

**CRITICAL NURSING BEHAVIORS IN CARE FOR THE DYING
ON ADULT MEDICAL UNITS**

BY

JOAN E. HARBECK

A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of

MASTER OF NURSING

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A special thanks you to my husband Richard, and my children, Chris, Kathy and Jackie, who were always there with encouragement, patience and love, throughout the writing of this thesis. I would not have achieved success without their ongoing support.

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"CRITICAL NURSING BEHAVIOURS IN CARE FOR THE DYING: ON ADULT MEDICAL UNITS"Abstract

Despite the widespread belief that illness can be cured and that the tasks in hospitals are intended to preserve life, the majority of people die in a hospital, many on non-specialty units such as a medical ward. Nurses on medical units are in a key position to meet the needs of dying patients. Little is known however, about what constitutes effective nursing care for the dying or what influences 'expert' nurses to care for the dