wouldn’t do it that way but I could do it so and so, you change or modify what they have been doing... (Sam, p.2).

Sam, later in her interview, went on to explain some of the demands made on the new graduate nurse as she cared for the dying patient and his/her family and the role of the role model:

The importance of having a good role model, who will take the time to sit down and go through the whole episode, who is not frightened about talking about death.... Inexperienced nurses who are allocated someone who is dying because the patient is not acutely unwell, but are often quite complex.... They haven't had the experience of dealing with the complexities of families and crises. It is hard enough when you have had families going at each other from one side of the bed to the other and outside in the corridor, and we have all experienced that type of thing.... then so often they [new graduate nurses] are given that and get left, thrown in at the deep end, and so they learn by their mistakes... not such a good way to learn (Sam, p.9).

One participant recognised and described the influence of patients and families in the development of her knowledge and skills to care for the dying. Mic referred to "working closely with families, patients and developing good relationships, positive relationships and in a process of reflecting following situations, reflecting on what was learnt..." (Mic, p.1).

Sam made the link between learning the intuitive knowing by observing role models or observing experience in action, saying:

How do nurses intuitively know things, we just know... how can you know that somebody is going to die, you know that the person is going to go off so to speak...it is a hunch but it is based on the objective... how do you explain that to somebody, how you actually care for the dying person plus their family, most of that is intuitive, you've learnt it from role models all the way through, you have been doing it for such a long time that you don't actually pay any attention... even when you ask people you know, you can't actually articulate what you do.... how you do it, it is not easy...it's very hard to actually try and work out how you know this stuff it's just there... culture, beliefs and values, your own belief system has a huge amount to play in this, in the event and the cultures... in terms of death and dying.... (Sam, pp.12-13).

Interestingly one of the most influential people early on in the career of the participants was Elizabeth Kubler-Ross. Kubler-Ross was mentioned by eight of the participants at some stage of their interview. Lyn said "I developed a passion, I wished that dying people could die with dignity and peace so I read a lot of Kubler-Ross's books (Lyn, p.3). Similarly Pat said:

...the thing that really stuck in my mind (through the process of laying out the dead) is that when a person is dead or dying you treat them with the same dignity and respect as if they were still alive, after that I seemed pointed in the direction of medical [to specialise in]...I dealt with a lot of people who were dying and read Kubler-Ross's books...in our nursing classes I was disgusted, she was a theorist whose writing had been tabooed and I was very interested in it...I got the books and read them...her book *Death and Dying*...around the whole grief process...thinking back over what I had done, she was pretty right (Pat, pp.5-6).

The writings of Kubler-Ross allowed the nurses to link the practical aspects they had viewed in the clinical setting with her description of the stages, and the process of dying. Phil remarked that at about the time of the Second World War when death was taboo, private and not talked about, then "Elizabeth Kubler-Ross started looking at death not as a negative thing but looking at all the positive things you can achieve when you are dying" (Phil, p.9). So in many ways Elizabeth Kubler-Ross had influenced these nurses early on in their career. She had made it possible for nurses to talk about the process of dying and death itself.

4.3.2 Observing Experience in Action

Observing experience in action was a large part of how the participants believed they had gained their own intuitive type knowledge and the skills related to care of the dying. This was the means by which they learned what worked well and what did not in terms of a 'good death', for the patient, the family and the nurse. Lyn described a 'good death' in this way:

...experiences in nursing [in different settings] just pick up a lot of experiences from working with dying people as to what becomes dignity or a 'good death', where family members are around and they [the patient] dies peacefully and at peace... they're not in pain and they're spiritually at rest, that is so important (Lyn, p.4).

What the participants deemed worked well they then integrated into their own practice. What was particularly important was that at the end of the process the nurse knew she had done a good job, that she had done her very best for all involved. Phil explained it this way:

I think that caring for the dying is such a privilege and it is jolly hard work, it is a great job and it is a great thing to be able to nurse

somebody and take care of their family and do it well and actually feel at the end of it, yes, I have done a good, that was a good death and kind of really enhance the whole experience for everybody (Phil, p.6).

The participants described the 'ideal situation'. Lou said:

...if you are exposed to the ideal situation where the person dies a peaceful death, you know that is the ideal and if you have been exposed to ones that don't ever get to the ideal, for whatever reason, ... it could be a pain management issue.... Sometimes it is the family dynamics that can actually interrupt the process (Lou, p.2).

Rob viewed the ideal as "knowing I have done a good job and... the family felt it went well too" (Rob, p.10).

The participants gave recognition to the part that all members of the health care team played in providing a 'good' death experience for all involved. Members of the multi-disciplinary team brought different strengths and weaknesses and all could share in the reflection process.

4.3.3 Reflecting on: What Worked Well...Or Didn't

An important part of determining the ideal and the less than ideal death was the ability of the nurses involved (that is the experienced and the new graduate nurse) in caring for the dying patient to reflect on the situation. This process of reflection involved reflecting on personal experiences and experiences in nursing. There was a link made by the participants toward reflecting on personal experience and how the associated learning could be transferred into enhancing nursing practice. Chris remarked that reflection involved "spending a lot of time thinking... it made me question what am I doing... the best I can for people... I suddenly realised they were very likely going to die" (Chris, p.11). Mic described the reflection process like this:

...developing good positive relationships with families and in a process of reflecting following situations, reflecting on what was learnt, what perhaps you could have done differently, what you did well... and using those insights to change, improve how you care for someone subsequently, experientially, personally and theoretically (Mic, p.1).

Reflection was the means by which, in particular, the nurses involved determined if the death, and what occurred, was less than ideal. Sam described it this way:

I suppose you know, that is how you learn, ...is going back to seeing things that have affected you... or other people... while the ones that actually have been managed extremely well stay with you and they do, and each and everyone of them is so different but it is the badly managed that really stay there and you work with them doing reflective stuff, trying to work out how you could actually do it in a different way, if you were having difficulty with some part.... (Sam, pp.4-5).

Rob called this process of reflection as holding a "post mortem" (p. 8).

She said:

We are supportive of each other [colleagues], we brainstorm, we share things, we offer help and suggest things and no one takes offence. If we have a death where things maybe haven't gone as well as they could, I try to learn from that and think what could we have done differently, where did we go wrong, sometimes we didn't, sometimes we have done everything... occasionally with the best intentions, the best liaison and everything that we put into place, it doesn't happen... I think I almost have a post mortem with myself and my colleagues, I think that is important, the sharing, support, I have just learnt by experience, but... how do we teach experience? (Rob, p.8).

Summary

The participants described the impact of 'good' role models, in terms of largely nurses, but also patients and family members, as nurses gained clinical experience. Role models influence nurses' formation of their own values and attitudes toward death as well as assisting them to link theory and clinical skills. The participants described the practical, intuitive type and 'on the job' knowledge and skills that had been learned by observing the experienced practice of other nurses as role models. This occurred in addition to reflection on their own practice. This was the means by which nurses learned what worked well and what did not in achieving a 'good' death outcome for their patients. The participants then integrated into their own practice, what they saw had worked well for those experienced nurses. The influence, in the clinical setting, of experienced nurse role models should never be under estimated.

4.4 WORKING ALONGSIDE

In response to the question: “*How do you currently share your knowledge and skills of care of the dying with less experienced nurses?*” the participants showed a strong response when answering this particular question. There was a real emphasis on the importance of *sharing* stories and experiences on a *one-to-one* basis with the new graduate nurse. The participants recognised and described the real need to share the entire process of dying with the new graduate nurse. The result was an ability to ‘*seize the moment*’ (Lou and Phil) in the endeavour to recognise and utilise a “teachable moment”. Two of the participants recognised and described when ‘*you see a little light go on*’ (Lou and Pat) meaning integration of the theory and the practical for the new graduate nurse in the clinical setting.

4.4.1 Sharing the Stories of Clinical Experience

There was a feeling among the participants that the physical care and symptom control skills are easy enough to pass on to the new graduate nurse. But the communication skills are much more difficult to ‘teach’, that is to pass on to the new nurse. This is where the value of sharing stories and practical experience came in, the participants said. There was an emphasis on both the experienced and new nurse sharing those stories. A number of the stories have been included in the resource document in Appendix A. There was also recognition that both positive and disturbing or negative stories should be shared in the process of teaching and learning. Phil made the following very valuable comment in her interview “it wouldn’t matter how much you shared, it is often quite difficult to understand unless you are actually doing it or experiencing it yourself” (Phil, p.13).

During her interview Sam described asking herself,

Just how do you teach new grads? You can’t. I think they just have to learn as they go along, by role models, watching people who do it well and those who don’t do it well... I think it is trial and error... I make sure they have actually seen somebody dead, or be with the person when they are dying... I make sure the new grad stays with the patient so that they go through the process with them, this teaches them an awful lot (Sam, pp.5-6).

For the participants, part of supporting the new graduate nurse through the entire process of caring for the patient who is dying was the sharing of stories and experience (Lou, Mic). This sharing was both nursing and personal in nature. Mic explained the sharing of experiences this way:

I always say to the new graduate nurse to share experiences, that is how you learn.... I use experiences that I have had and quite often over lunchtime we will go through different things and different cases and things that might happen... if there are any questions... you build on your own life experiences and what occurs in the wards... (Mic, pp.12-13).

Stories and experiences of clinical practice are often the most easily remembered learning. The participants described the importance of sharing these stories as the experienced and the new graduate nurse worked together in the clinical setting. Chris had this to say about the importance of this type of sharing "I probably enriched my ability to find different ways people have handled things; I find story is central to, stories that people have spoken or stories that people have read and some case histories of them" (Chris, p.3).

4.4.2 Working Alongside – One-to-One – Experienced and Novice

There was a great deal of emphasis by the participants on the experienced nurse supporting the new graduate nurse through the process. Experience was gained by the new graduate nurse as she worked alongside (Mic, Pat, Phil, Sam) the experienced nurse, one-to-one caring for the dying patient and the family. There was a belief among the participants that the new graduate nurse was able to learn effectively on a one to one basis with the experienced nurse (Chris, Lou, Lyn, Pat, Sam). The emphasis was on working alongside in that one-to-one relationship through the entire process (Lou, Mic, Pat, Rob, Sam), providing explanation of what was happening and why, together reflecting on what went well and what could have been done better. Pat explained the process this way:

If I am one-to-one with a student and I have a dying person.... I will say, have a look at this, I won't discuss it over the person, but say, I want you to listen to the way Mrs Jones is breathing, I want you to feel this and then, afterwards, when we are outside the room we will discuss it more, what did you see, what did you think, what does that

indicate to you, why is this happening, why is that happening, and actually get them to think about the whole process...eventually you see a little light go on and they are starting to integrate their theory into practice and they know what they are looking at....

You have to work alongside them [the new graduate nurse] and you must always have that ability to put yourself back into the learner's shoes and think, what do they need to know, in order to do the job properly and you don't assume that they are ever going to understand what they are seeing so you have actually got to check, did you see that, what did you think about that, why was that happening... I also say to them [the new graduate nurse] whatever you are doing for a person you must always stop and think, what am I doing, why am I doing it, and whose needs am I meeting – own reasons, institutional... not patient or family need, then you need to seriously question... reform your behaviour and reapproach the whole issue (Pat, pp.11-12).

Rob described her relationship and the teaching process with the new graduate nurse like this:

The nurse and I, when we are going in to the patient, in between, I give them the folder and I say, are you aware of this condition, so we talk about the diagnosis and I always like to know their background [of the new graduate nurse], what they have done, what experience they have had so I know what I have got to base it on... I will give them a broad outline of what we have been doing, what has led to where we are at, go through the notes, how they first became aware of the diagnosis and the symptoms and signs, and problems that have arisen, how they have been addressed, what pain relief they are on. When we are on pain I always go through scenarios. I say to the new graduate nurse, now have you got any questions, think about it, ask me over the next few days.

If we are lucky we will have someone who is end stage it's a really good learning curve for them because some of them have never seen anyone at that stage (Rob, pp.10-11).

This idea of working alongside in a one-to-one relationship was emphasised by the participants as the ideal way to learn when caring for a patient at the end of life. Lou explained how she shared her knowledge and skills with the new graduate nurse in the clinical setting:

...usually I do it one to one as we are caring for the person, I will brief them [the new graduate nurse] and explain what I see, what I have assessed and how I am going to plan the interventions that I will do once I have assessed them. So I actually involved them in the whole process one to one (Lou, p. 3).

Pat described her sharing in this way:

If I am nursing someone who is dying I will haul in the new nurse to help with the cares and be with me while I'm with the family so that they can see it all.... the best way to do it is in the one to one situation. If I have a person to lay out I will always go and find anyone in the ward who has never done it before to come and do it alongside, so that the new nurse doesn't ever end up in the situation where they have no idea what to do (Pat, p.11).

Sam gave more idea of just how she communicated her knowledge and skills in terms of the new graduate nurse observing – watching, listening, asking questions of the experienced nurse. Sam said:

If there is somebody dying or has just died I would take the new graduate nurse in with me, they could watch, learn; I talk to them answer their questions honestly, try and instil in them not to be frightened about talking because most people who have got to that stage have actually come to terms relatively well, most people are quite open to discussion, you know what happens next, and where you go to, you know whether people are ready to discuss it, you just intuitively know that, I don't know how you teach/tell new graduate nurses that because you just know....

I spend a lot of time talking too, when people who have died and there are new graduate nurses in the ward, [I] take them along, make sure they [the new graduate nurse] understand it, answer their questions, individually or in a small group. I will always take opportunities if they present and use it as a teaching exercise (Sam, pp.5-7).

As the experienced and new graduate nurse worked alongside caring for the dying patient there was a sense in the interviews of the new nurse initially observing but becoming more directly involved in the care as her competence and confidence increased. Mic explained it this way:

I function most effectively in a situation working alongside a more junior person and them effectively learning from me as I go along. The junior person observing initially and [gradually] becoming more involved, seeing how I react, what I do, what I say... that is the ideal. Then being able to take that [junior] person aside privately and reflect, discuss, examine what is happening... that is the ideal (Mic, pp.2-3).

Summary

There is a real emphasis by the participants on sharing with the new graduate nurse the entire process of caring for the patient who is dying. During the process the new graduate nurse observes the experienced nurse

in action. The nurse gradually becomes more directly involved in the process as her/his confidence and competence increases. The experienced and new graduate nurse together, reflect on aspects of that process during the dying phase and after the death of the patient. Throughout the interview there was a real sense of one-to-one sharing/working alongside in the endeavour to 'seize the teachable moment' in the relationship and to 'see the light go on' for the new graduate nurse. As the nurses cared for patients through the process of dying they shared stories, to consolidate learning for the new graduate nurse.

4.5 CLINICAL SUPERVISION AND EDUCATION

In response to the question: “*What would enable you (in your opinion) to more effectively share your (experienced nurse with new graduate nurse) knowledge and skills around this area of care?*” the participants gave a somewhat different emphasis in their answers from what I had initially anticipated. They described (as discussed in 4.2-4.4) how all nurses might more effectively share their knowledge and skills around care of the dying. They described what all nurses, regardless of the amount of experience, required to enable them to be more effective in that sharing. It quickly became apparent that the participants, in describing what all nurses required, were also ‘alerting’ new graduate nurses to what they needed in order to care for the dying well. In addition, the participants were informing the new graduate nurse about how to care for her/himself, as she/he cared for patients who were dying.

Within the responses there was, firstly, a strong emphasis by three of the participants on nurses (both experienced and new graduate nurses) being able to recognise the signs of ‘*burnout*’, also called compassion fatigue or vicarious traumatisation. It was important to recognise the possibility of, and signs of ‘burnout’ and so limit it in clinical practice. Along with that emphasis was the need for all nurses to have ‘good’ *clinical or professional supervision* in their clinical practice.

A second and strong point, was the need for *ongoing education* for nurses caring for patients and families at the end of life. There was the recognition of *flexibility* in the mode of educational transferral and *personal* interest and need of the nurse. Phil had this to share regarding ‘good’ supervision and the place of ongoing education for nurses caring for the dying:

I just say, if you choose to work in this area, look after yourself and make sure you have good support, good supervision and take all the opportunities you have to learn, there are great opportunities you have to learn, there are great opportunities now in this field in terms of education in this country now... Post Graduate courses, fantastic conferences, learning opportunities, networking opportunities... some great opportunities.... It doesn't necessarily mean that care of

the dying is going to be in hospices, it is going to become bigger in nursing homes and in patients' own homes (Phil, p.12).

4.5.1 The Importance of Clinical Supervision

There was recognition and description by the participants of the demands made on nurses when they are involved in the care of patient who are dying, along with the needs and demands of family members during the process. There is a need for the nurses to care for themselves holistically and to have a balance (Phil). Clinical Supervision was one means described by the participants for nurses to be able to take 'holistic' care of themselves.

The participants saw it as part of their role, as experienced nurses guiding new graduate nurses, that they share their knowledge of 'burnout' in terms of the possibility of, the signs of, and how to avoid 'burnout' occurring. There was recognition of the real demands placed on nurses as they care for patients who are dying and their families. There was recognition of the nurses need for support for themselves while carrying out the care and afterwards.

The use of a clinical supervisor was a way for the new graduate nurse to share her experiences of caring for the dying in the clinical setting. She could share her feelings, have her feelings acknowledged, learn coping skills, be assisted to process information, be able to reflect on a situation and learn from it. The clinical supervisor was a person removed from the clinical setting and the role models in that setting.

The participants described what the nurse should look for in a supervisor, what constituted a 'good' supervisor and why it was important to have such a person. I believe many valid points were made in response to the question posed to the participants in this study.

Chris described how the supervisor could assist the nurse:

...not to be afraid of the fear questions, either through their own fear or what they sense in the patients...sometimes the nurse really has to stand with the patient, otherwise the patient can be very

alone...people are freed from their fears when they have spoken them.... Counsellors do some wonderful scenario training...workshops for nurses...but nurses are learning otherwise from [other] nurses who do talk about these things...but most often we are left with our own fears or we get superficial reassurance, it is not usually reassurance we want when we are telling about a fear, we want somebody to acknowledge that we are actually feeling fearful, we know they can't fix it (Chris, p.10).

Phil explained what to look for in a 'good' supervisor in clinical practice.

She said:

I cannot stress enough the importance of finding someone who is really good at clinical supervision or professional supervision or whatever you want to call it, somebody who really understands what is required of you when you are caring for someone who is dying and their family and someone who can help you process stuff so you are not getting caught up in the situation and really look at some of those feelings that go with caring for people in that situation is really important (Phil, pp.16-17).

The participants discussed and described in their interview why the new graduate nurse should have a clinical or professional supervisor (Chris, Phil, Rob). Phil explained the importance of "having very good professional supervision" (p.6). She said:

It is something that nurses should ask for and I think as new graduate nurses, use it as a negotiating [tool], I just feel so strongly about that because I think that caring for the dying is such a privilege and it is jolly hard work and it is a great job. It is a great to be able to nurse somebody and take care of their family and do it well and actually feel at the end of it, I have done a good job, that was a good death and kind of really enhance the whole experience for everybody [involved] (Phil, p.6).

Chris described the role of counselling or supervision for professionals in other careers. She said that the importance of counselling and supervision, is that it:

...gives people time to talk about the death... time aside to talk about what has happened... to take some learning out of it... chaplains have supervision, counsellors have to have supervision, supervisors have to have supervision. All sorts of professional people now have to have supervision which is their reflective time to say, how am I coping, what are my strengths, what are my areas of difficulty, what things might have rocked me in the last week or two... it's time for

self-care, it's all about self care... compare with Lifeguards, firemen (Chris, pp.2-3).

Rob talked about the nurse remaining safe in her practice and the impact of supervision in the clinical setting particularly, in that:

I talk to them [new graduate nurses] about "burn out". I tell them about the counselling process, palliative care or not, never go outside of your comfort zone where you don't feel safe doing a procedure, you must ask for supervision, you are looking after yourself and you insist on supervision... liaise with [other professionals], then you know you have done something about it (Rob, p.11).

4.5.2 The Role of Ongoing Education

The participants discussed and described the importance of flexible and personal ongoing education for new graduate nurses caring for patients and their families at the end of life. Sam had this to say about the need for greater post-basic education:

I don't think we do it in our current education system... briefly cover grief... talk about Kubler-Ross and the grief process, how many steps there are, you didn't actually understand it... I think Care of the Dying courses are very valuable because it allows people to participate without participating in a death if you like. It is just having the skills to communicate what you want to be able to communicate to the new graduate nurse and that really comes with time, comes with experience, I don't think you can ever instil that into people it is just something that comes when you feel comfortable with death yourself, whether it is people dying around you, patients, your family, facing your own mortality, thinking about your own death and once you actually start feeling comfortable then you can communicate it better to other people, there are no books to read (Sam, pp.8-9).

For the participants, ongoing education included workshops, study days, books, resources, tutorials as well as short times of reflection. The flexibility of such education meant an increased amount of support available to nurses and increasing ability to attend. The personal nature of the education allowed for different circumstances related to care of the dying, the circumstances of the patient, family, nurse and/or the environment.

Chris discussed the importance of ongoing education for nurses in terms of keeping up to date. She said:

...nurses are resources in the community amongst their families and places they mix and people have high expectations and often ask them questions and for me knowing what books and resources, for me it is often books or organizations... [we] can get a bit out of touch (Chris, p.16).

Summary

In this section there is an emphasis by the participants on the nurse caring for her/himself holistically. An important part of this care is being able to recognise 'burnout' and to have effective clinical or professional supervision. The majority of the participants in this study had been involved, over lengthy periods of time, with the care of patients at the end of life. It was acknowledged that caring for patients who were actively dying was a privilege, a challenge and also emotionally and spiritually draining. The participants described in their interviews what had sustained them in this area of clinical practice. There was recognition of the need to talk to someone who understood the fears and the issues, to be able to 'off load', to reflect on and gain learning from specific situations and to know that one had done their very best.

The second aspect that had sustained the participants was recognition of, and involvement in, ongoing education. This involvement allowed them to keep their clinical skills and knowledge up to date. It also allowed them to network with other nurses working in similar clinical areas. This involvement too, was part of looking after themselves as they cared for patients at the end of life.

4.6 SUMMARY

This chapter has described key ideas in each of the four sections. These are:

- how the nurse recognises, holistically, that the patient has entered the active phase of dying and the nurse's use of intuition as part of his/her knowledge as he/she cares for a patient at the end of life;
- the importance of observing, and working with role models in clinical practice, observing experience in action in order to reflect on what worked well and what did not toward achieving a 'good' death;
- the relationship between the experienced and the new graduate nurse as they work together, one-to-one, to provide the physical care for the patient, share stories of care and reflect on the process;
- the importance of clinical supervision and ongoing education for nurses in order to avoid 'burnout' and to care for the dying well.

In the following chapter there will be a discussion of the findings and recommendations for implications in nursing practice and education.

CHAPTER FIVE

DISCUSSION

5.1 INTRODUCTION

The discussion in this chapter links my interpretation of the findings to the literature. The first part is divided according to the major themes identified in the previous chapter. Later parts discuss the implications for, and recommendations for nursing practice and education. This chapter concludes with possibilities for future research.

5.2 DISCUSSION OF THE FINDINGS

Murphy (2003) has the following to say in regard to classroom and clinical teaching/learning:

Education is often delivered away from the clinical arena and context of care and thus away from real life experience of caring for the dying patient and his or her family. This may act as a barrier for the translation of theory into practice in the clinical area (p.106).

The Registered Nurses in this study, like those referred to in the methods chapter, with experience in care of the dying, acted as role models as they worked with new graduate nurses in the clinical setting. Within this role, on a one-to-one basis these nurses shared their experience in terms of intuition, providing holistic care, familiarising the new graduate nurse with the process (from the patient entering the active dying phase of illness through to after death care) and reflection on the process. The sharing related to patient care in terms of 'hands on' care and the sharing stories of care and experience. The sharing also related to the nurse caring for him/herself in terms of ongoing clinical supervision and education.

5.2.1 Recognising the Dying Stage

The participants in this study described the holistic decline of the patient as he/she approached death. Changes could be observed almost simultaneously, in the physical, emotional and spiritual dimensions of life. Ellershaw and Ward (2003) say "Health professionals are sometimes reluctant to diagnose

dying...this is the very moment when the (hospice) model of “intensive palliative care” should come into action, providing physical, psychological, and spiritual care for the patient and the relatives” (p.32).

The ability to recognise that a patient had entered the ‘final’ phase of illness, of life, often involved the nurse’s intuitiveness according to the participants in this study. Intuition is an important component in how the experienced nurse recognises the patient entering the active phase of illness and providing holistic care within that phase.

Benner and Tanner (1987) define intuition as “understanding without rationale” (p.23). Intuition cannot be taught in the classroom. This intuitiveness involved the nurse’s ability to pick up often subtle cues or clues concerning the patient’s declining condition. This ‘sixth sense’ or professional intuition, is the voice of experience, described as ‘you just know’ or getting a sense of something, or having ‘seen it’ before in other patients. These subtle cues are picked up on more easily if the nurse has been caring for the patient over time and knows them and their condition quite well. Thus it the nurse’s nursing experience and her/her experience of this particular patient and perhaps knowing the family also.

The participants in this study showed that intuitive judgement arises from within an experienced nurse who has a vast range of similar circumstances, situations and experiences to draw upon. They provided examples related to the care of a patient who is dying, signs such as a change in breathing pattern, a change in the warmth/colour of the skin, change in consciousness, general listlessness. It is about the rapport that experienced nurse has built up with the patient and family and that nurse’s subsequent ability to ‘pick up’ subtle cues or get a ‘hunch’ that something is about to/has changed, even if not easily able to explain it. It is about being able to see the ‘whole picture’ – the physical, the emotional, the spiritual, and make an ongoing assessment of the patient’s condition. It is about communicating with the patient’s family, detecting changes between the patient and the family.

5.2.2 Role Models: Watching, Reflecting

Watching and observing colleagues in action, often later to be regarded as role models, plays a large part in the teaching/learning process in the clinical setting. Beck (1997) makes the following comment: "Expert nurses are the role models who act as mentors or instructors to the less experienced nurse or nursing student" (p.414). The experienced nurses in this study described gaining their experience by observing/working with experienced nurses themselves. The participants in this study described the impact of role models, particularly early on in their nursing career. These participants described how they watched role models in action and learnt what worked well and what did not, in the clinical setting. They also described how they learnt the more intuitive aspects of patient care, those aspects of care that may be more difficult to articulate.

It was from role models that, as described by the participants in this study, they learnt 'the ideal' and the 'less than ideal' aspects of caring for a patient who was actively dying in the clinical setting. Beck (1997) suggests that "when nursing students begin caring for dying patients they can be inked up with expert nurses on the unit where the novice students are assigned" (p.414). Her idea is that the novice nurse begins in the observing role and gradually, while supported by the expert nurse, becomes more directly involved, taking on more of the direct care and responsibility.

The participants described one-way intuition could be 'caught' as opposed to being taught, through novice nurses observing experienced role models in action. The importance of, and indeed the impact of good role models in clinical practice should never be under-estimated. Hoban (2004) says "Role models provide an instrumental element – teaching skills and behaviours; and an inspirational element – motivating people and giving them a vision of where they are heading in their career" (p.22). 'Good' role models practice excellence in clinical care and support others (and not just nurses but other health professionals) to practice that same excellence. Observing such nurses also assists the inexperienced nurse to ascertain what worked well, or did not in terms of achieving a satisfying outcome for the nurse as he/she cared for the dying patient. The aspects of care that worked well or did not determined an

ideal death or a less than ideal death. It was about the nurse knowing he/she had done a 'good job' at the end of the day – that the patient had had the best care that was available. The new graduate nurse could then integrate into his/her own practice that which he/she had determined contributed to the best care.

An important part of the process was the ability of the experienced and the new graduate nurse to reflect on the care given – both during the process and after the death. The nurses involved reflected jointly and as individuals. In this reflection, the nurse asked: what went well and what could have been done better, how could it be improved, what could I do better next time? Pitorak (2003) calls this process of reflection "professional review" (p.50). Pitorak (2003) says that this review allows the nurse to ask "What did I learn professionally and personally from taking care of this patient and family? This also allows for the identification of questionable decisions and mistakes made, to ensure they are not repeated" (p.51).

5.2.3 Working Alongside

There is a dearth of literature about how the new graduate nurse might best learn informally in the clinical setting, to care for patients who are actively dying. The participants in this study placed a great deal of emphasis on the experienced nurse working alongside, on a one-to-one basis with the new graduate nurse. In some ways this point was the 'crux' of this study. The experienced nurse supported the new graduate nurse through the entire process (from identifying holistically that the patient has entered the active dying phase of illness through to after death care), providing 'hands on' care and reflecting on the process. The new graduate nurse began by observing the experienced nurse in her role. There was a sense that early on in the experienced-novice nurse relationship the experienced nurse had a lot of direct input in to the patient's care and supporting the less experienced nurse. As the relationship developed and the new graduate nurse became more confident and competent the experienced nurse could withdraw more, providing the new graduate nurse with more of the responsibility. The relationship is ongoing and evolving, as described by the participants in this study. The experienced nurse remained available to support and provide feedback to the new graduate nurse.

The one-to-one relationship between the experienced and new graduate nurse was described by the participants in this study not only in terms of 'hands on' care but also in the sharing of stories of care. Stories are a powerful way of sharing clinical experience, of integrating theory and practice, the 'know what' and the 'know how'. The experienced nurse uses this means to describe to the new graduate nurse "I am doing it this way because...", "in the past this happened". Stories are powerful and they are remembered. I was not able to locate any useful links in the literature regarding such relationships.

There was a feeling described by the participants in this study that physical care and symptom control skills can be taught as 'hands on' care is provided. But other aspects such as communication skills and dealing with the emotions of others are more difficult to 'teach' or pass on to another nurse. This is where the value of sharing stories and experiences came in, the participants said. A number of such stories have been included in Appendix A. It is anticipated that such stories may be able to be used in Workshops, reflected on in the clinical setting, useful for role plays, used as a basis for ongoing debate and discussion. Stories such as those in Appendix A highlight cultural and ethical factors that may be difficult to 'teach' in the classroom or clinical setting.

5.2.4 Clinical Supervision and Education

The participants emphasise the importance of ongoing clinical supervision and education in order that they provide safe and up-to-date care in their practice. Within the one-to-one relationship, between the experienced and new graduate nurse, the novice nurse learns how to care for her/himself in terms of the sometimes demanding and emotionally taxing care provided by the nurse.

Where the participants began their interview describing how to recognise, holistically, that the patient had entered the active dying phase of illness, the interview invariably concluded with a description of how the nurse should care for her/himself holistically. Clinical supervision was one means the participants in this study described the nurse being able to care for her/him holistically. Thus this was part of the ongoing relationship between experienced and new graduate nurse. The experienced nurse shared her/his knowledge of the signs of

'burnout', how to avoid it, strategies to minimise it, how to choose a suitable supervisor and what the role of that person was. This aspect was *not* part of the original literature review but there is a wide variety of literature available on clinical supervision and burnout, for example Cole (2002), Sloan and Watson (2002), Spouse and Redfern (2000), Teasdale (2001), Teasdale (2000), Yegdich (1999).

The role of ongoing education as described by the participants was that it allowed the new graduate nurse to keep up-to-date. Education allowed nurses to support each other, it provided an avenue for reflection and discussion, to talk about death, education allowed nurses to 'practice' communication skills in a safe environment.

5.3 IMPLICATIONS FOR NURSING

5.3.1 Nursing Practice

The Registered Nurses described in detail the one-to-one learning that occurs between the experienced and the new graduate nurse. This one-to-one relationship ideally begins as the patient's health deteriorates (physically, psychologically and spiritually). That nurse-to-nurse relationship continues through the active dying phase of illness, at the time of death and during the after death care. The other findings of this study 'hang' on this one-to-one relationship.

Within the experienced-novice nurse relationship the new nurse observes, participates in 'hands-on' care within the supportive relationship and reflects on that care given. In addition, within that relationship the nurse also cares for him/herself in his/her reflection, considering the place of clinical supervision and ongoing education needs.

The experienced nurse acts as a mentor, coach, role model, support person. The new graduate nurse observes and provides the 'hands-on' care within the supportive environment. The new nurse gains knowledge from the experienced nurse in action – observing her intuition, communication and assessment skills

as well as gaining an idea of ideal and less than ideal care. The new graduate nurse is able to 'put the pieces together' – theory and practice in an endeavour to 'seize the moment' or 'turn the light bulb on' that is, to have an 'aha' moment.

I believe there is a need to consider how such one-to-one relationships, between the experienced and new graduate nurse, may be initiated and fostered in the clinical setting when caring for the patient who is actively dying. Such a relationship is required to be established *before* the patient enters the actively dying phase of illness. To be effective the relationship continues until the after-death care is completed. Obviously the length of time involved will vary enormously and the new graduate nurse may not be able to follow through with the one experienced nurse, if the relationship and associated support becomes necessary over several days.

5.3.2 Nursing Education

From the informal conversations I have held with students and new graduate nurses as we have worked together in the clinical setting, it appears that there is little time spent in the classroom discussing death and dying and the related care. This situation may be partly due, not so much to the anxiety associated, but to the discomfort such a topic may create.

Even if time is spent in the classroom discussing death and dying, such discussion may be limited by personal experience. This may well be a good place to begin, as nurses can identify and describe their biases and assumptions associated with positive and negative personal experiences. A nurse during her training, or as a new graduate nurse may only have personal experience as the base of her practice in the clinical setting. But it is important that personal experiences are, at some stage, linked to professional experiences in the clinical setting. It may be that, a nurse upon graduation has never had to deal with dying and death, either personally or professionally.

An important point to make is that women and men entering nursing training these days are very often mature students rather than school leavers. As such they have often been involved in another career before entering nursing. These

beginning nursing students or new graduate nurses have a variety of life experiences. They may also have had experience with dying and death. They may also come with a variety of “baggage”, arising from those experiences. The classroom is a very good place to discuss those experiences and the associated baggage, in an effort to deal with it before entering the clinical setting.

The Resource Document (Appendix A) that contains stories from the clinical practice and the written clinical narratives of the experienced Registered Nurse participants in this study could be used as a means for sharing ideas (as a supplement to the findings of this study), to form the basis of discussion and debate, role plays, reflecting on clinical scenarios. Utilising this document may serve as a means to link classroom theory and clinical practice.

5.4 RECOMMENDATIONS

5.4.1 Nursing Practice

The Concept of ‘Care Pairs’

It has come to my attention over the past months that in some areas of clinical practice, particularly in long-term care areas, the nursing staff provide care in ‘care pairs’. I could find little in the literature, nursing or otherwise, concerning this concept. I did though, find an article written by Debra Wood (2003) entitled “Care Pairs Program Takes Care of New RNs”. The article describes a Care Pairs program piloted in Florida Hospital two years ago with great success. Wood (2003) in the introduction, says “Thanks to a new residency program called Care Pairs that teams [new graduate nurses] with seasoned RNs, med/surg nurses at Florida Hospital Orlando no longer make the GN-to-RN transition alone” (p.1).

Within the Care Pairs program, if there are four nurses (Registered and Enrolled nurses) on a shift they are paired together. Each nurse has his/her own patient load but two nurses work together when it is necessary, for example in the safe transfer of immobile patients.

Wood explains that beginning nurses, following their ward orientation period, select their own Care Pair experienced nurse, in other words the Care Pairs choose each other. Wood (2003) also states that "Being part of a Care Pair is not for all experienced nurses" (p.2). The experienced nurse is seen as a resource person, a mentor and source of information.

Wood (2003) says that within the Care Pair relationship "the experienced nurse... tends to her own patients and may answer [the mentee's] questions, walk her through an unfamiliar procedure, or provide a second opinion about a wound assessment and whether to call the physician. Care Pairs cover each other's patients while on meal breaks and stay together for three to six months" (p.3).

I believe the concept of 'care pairs' would be appropriate in care of the dying. Ideally one nurse of the pair would have considerable clinical experience in caring for patients who were actively dying and their families. The two nurses would be involved in the 'hands on' care throughout the process of dying. But in addition they could support each other, reflect on the care provided and the process, at the time of death and after the death.

Resource Nurses

Many clinical areas have Registered Nurses, often with considerable experience, who are resource nurses for specific disease processes, such as cardiac and respiratory as well as diabetes and pain management. Why not have resource nurses in clinical areas for management of care of the dying? Such nurses could liaise with the local hospice and palliative care teams to ensure patients received the most effective care and management.

These resource nurses could attend regular ongoing education in order to keep themselves up-to-date and communicate to/educate and support staff in their clinical areas. These nurses would be members of the team but be recognised as 'experts'/resource persons in their areas with regard to care of the dying. These nurses could have input into policy and management decisions made that would affect the care of such patients.

Sharing Stories

The stories of clinical practice that the nurses shared in their interviews and the written clinical narratives for this study are included as a Resource Document in Appendix A. These stories are included to supplement the data gathered and analysed. The stories form a resource document for nurses working with patients who are dying in the clinical areas. It is anticipated that the stories will be placed in the areas as a means of allowing continuing discussion and debate about the care management of patients who are dying. The stories may form the basis of informal discussion, assist with reflection, provide ongoing education, or assist a debriefing exercise after a 'traumatic or difficult' death in the clinical setting.

Although this study has focused on patients who have passed from being terminally ill (that is chronic illness) to entering the active dying phase of illness, it would be useful to research nurses' experiences of sudden death in the clinical setting. Sudden and unexpected death may occur in any clinical setting, not only in the Intensive Care Unit or Emergency Department. Whether a nurse is experienced or a new graduate nurse, he/she requires support during/after a sudden, traumatic or unexpected death.

The concept of 'care pairs', the use of resource nurses and the resource document could be used in a variety of clinical settings, such as inpatient wards, rest homes, nursing agencies, hospices and community health areas. Nurses involved in these areas could form communities of practice, linked by their concern for, or passion about care of the dying. Wenger & Snyder (2000) describe communities of practice as "groups of people informally bound together by shared expertise and passion for a joint enterprise" (p.139). The members of the community could share information, provide guidance, discuss problems, develop professional skills and foster best practice. The members may not all be nurses but could be multi-disciplinary and/so multi-professional in nature.

5.4.2 Nursing Education

In the classroom, in preparation for clinical placements, Registered Nurses with experience in care of the dying working in clinical settings could be invited to *participate in discussion* with student nurses or new graduate nurses. In this way the experienced nurses have an opportunity to *share their clinical knowledge* and skills with new nurses prior to, or during their clinical placements. The Resource Document in Appendix A could be used as a basis for such discussion.

In the clinical areas *one-to-one nursing relationships* could be developed, with experienced nurses as role models and support persons for new graduate nurses. Ongoing education could be provided in terms of workshops where experienced and new graduate nurses shared their knowledge and skills.

The Resource Document (Appendix A) is intended to supplement the findings and ideas in this study, to be used by individuals and *in workshops* – the basis for ongoing discussion and debate about the clinical management of patients who are dying. The stories of clinical practice in the document could be used as the basis for role-plays, scenarios, development of communication skills, discussion of the management of clinical situations.

5.5 FUTURE RESEARCH

A further Qualitative study should interview *new* graduate nurses about their initial experiences of caring for patients who are actively dying. Questions should focus on: how they coped, the degree of support available and provided, appropriateness of their education, both in the classroom and in the clinical area toward providing the care.

I believe there is a need for continued and ongoing debate about how patients who are dying may best be cared for in the clinical setting. An important part of this discussion is how nurses might best be prepared to provide that care competently and confidently in the workplace, regardless of the setting.

Research is required with *nurse educators* who work in training institutions to further debate how nurses are prepared to care for the dying, in order to more closely align classroom teaching/learning with the care provided in the clinical setting.

I believe there is also a place for research involving multi-disciplinary professionals working in palliative care areas in conjunction with those working in other areas to explore how care of the dying might best be taught/learned *in the clinical setting*.

5.6 SUMMARY

The one-to-one relationship between the experienced nurse and the new graduate nurse is central to a positive experience of caring for a patient who is dying. Not only can the nurses together provide the bedside care, they can also share in the reflection and the emotional support during and after the dying and death. The experienced nurse is the mentor, role model, coach, teacher and support person. The new graduate nurse observes and provides care in a supported environment. As that nurse becomes more confident and competent he/she is able to take on more of the direct care with the experienced nurse still providing support, but less directly.

There is a role for experienced nurses to be involved in the new graduate nurses' classroom learning. Nurses could use their experience to manage ongoing discussion regarding the care of patients who are dying. Stories from clinical practice are a powerful way to share knowledge and skills as well as management issues that arise in clinical practice. Examples of such stories are included in the Resource Document in Appendix A.

Ongoing research is important, particularly in an endeavour to describe the experiences of new graduate nurses from their own perspective. It is important to ascertain whether these nurses felt prepared, educationally, to care for such patients and how supported they felt as they cared for a patient who was dying. It would also be useful to ascertain from these novice nurses what additional resources they see could benefit both them and nurses in the future.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

This chapter provides a final summary and reflection of the study. There is consideration of whether the questions have been answered, personal conclusions, and a brief review of the recommendations from the study.

6.2 WHAT WERE THE QUESTIONS?

The questions for this study were:

What clinical knowledge/skills do 'expert' Registered Nurses possess that allow them to care competently and confidently for patients in their final forty-eight hours of life?

How might these experienced nurses most effectively share their knowledge/skills with new graduate nurses in the clinical setting?

In order to answer the research questions I chose to interview Registered Nurses with expertise in caring for patients who were actively dying. A semi-structured interview allowed me to listen to the nurses' stories and to gather the depth of information I required. In addition to the interview I asked the nurse participants to write a clinical narrative in conjunction with some aspect of care of the dying. This written piece of work would provide me with an added dimension to the study. The written work would also allow the nurse participants to reflect on the incident, and to write down their thoughts, emotions and capture how the incident had caused them to change their practice.

In the interview I asked the participants to describe the transition from being terminally ill to entering the active phase of dying. Together we explored how these experienced nurses had themselves learned the clinical skills inherent in care of the dying. Finally I explored with the nurses how they saw they might most effectively share their knowledge/skills of care of the dying with new graduate nurses.

My aims for this study were firstly, to describe the clinical experiences of Registered Nurses with expertise in care of the dying in a variety of practice settings. In conjunction with the study, and as a supplement to the findings I sought to develop a written clinical document whereby the experienced nurses could share their knowledge and skills with new graduate nurses. This document would allow me to share the nurses' stories of practice and written clinical narratives.

6.3 HAVE THE QUESTIONS BEEN ANSWERED?

I believe that these questions for this study have been answered. The aim of interviewing experienced Registered Nurses from a variety of clinical settings was very satisfactorily achieved. The nurses had up to forty-five years experience between them in nursing and of that they had spent ten to twenty years caring for patients who were dying. The participants were nurse managers, nurse educators, District Nurses. They practiced in acute medicine, Hospice/palliative care, nursing agencies, aged care facilities, rehabilitation and education.

The nurse participants described how their clinical experiences were inherent in caring for patients who were dying. Amidst the experiences the nurses described holistically how they recognised the patient had entered the active dying phase of illness. A large part of how the nurse *knew* the patient had entered the final stage of illness was the intuitive aspect of care. The ability to gain a sense of something, developing a sixth sense, recognising subtle cues, of recognising similar cues in other patients and carrying these over in to a new situation.

The experienced nurses described in their interviews how they had gained their own clinical knowledge and skills associated with care of the dying. "Good' positive role models and mentors had a major impact on the nurses. There was a sense of observing and working with these role models and of observing experience in action. It was by means of observing experience in action that the nurse participants described how they had learned the more intuitive aspects of care. This was also the means by which they had learned what worked well (they integrated these aspects in to their own practice) and what did not work

well, in other words what constituted a 'good death' or an 'ideal situation'. An important part of working with positive role models, of observing experience in action and determining what worked well...or didn't, was the process of reflection.

For me, the turning point, (that is, the 'aha' moment) of this study was reached when the nurse participants were asked how they currently shared their clinical knowledge and skills with new graduate nurses. There was a strong emphasis on one-to-one sharing with the new graduate nurse throughout the dying process, in terms of providing 'hands-on' care, of sharing stories of care/experience and reflecting on the care given. The learning was an informal sharing of knowledge and skills, in terms of being involved together in that process.

The benefit for the experienced nurse in the one-to-one relationship was in the ability to 'seize the moment' (that is recognising the teaching/learning potential in a particular situation) or to see 'the light bulb go on' meaning that the novice nurse could be seen to be integrating theory and practice, determined by an 'aha' moment. The benefit of the relationship for the new graduate nurse was that he/she was supported as she worked with the experienced nurse, initially observing the care provided and as her confidence improved becoming more involved in the 'hands on' care of the dying patient and the family.

In the final section of the interview I asked the participants what would enable them to more effectively share their knowledge and skills with new graduate nurses. The participants gave quite a different emphasis in their answers than I had expected. They described what all nurses (experienced and new graduate nurses) caring for patients who were dying, required in order to be more effective in their sharing. The participants described the importance of clinical supervision and ongoing education.

The experienced nurse participants in this study began their interview by describing how nurses know, holistically, that a patient has entered the active dying phase of illness. The participants concluded their interview discussing

how nurses could/should care for themselves holistically when caring for patients who are dying.

Some of the stories of clinical practice that the nurse participants shared in their interviews are included in Appendix A. Three of the nurse participants wrote a clinical narrative and these are also included in the Appendix. These parts of the study are included in a Resource Document as a supplement to the study findings.

6.4 PERSONAL CONCLUSIONS

There are laughter and tears often when a baby is born into the world. There are laughter and tears at the time a loved one dies. The whole range of emotions expressed and experienced at these times is not so very different. I believe that, as nurses, if we spent as much time considering end of life care and the associated issues as we do considering care at the beginning of life, we would do it much more effectively. After all we would not leave a new graduate nurse to bring a baby into the world alone and unsupported, so why place an often inexperienced nurse in that position when the patient is actively dying?

Just how death and dying are dealt with, or not dealt with, is not a nursing issue alone. Society on the whole ignores or puts in the 'too hard basket' issues associated with death. How many of us prepare for our own death ahead of time? How many of us are even willing to think about such a thing, ahead of time?

6.5 RECOMMENDATIONS

Several recommendations have been made as a result of the findings of this study and how each might be implemented into clinical practice. These are as follows:

The concept of 'care pairs' in which nurses work in pairs in their clinical setting. Each nurse has his/her own patient load but work in pairs, for example if a patient's care is demanding physically or emotionally. Ideally an experienced and a new graduate nurse work together, although this may not always be possible.

The second recommendation is that clinical areas have **resource nurses** for management of care of the dying. Resource nurses would function in a very similar way to such nurses for diabetes, cardiac and respiratory disorders and the like. These nurses could liaise with palliative care specialist nurses, hospice staff and attend in-service sessions to ensure patients in the ward received the most appropriate, effective and efficient management. These nurses could also have input into policy and management decisions regarding care of such patients.

The third recommendation concerns the **stories** of practice and narratives that make up the **Resource Document** in Appendix A. This document could be placed in clinical areas to open up ongoing discussion and debate about the care and management of patients who are actively dying. The stories could be used to assist with reflection or debriefing after a 'traumatic' or sudden unexpected death, to provide ongoing education in the clinical area. The document could also be used in the classroom as the basis for discussion, role-plays, scenarios, development of communication skills and so on.

Wenger and Synder (2000) introduced the idea of communities of practice, groups of people brought together informally by their overwhelming interest and passion for a particular "enterprise" (p.139). Such groups of people with a passionate interest in care of the dying could be brought together to share information and voice concerns in clinical practice arising out of the 'care pairs' work, as resource nurses or to discuss and debate stories of clinical practice. Such groups would not only be made up of nurses but be multi-disciplinary in nature.

In terms of learning in the classroom setting any formal discussion regarding the care of patients who are dying could involve nurses with experience of caring for such patients. In this way the experienced and new graduate nurses could share their experiences and knowledge in the classroom prior to the new nurses caring for these patients in the clinical setting. The relationship between these nurses could be ongoing to some extent, perhaps with semi-regular meeting and discussion of the new graduate nurse's clinical experiences, as reflection and debriefing.

6.6 SUMMARY

It is imperative that the first experience is positive when a new graduate nurse is caring for a patient who is dying. That first experience, whether it is positive or negative, will influence the novice nurse for much of his/her career.

The experienced nurses in this study recounted their own initial experiences and the role models who were important for them. They described how they observed experience in action in the endeavour to reflect and focus on what worked well or did not. Thus these nurses were specific in what they integrated into their own practice with the aim of a 'good' death for the patient and family. In their description of how they currently shared their knowledge and skills with new graduate nurses it was the one-to-one relationship that was emphasised. Within that relationship the physical 'hands-on' care of the patient was shared, along with stories of care and reflecting on the care given. The new graduate nurse was supported throughout the process and became more independent in the care as his/her competence and confidence increased. The experienced nurses also described how new graduate nurses could care for themselves in terms of avoiding 'burnout' by emphasising the importance of clinical supervision and ongoing education.

Within the recommendations there is emphasis on the new graduate nurse being supported both educationally and emotionally. Ideally the experienced and new graduate nurse work together in the clinical setting, together they manage the care of the patient who is dying. The experienced nurse may be involved in the hands on care and/or a resource nurse. The Resource Document included in this study is intended to be used by staff in the clinical area or classroom setting to facilitate ongoing discussion, debate and reflection about the care of, and management of the dying and their families. There will always be the laughter and the tears as nurses care for patients who are actively dying regardless of the clinical setting.

APPENDIX A

**DYING TO KNOW:
REGISTERED NURSES SHARE THEIR STORIES OF CARE OF THE
DYING
IN THIS RESOURCE DOCUMENT**

**Faye Alison Davenport
2004**

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INTRODUCTION

The following are stories from clinical experience that the participants in the study completed by Faye Davenport (2004) shared during their interview (the stories are categorised under the major headings in the data analysis chapter of the study). Written clinical narratives from some of the participants are included. The stories and narratives are described in the words of the participants.

These stories will provide the content for a proposed* Resource Document to be held in clinical areas as the basis for nurses' reflection and discussion of issues surrounding care of the dying. The final copy of this document will not necessarily take exactly the same form as presented here.

Many thanks to Mic, Lou, Phil, Pat, Kim, Rob, Lyn, Chris and Sam for their honest and heartfelt contributions toward this document.

Sam:

Learning to Care for the Dying is Like Learning to Garden

When you first start out, you don't know where to put the plants. You haven't got a clue what to do, you know you have to spray the roses and to prune them in a certain way. As the years go by, **you get more experience** and **you get more confident** at it. Then you will take bigger jumps, you will cut the rose bush back by one third, the next time you will cut it back by two-thirds, which it should be. You are actually doing the pruning and following the protocol of spraying or whatever and that is what it is all about, without looking up a manual, nursing is no different....

1. *Recognising the Dying Stage*

Rob:

The lady had breast cancer and she was being cared for at home. She had to go and have a CAT scan. She said "I know it is everywhere [that is the breast cancer]". She was quite a **religious lady** and she said "I have friends **praying** for me. After the scan she said "while I was in there I had this great feeling of **peace**". As her nurse, I replied this way: "All the **Guardian Angels** were around you, looking after you; quite often when people die they have that feeling in the house and the family will notice a great feeling of **beautiful peace** when they walk in". It is not always there.

I think that because of my years of nursing experience, I go with the flow. I say to the family, we deal with problems [physical, psychological, social, spiritual] as they occur. We [the nurses] are only a telephone call away. The family are so relieved to hear that.

Lyn:

I was on night duty and was looking after a male patient about forty-eight hours prior to him dying. He began moaning at night. I assessed him and thought maybe he was in pain, he couldn't speak. He would mumble no, when I asked if he was in pain.

The following night when I arrived on duty I had a thought, maybe it was **spiritual anguish** he was suffering from. I said to him, "**would you like me to say a little prayer**" and he nodded his head. He just looked **so peaceful** after that. **Incredibly peaceful**. He had kept moaning up until that time of the prayer, so it was a **spiritual thing** for him at that time. I think maybe it is under estimated that people have **spiritual anguish** sometimes.

Rob:

A young woman had been suffering for years from breast cancer. Her elderly parents came to visit from overseas. The woman was being cared for at home. As the nurse I had tried all I could for the patient but she was still **fighting and distressed**. Her parents had learned from someone who was an Aromatherapist that lavender oil could be useful in certain situations. It did my very best to find out more about the uses of lavender oil in such situations [in order to practice safely]. It was suggested that the oil could be put directly on the skin, and to try it on the area of the throat. It gave this patient **pain relief** and a **peace** we had not been able to achieve before.

For lower back pain we recommend Lavender massage cream with a wheat bag and we have had good success for secondary bone pain.

A written clinical narrative as shared by Rob:

Tom was a fifty-eight year old farmer who had one lung removed for metastatic melanoma (the primary tumour was never found).

Following radiotherapy treatment he developed a large fungating malignant area on his upper abdomen, the size of a dinner plate.

I (Rob) cared for him in the inevitable terminal phase of his illness. He was prone to anxiety attacks causing breathlessness in the last week of his life when his daughter who practised aromatherapy used undiluted lavender essential oil on his throat and temple (this and tea tree oil are the only two oils that can be used undiluted on the skin).

This had a dramatic effect on Tom's anxiety and he relaxed and his breathing improved in a short time.

I have an interest in complementary health but have never witnessed essential oils used in terminal nursing and I was impressed and pleasantly surprised at the results of this practice. I felt it was holistically beneficial for the patient, being non-invasive and no extra medication was required.

I shared this clinical experience with my colleagues and researched the properties of lavender oil which has calmative and relaxing properties.

Reflecting on the uses of lavender oil and discussing it with hospice nurses has encouraged me to use lavender products with other patients who have secondary bone pain, anxiety and insomnia.

When I have UCOL nursing students and we discuss palliative care I cover the use of lavender oil as a complementary aid to orthodox nursing skills and medication.

Other nurses I have networked with have had similar experiences with lavender oil and have been inspired to use it with positive feedback.

In Tom's case his personal anger, grief and anxiety covering his own mortality were discussed, we shared and wept together, along with his wife, during these massage sessions. The partnership between nurse, patient and family is enhanced when a health professional can achieve peace of mind and body through touch and massage. Reassurance and trust are built in these quiet moments when often the nurse can alleviate spiritual concern and worries about the family they will be leaving behind. No one can prepare the family for the individual pain of personal grief but I explain the grieving process and what may occur as I did in Tom's case, and it did help to ease Tom's wife's grief. She still uses lavender oil and associates it with the final loving peaceful moments she had with Tom.

2. Role Models: Watching, Reflecting

Pat:

I was about three weeks into my nursing training and, as part of the teaching of communication skills, the student nurses had to go over to the wards for a couple of hours over morning tea time to give out the morning teas. Thinking about it, it was a very sensible way of making nervous, new nurses interact with people we had never met before, to go up to a stranger and ask if they would like a cup of tea. "Mrs Bloggs, would you like a cup of tea?" The first Mrs Bloggs I walked up to was dead. The woman was in a four-bedded room and she had just quietly expired in her bed.

My nursing friend and I pulled the curtains round and went to find a senior nurse. We said that the patient in that bed in room so and so, we think she is dead. That was my first nursing experience, offering a cup of tea to a dead woman. We carried on with the tea round in this acute medical ward. By the time we had finished the tea round, two other patients in the ward had died.

So following completion of the tea round we moved into helping lay out the dead... and that was our first experience of nursing. I remember thinking to myself at the end of that day, after that experience, if I can deal with that on my first day, I can deal with anything.

I remember that senior student, a three striper, we approached when we found that patient had died, **I remember she took me through the whole process of laying out of the dead...** and the thing that stuck in my mind at that point was that when a person is dead you treat them with exactly the same dignity and respect as if they were still alive. After that I seemed to be pointed in the direction of medical nursing... and dealt with a lot of people who were dying.

Phil:

I came on to a night shift and a female patient was obviously dying, in the terminal phase of illness. Everything was happening very quickly and as the nurse I did not have time to get **the feel for the essence of the person**. The situation was difficult because the patient was agitated and she was finding it increasingly difficult to breathe. It was also distressing for her partner and daughters.

It was lovely listening to the daughters talk about their mother. I was **able to get a real feel** for the mother in a short time. When she did die I was really able to **remember** what the daughters had said about her. When we came to lay her out I was able to **remember**, for example, that their mother liked to hold a nice handkerchief. When I opened the drawer there were these beautiful hankies. We put a hankie in her hand. Around her we put some lovely photos and pictures the grandchildren had drawn for her. We put one of her lovely bedjackets on her. She looked lovely with a rose. When the family walked into the room they could say, there were things from the children. It was lovely for the family to see that rather than just a body lying on a bed... try to **personalise it** [the death] and **to make a difference**.

Pat:

I can look at a patient and know whether we [the patient and myself] are looking at days or hours [until the patient dies]. I remember actually doing that. I was working on a medical ward and a woman went into acute congestive cardiac failure. I walked into the patient's room, I had a student nurse with me. I took one look at the patient and thought...we have got to act right now and we did just that. We sent someone off to get the medical staff member immediately.

The very next day the student nurse's Tutor asked me to go through that process regarding the patient the day before, **to go through the**

process step by step for [with] that student nurse. The Tutor and the nursing student had been doing some work around the difference between a competent nurse and an expert nurse. Apparently, without realising it, I had given an example of an expert nurse in action, that day before.

This was an interesting exercise for me to go through piece by piece what I had done and how I had known what I needed to do. I had walked into that patient's room and I looked at the patient and I knew that something was wrong [that something had changed]. The first question was, "how did you know what was wrong?" You don't think about it. I had never considered myself to be an expert nurse. I considered myself to be competent and dedicated... but not an expert. I think it is called unconscious competence.

A written clinical narrative as shared by Chris:

'A Journey with Tania – June to December'

The following clinical incident precipitated a change in my understanding of holistic care and empowerment of the client and resulted in a significant change in my nursing practice.

I use the following headings:

Introducing the client

Introducing myself

Assessment – the client and her needs

Care plan – reviewing and reassessments

Death – the week of farewells

The Service

Bereavement support – parents, close family and friends

Reflection – on this experience and my learning

Introducing the client

Tania is twenty-seven years of age and an Accountant working overseas. She has a partner who lives with her. They play sport, listen to music and like to travel.

Tania was diagnosed with melanoma four years ago. She has had surgery to remove tumours on several occasions. After a period of remission she had new tumours and she had made the choice to have palliative care from this time onwards.

Her boyfriend/partner has left the relationship and Tania has returned to her parents' home which is where I became involved in her care.

Introducing myself

My name is Peg. I am a Registered Nurse and Midwife with an interest in spirituality and healing under a holistic approach, which involves psychological, emotional as well as physical care.

A time that I spent working for Hospice in the area of Bereavement, caring for families over the two years following the death of their loved one had already helped me to value the courage and independence that so many of our terminally ill clients were able to maintain.

This allowed me to meet Tania with some learning, and respect for the losses that she had already faced, with my attitude of being willing to listen to her. And to co-operate with her in her self care.

Assessment

At our first meeting, soon after Tania had returned home from overseas. I introduced myself and told her a little about my family. We talked about her life and her illness. I was able to ask her, where did she think I may be able to help her?

Tania's first response was that she did not think that she needed a nurse at the moment.

I asked her if she would like a foot massage a couple of times a week-we arranged dates and times.

My assessment:

I observed on my first visit; Tania was able to meet her own hygiene needs. She was able to organise a suitable diet. She self medicated orally and kept records clearly. She could manage short walks. She kept contact with an old friend and reconnected with school friends.

She had established medical/hospital support. Tania had lost body weight and needed to rest frequently.

Tania had integrated some of her losses with courage and determination. Tania was setting short-term goals for herself, regarding outings, visiting and meeting with friends.

Care Plan

First visit; Tania had already met most of her needs with family assistance. She agreed to try some massage, we commenced twice weekly foot massage, this developed into full body massage over a period of weeks.

My process

As I began to spend time with Tania we established a routine

She liked to lie on her bed.

To listen to music – headphones.

To allow the aromas, touch and music to touch her.

We created a peaceful setting-no visitors/calls etcetera.

I was able to enjoy the light massaging without the need to keep up conversation.

A major step I thought, was, that I left quietly without words.

Tania would then stay there for a further hour or more – until lunchtime.

Outcomes

Tania seemed to experience pain relief from the light touch massage.

Her medication needs lessened.

She was able to sleep following the sessions.

Skin texture and muscle tone were maintained.

Tania drew emotional strength from her time of reflection.

Over the period of months we continued this pattern. The time came when Tania's condition was seriously weakened. She had a day when walking was almost beyond her and plans were made for a care conference the next day to assess the change in condition.

During the night Tania became more ill... comatosed and she died shortly afterwards.

I felt happy for her that she had achieved her desire for independence to the end of her life.

Over the course of my time with Tania I had become very fond of her and I felt satisfied that we had achieved a high quality of care for her through the use of aromatic light massage and helping her to create a time and space in her day for the reflective time that accompanied the massage.

The Power of Touch as a Healing Tool

Touch conveys more than words: it strengthens the mind.

Touch maintains skin integrity and muscle tone.

Touch helps relaxation, creativity and pain relief.

Tania was able to paint, write poetry and leave gifts for her family.

Touch had strengthened Tania's ability to stay focussed on remaining as independent as possible.

Touch had optimised Tania's quality of life.

I had learned that nursing can be about accompanying a person through the illness using skills that may not be central to the medical models, by learning to assess the spiritual strengths and values of each client, then work towards respecting, maintaining and strengthening them. Taking time to listen to them well. This requires sensitivity, understanding and commitment to remain non-judgemental and client centred, which may

move the nurse beyond known practice or comfort zones and previous skills area, into touch, massage, meditation, music, art, autobiography.

This client took me on this journey, my practice is now more comprehensive or holistic. I am committed to encouraging nurses to assess the spiritual strengths/values of their clients and plan care accordingly. Holistically in the widest sense – using creativity as appropriate. Touch or light massage has much to offer the nurse as a toll for healing.

3. Working Alongside

Lyn:

Not so long ago I (Lyn) was looking after a lady who was dying and she needed regular suctioning. The new graduate nurse appeared quite terrified of doing that because she hadn't done it before. I said **I would work with her** and it was really enjoyable, showing her how to do mouth cares and regular turning and comfort, basically it is just comfort and also working with family members.

Lyn:

There was a new graduate nurse who obviously did not know what to do. The female patient was dying and the nurse didn't really know she was dying. **I encouraged him** to telephone the family and ask them to come up... the woman died quite quickly after that. The nurse said "what am I going to do now, they [the family] have been told that she is poorly but she has actually died before they have even got here?" He panicked a bit and met them at the door and he said, "oh, she is in there, if you want any help I'll be in my office". **Thank goodness I was there**, I went in the room, made her look rather beautiful and greeted the family members... and hopefully **the nurse learnt from that**. He wasn't callous, he just hadn't looked after a dying person before. **I guess he learnt from this experience.**

Lou:

As a Senior Registered Nurse I was caring for a gentleman who had terminal cancer. I had a new graduate nurse working with me. **I took her with me and we went through the whole process**, I explained the situation. The patient was end stage by this time. The new graduate nurse asked me if she could give the patient some oxygen. I went in and assessed the patient. I said, "it's a bit late for that, you need to telephone the family, tell them he hasn't got long; prepare the patient and prepare the unit, the room". **So the new graduate nurse was involved in the whole process and I was there to support her** because she was in the role of the Registered Nurse. **I was supporting her, explaining what I saw, what I wanted to do about it, and the steps from there.**

Lyn:

The male nurse didn't realise the elderly patient was dying. I was aghast when I looked at her. I thought, oh my goodness, she is only about fifteen minutes away from dying. Sure enough she was. **I suggested quite strongly** that we needed to put the patient in a side room. This was in the evening, we were so aware of the other patients sitting up there... their body language. The nurse said "you can't do that, we haven't got any spare room". I said "perhaps we could put a male patient in the room, temporarily, it has happened before". The male nurse said "we don't normally do that". I said "well look, this is different, **this is just a different situation**, it won't be for long". **We worked it out** and the dying patient was put in a side room. You have to think of other people, other patients, they know what is going on, they are not silly... some of them can be devastated if someone dies in the evening or in broad daylight in their room, it is horrendous for some of them. You are not just thinking of the patient and the family but **you are thinking of other people** as well. It takes you back to the 'bad old days'.

A written clinical narrative as shared by Mic:

I was working in ICU in London caring for a three year old boy who had sustained a serious head injury. His parents were strict Muslims. It was the day of assessing brain function and the first set of tests indicated brain stem death. I spent time answering questions from the parents meeting with the consultant but I could see that the wife was being excluded more and more by the husband. At the time I just attempted to include them both in the process. It was not easy connecting with them though I did everything possible to respect their strict cultural/religious beliefs. I was finding it difficult caring for the boy emotionally as it raised all those questions, the main one being, why a little boy? Brain matter was leaking out of his ear and it became obvious that the second set of tests would confirm brain stem death.

The father was increasingly keeping his wife in the background as more family members arrived. It became obvious that only the men were in the forefront of everything that was happening and that this was more of how their culture dealt with death and dying. I found this difficult to deal with at the time and it really challenged me in the area of providing non-judgemental care. I was making judgements and could understand this exclusion of the mother from her baby boy. It just seemed so wrong.

I kept these thoughts and feelings bottled up and by the end of the shift I was exhausted. That evening I telephoned a colleague because I wasn't sure if I could care for the boy and his family the next day. Anyway that conversation helped me to off load and with the support I received I was able to meet the challenges of the next day. It made me realise that I should have done this earlier in the shift and not let it bottle up. Although the next day was one of the toughest days of my nursing career, and emotionally draining I was able to give my best practice with the help of my colleagues. This experience taught me the importance of sharing my feelings when things get tough and not hold on to them. This would be one insight I would pass on to a new graduate nurse.

4. Clinical Supervision and Education

Rob:

I always talk to students about **'burn out'**. I describe how I put a white light of protection around myself and I always ask for help from the big chief [God] when I go in and say, please give me the strength to do this and I think I go through the motions but I **protect myself from 'burnout'**. We have all been through 'burnout' and that comes with experience. I teach the students to be aware that you can give too much and then you are no good to yourself or anyone else. It is really good that when we do have students and have patients receiving palliative care, even if they are not end stage. I go through scenarios and tell them about experiences I have had, to share those experiences is a learning thing. If we have interesting cases we will swap the students between us [the nurses on the team] so the students get different perspectives of what we are involved in.

APPENDIX B


Human Ethics Committee: Wellington

20 June 2003

Faye Davenport
[REDACTED]

Dear Faye

**Re: MUHEC: WGTN Protocol - 03/115
Registered Nurses Share their Clinical Knowledge of Care of the Dying**

Thank you for the above protocol that was received and considered at the Massey University Wellington Human Ethics Committee meeting on 11 June 2003.

The protocol was approved, subject to approval by Dr Pushpa Wood, Chair/Mr Jeremy Hubbard, Acting Chair, of the reply to the following questions and comments.

PART III: PROJECT DETAILS

6. Risks and benefits

- 6.2: The answer should be N/A (not applicable) as participants are not being treated.

INFORMATION SHEET

- **Confidentiality issues:** During the process of data collection the researcher can store the information. Once the data has been analysed it should be stored at Massey University by the Supervisor.

RESPONSE FORM

- It is suggested that "*ethnic group*" be used rather than "*Pakeha, Maori, other.*"

CONSENT FORM

- Try to reduce this form to one page, eg "*I have read the Information Sheet and I understand the research project. All my questions have been answered.*"

TRANSCRIBER'S AGREEMENT

- Please simplify, using the format in the guidelines on the web site.

Please ensure that all documentation being sent out to the public is on Massey University letterhead.

The Committee congratulated the researcher on a very thorough, good quality application.

Te Kunenga ki Pūrehuroa



Please supply to Norma Wiley (Secretary) one copy of your reply.

Any departure from the approved protocol will require the researcher to return this project to the Massey University Human Ethics Committee for further consideration and approval.

Yours sincerely

A handwritten signature in black ink, appearing to read 'P Wood', is written over the printed name of Dr Pushpa Wood.

Dr Pushpa Wood (Chair)
Massey University Human Ethics Committee: Wellington

Cc: Alison Viskovic, College of Education, Wellington



Wellington Campus
Private Box 756,
Wellington,
New Zealand
Telephone: 64 4 801 2794
Facsimile: 64 4 801 2692

Human Ethics Committee: Wellington

25 July 2003

Faye Davenport
[REDACTED]

Dear Faye

**Re: MUHEC: WGTN Protocol - 03/115
Registered Nurses Share their Clinical Knowledge of Care of the Dying**

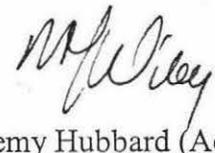
Thank you for forwarding the amended documentation as required by the Massey University Wellington Human Ethics Committee.

The amendments you have made now meet the requirements of the Massey University Human Ethics Committee and the ethics of your protocol are approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, a new application must be submitted at that time.

Any departure from the approved protocol will require the researcher to return this project to the Massey University Human Ethics Committee for further consideration and approval.

A reminder to include the following statement on all public documents: "This project has been reviewed and approved by the Massey University Human Ethics Committee, WGTN Protocol 03/115. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Acting Chair, Massey University Wellington Human Ethics Committee, telephone 04 801 2794 ext 6358, email J.J.Hubbard@massey.ac.nz.

Yours sincerely




Jeremy Hubbard (Acting Chair)
Massey University Wellington Human Ethics Committee

Cc: Alison Viskovic, College of Education, Wellington

Te Kunenga ki Pūrehuroa

Inception to Infinity: Massey University's commitment to learning as a life-long journey



16th July 2003

fayedav@inspire.net.nz

Dear Fay

Dying to know: A qualitative Study Exploring how Registered Nurses Experienced in Care of the Dying may best share their Knowledge/Skills with New Graduate Nurses in the Clinical Setting.

Investigator: Faye Davenport

Manawatu/Whanganui Ethics Committee Registration No: 03/31

The above study has been given ethical approval by the Manawatu/Whanganui Ethics Committee.

We would also like to commend you on your well-designed research project. The committee have only two suggestions that you may wish to consider.

- Page 14 – the committee suggest Oriana Paewai Maori Health Unit MidCentral Health as a point of contact if required.
- Page 4 (1.2.2) – It was suggested that the word inherent be changed to necessary.

Accreditation

This Committee is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Progress Reports

The study is approved until February 2005. The Committee will review the approved application annually. A progress report is required for this study on 1st August 2004. You will be sent a form requesting this information prior to the review date. Please note that failure to complete and return this form may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Amendments

All amendments to the study must be advised to the Committee prior to their implementation.

General

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Please quote the above reference number in all correspondence relating to this study.

Please note a new version of the application form (EA0502) is now available either by email from the Administrator or from the Health Research Council website, www.hrc.govt.nz. Form EA0699 will not be accepted after 31 December 2002.

Yours sincerely

Sheryl Kirikiri
Administrator

S Kirikiri – davenport faye email 30.07.03

30th July 2003

Fayedav@inspire.net.nz

Full Study title: Dying to know: A qualitative Study Exploring how Registered Nurses Experienced in Care of the Dying may best share their Knowledge/Skills with new Graduate Nurses in the Clinical Setting.

Investigator: Faye Davenport

**Ethics Reference No: Manawatu/Whanganui Ethics Committee
03/07/031**

Thank you for your amendments dated 27.07.03. We wish you well in your study.

Approved Documents
Amendment No 1 dated 27.07.03

Yours sincerely

Sheryl Kirikiri
Administrator
Manawatu/Whanganui Ethics Committee

The Advertisement (see next page)

(size of advertisement: 12cm x 7cm)

The advertisement will be placed in the two local community newspapers, the Guardian (to be placed in two Thursday editions at a total cost of \$240) and the Tribune (to be placed in two Sunday editions at a total cost of \$240)) newspapers.

The Poster (see next page)

Permission will be sought from Team Leaders/Clinical Nurse Coordinators of clinical areas to place the poster in staff areas of the following: the local Hospice, medical/surgical wards in the Public Hospital MidCentral Health, the District Nurses rooms, Home Care agencies, Rest Homes with hospital wings in the Palmerston North area.

I will initially telephone the areas to ascertain who is the appropriate person to send a letter to seeking permission to display the posters and provide information sheets. I will then send a letter seeking that permission. The letter will be followed some days later by a follow up telephone call. Copies of the Information Sheet will be sent with the poster. A copy of the letter follows (see page 115).

(Massey University letterhead)

Registered Nurses Share their Clinical Knowledge of Care of the Dying

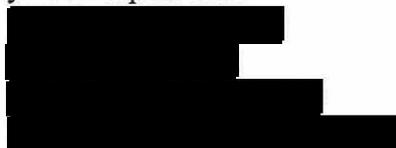
Are you a Registered Nurse with Clinical Experience in caring for patients/clients who are in their last 48 hours of life?

Would you be interested in sharing your clinical knowledge and skills of this area of care with new graduate nurses?

The background: I believe that the new graduate nurse's clinical knowledge of caring for patients at the end of life is often learned in a 'piecemeal' way. This situation can be detrimental to both the nurse and the patient. The aim of this research is to explore how nurses with clinical experience in care of the dying may best share their knowledge/skills with new graduate nurses learning about the clinical care of patients at the end of life.

If you are a Registered Nurse with expertise in care of the dying, practising in the MidCentral Health region, and wish to know more about the study, please contact:

Faye Davenport R/N



This study has been approved by the Manawatu Whanganui Ethics Committee (no. 03/07/31) and the Massey University Human Ethics Committee (WGTN PROTOCOL 03/115).

[This is the outline of the advertisement and poster for the study]

(Massey University letterhead)


Palmerston North

Date

Dear.....

I am a Registered Nurse working in the Regional Cancer Treatment Service, MidCentral Health. At present I am completing the Thesis component of a Master of Education (Adult Education) degree through Massey University College of Education, Wellington. My Supervisor for this study is Alison Viskovic.

The title of my Thesis is *Registered Nurses Share their Knowledge of Care of the Dying*. In this study I wish to explore how Registered Nurses with experience in care of the dying might effectively share their clinical knowledge/skills with new graduate nurses.

I wish to invite Registered Nurses from clinical areas such as the hospice, medical/surgical wards, District Nursing, Home Care agencies, Rest Homes to participate in this project. Participation will involve a semi structured interview (duration one to one and a half hours) and writing a clinical narrative (duration approximately one hour).

I am writing to you to ask for your written permission to advertise the study, in the form of a poster, in staff areas of your institution. Along with the poster I am including an Information Sheet providing information about the study. I would be willing to come and talk with staff about the study if you thought this was helpful and appropriate.

I will contact you in a few days following the delivery of this package, to discuss any concerns or answer any questions you might have.

Thank you for giving this study your attention.

Yours sincerely

Faye Davenport


(Massey University letterhead)

Registered Nurses Share their Clinical Knowledge of Care of the Dying

INFORMATION SHEET

Introduction:

The Principal

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

The Research Supervisor: Alison Viskovic
Senior Lecturer
Dept. of Social & Policy Studies in Education
Massey University College of Education
Private Bag 756
Wellington
Telephone: (04) 801 2794, ext. 6713
Email: A.R.Viskovic@massey.ac.nz

You are invited to take part in this study. Please consider whether you wish to take part. Your participation is entirely voluntary.

Background: I am a Registered Nurse with more than fifteen years' experience in the Regional Cancer Treatment Service. This study forms the Thesis component of my Master of Education (Adult Education) degree. I have an ongoing interest in quality of care for patients at the end of their life.

Within nursing there is a huge amount of 'hidden' knowledge and expertise. New graduate nurses may have classroom knowledge of care for the dying but little or no direct clinical experience. This situation is detrimental to both the nurse and the patient. How does the new graduate nurse become competent and confident in caring for dying patients and their families?

The aims of this study are: firstly, to explore how nurses with clinical experience in care of the dying may best share their knowledge/skills with new graduate nurses.

The second aim is: the development of a written clinical document whereby the experiences may be shared in the practice setting.

Selection of the participants. The participants will be selected based on their expression of interest in taking part in the study. A total of twelve Registered Nurses with clinical experience in care of the dying will be selected from a variety of practice settings within the MidCentral Health region – hospital ward, hospice, rural/community, rest home/agency care. Not everyone who volunteers will necessarily be accepted, for example if too many offer from one type of setting. All volunteers will be notified promptly whether they have been selected.

Collection of the information. You will be asked after giving written consent, to take part in a semi-structured interview, of one to one and a half hour duration. The interview will be held at a time and place to suit you. You have the right to have a support person present during the interview if you wish. You will be asked to consent to having the interview audio-taped and you have the right to decline. You do not have to answer all of the questions. You may request that the interview and/or the recording be ceased at any time during the interview. You will be given the opportunity later to edit the typed transcript of your own interview.

You will be asked to provide a detailed written (or oral if you prefer) clinical narrative describing an experience that impacted upon you, including your feelings and reflections. The interviews and collection of narratives will take place between 1 August 2003 and 31 January 2004.

The audio-tape, a copy of your interview transcript and written narrative will be made available to you at the conclusion of the study. You may ask for these to be destroyed if you wish.

Confidentiality issues. The audio-tapes will be transcribed by an independent person who will sign a confidentiality form. During the process of data collection the audio-tapes and transcriptions will be held in a locked filing cabinet by the researcher and will be available to the research supervisor. Once the data has been analysed the information will be stored at Massey University by the Supervisor. No material that could personally identify you will be used in any reports or publications of this study. Each interview transcript and written narrative will be identified using only a number.

Communicating the results of the study. You will be given a summary of the research report at the conclusion of the study and you may discuss the results with the researcher. The research will be published as a thesis and be placed in the Massey University library. The results of the study may also be shared at conferences and published in journals. There may be a delay between data collection and publication.

If you do agree to take part you are free to withdraw from the study at any time, without having to give a reason. Participation in the study may also be stopped if the interviewer feels it is not in the participant's best interests to continue.

The benefits of this study: to extend the clinical nursing knowledge/skills in the care of the dying by allowing experienced nurses to share with new graduate nurses.

Debriefing: should emotional issues result from participation in this study, ongoing support will be available.

Ethical approval: This project has been reviewed and approved by the Massey University Human Ethics Committee, WGTN Protocol 03/115. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Acting Chair, Massey University Wellington Human Ethics Committee, telephone 04 801 2794 ext 6358, email J.J.Hubbard@massey.ac.nz.

This study has received ethical approval from the Manawatu-Whanganui Ethics Committee, Protocol number: 03/07/31

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Advocate, telephone (06) 353 7236.

Please do not hesitate to contact myself or my supervisor if you have further questions about the study.

Thank you for taking the time to read this Information Sheet and considering whether to take part in the study.

Response Form

Name:.....

Address:.....

.....

Telephone:.....

Email:.....

Years of experience in nursing:.....

.....

Years of experience in caring for the dying:.....

.....

Current area of clinical practice:.....

.....

Ethnic group:.....

I have read the Information Sheet about the study "Registered Nurses Share their Clinical Knowledge of Care of the Dying" and am willing to be a participant in the study. I understand I will be asked to participate in an interview and make a written response. I understand that I will be notified by Faye Davenport whether or not I have been selected to participate.

Signed:.....

Date:.....

(Massey University letterhead)

Registered Nurses Share their Clinical Knowledge of Care of the Dying

CONSENT FORM

THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF FIVE YEARS

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being audio-taped.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature:.....**Date:**.....

Full Name – printed.....

Request for Interpreter

English:	I wish to have an interpreter	Yes	No
Maori:	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero	ae	Kao
Samoan:	Ou te aman'o ia ai se fa'amatala upu	Ioe	Leai
Tongan:	Oku ou fiema'u ha fakaonulea	Io	Ikai
Cook Island:	Ka inangaro au I tetai tangata uri reo	Ae	Kare
Niuean:	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu	E	Nakai

Other languages to be added following consultation with relevant communities

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QUESTIONS TO GUIDE THE SEMI-STRUCTURED INTERVIEW

How would you describe the transition from being terminally ill to entering the active dying phase of illness?

What factors have influenced how you have developed your own knowledge/skills related to care of the dying?

How do you currently share your knowledge/skills of care of the dying with new graduate nurses in the clinical setting?

What would enable you to *more effectively* share your knowledge/skills with these nurses in the clinical setting (in your opinion)?

INFORMATION TO GUIDE THE WRITTEN CLINICAL NARRATIVE

Describe, in detail, a clinical incident (positive or negative) you were a part of, which precipitated a change in your nursing practice related to caring for patients who are dying. Include your thoughts, feelings and reflections on the incident.

As you write the description think about the following:

What changed in your practice as a result of this incident?

How could/would you use this incident as you share your clinical knowledge/skills in this area of care with new graduate nurses?

Send narrative to: Faye Davenport



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TRANSCRIBER'S AGREEMENT

I.....(Full Name – printed)

agree to transcribe the tapes provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project.

TRANSCRIBER

Signature:.....**Date:**.....

WITNESS

Signature:.....**Date:**.....

Full Name – printed.....

APPENDIX C

The following page is a sample page of colour-coded interview transcript from the data analysis phase of the research. In the **bold type** are the interviewer's questions/comments.

The key to colour coding and themes identified is as follows:

Pink – experiences, experiential

Green – the holistic, the physical, psychological, spiritual dimensions

Yellow – communication, conversation, intuition

Purple - relationships

Blue - reflection

INTERVIEW ONE

How would you describe the transition from being terminally ill to a patient entering the active dying phase of illness, like your physical and psychological kind of changes. From being diagnosed as terminally ill, "The Active Dying Stage". Well I guess **in my experience** the **terminal stage** would entail I guess the **finding out that you were terminally ill**, the **grieving process** that follows that. Yes I mean that's the **Psychological bit the grieving process**, the **shock**, the **denial** and in the **physical changes** which would be the **gradual deterioration in independence and ability to do things for themselves**. As well as **holistically, spiritually and emotionally** the impact that it has there as well and certainly the **end stage** is, I guess **in my experience** in the intensive care would be more a state where you are caring for a person but it's almost as if there is a body there but there is no, you know like a sphere or something **leaving the body**, you know there is like, I mean often we have these discussions in ICU that you are caring for someone but it's often a **sense that where the life force were there is leaving or moving away** and you're effectively just caring for a body, if that makes sense and it is often a common thought. I guess that would be, I mean if I had more time to reflect on it then I would probably be able to provide a bit more detail but off the top of my head. **But, I guess sometimes it is sometimes something that you feel as opposed to something that you see, know what I mean.** Yeah, I think a lot of it I guess is obviously, as you are aware, **intuitive, you get a sense of something from someone**, you know, I mean, even I guess if, even with my times in Coronary Care, **you get a sense** of someone in the Coronary Care Unit who was, **something wasn't quite right** and then of course you know **something would happen, they would have an arrest or their condition would deteriorate** and, so yeah I guess there is a lot in that, a lot of talk about the **intuitive feeling**, you know. **Often Nurses have a lot of information in their heads which isn't necessarily easy to share or to describe perhaps.** No no, yeah that's right. It's I guess it's not, we don't see it written down in any form, I guess, yeah I mean the fact that **I can relate to having this conversation with many other**, you know, Nurses suggests that it is quite widespread, you know, a lot of people think in the same way or **experience the same feelings** as well. **Whatever setting they work in I guess.** Yeah whatever setting I mean, you know, um and it's, yeah for settings I have worked in but settings I have worked in but I have talked to people who have worked in different settings as well. **Sure** you know it's been the same. Yeah. **So what factors have influenced how you have developed your own knowledge and skills related to care of the dying? Are there specific factors or specific things that have influenced your learning or people or.** I think, yeah, I mean **experiential learning** I guess there has been some significant, I guess situations, early on in my training or in my work in ICU or Coronary Care where you have been **working closely with families, patients and develop good relationships, positive relationships** and in a process of **reflecting following those situations and reflecting on what was learnt, what perhaps you could have done differently, what you did well and you know using those insights to change or you know, improve how you care for someone in sort of subsequent times so like experiential but not only experiential**, I mean I think personally is a powerful learning method for me but theoretical as well, I mean I have done a lot of post basic, you know post reg training in England, you know ENB courses and the theory that comes from that, I guess that **learning skills** like counselling but being able to feel comfortable in that situation where somebody is dying and **being able to sit with them and recognise the silence and times that it is appropriate to speak and other times when it is appropriate to be quiet**, you know that sort of thing really so I guess there are **role plays** that you can do and that sort of stuff is helped to guide my practice, yeah, I mean I guess a lot of people would say perhaps also that **personal experience of dying** and whilst I have had some, not really of anyone that I have been very close to, so in that sense I haven't got that to draw upon, but certainly I guess, from a Nursing perspective, I consider that I have **been pretty close** to those that have died so you know I have certainly got that to draw on. So yeah, I guess that the factors would be **a combination of the experiential and some theory** of the courses I have done as well that would help. **A combination** yeah a combination I say rather than, and I guess as I have you know, I'd like to think that **as you get older you get a little bit wiser** you know and **definite life experiences** and **I guess you've got more to draw on** that's right. If I think back on my days in ICU and Coronary Care I was younger then and now when I know, you know I would probably be a little bit different, **life experience I guess is a great leveller as well as learner.** So yeah that would be the main thing. **So moving on from that, how do you currently share your knowledge and skills of Care of the Dying with?** Well presently **I am involved in delivering** the National Certificate in Support of the Older Person which is a Level 3 Certificate to Caregivers and one of the units 5013 is Caring for the Person who is Terminally Ill. **Right** so we cover various components to that but essentially we look at **what it is to be terminally ill, the effects that it has on the person emotionally, physically, holistically** then how, as a Caregiver, what their **needs** could be and they can meet those **needs** and we talk about **communicating**, for example **with the patient or the family**, whanau who is terminally ill, we sort of have **role plays** and **discussions, experiences** and join those. We begin it by, like with all the other class we

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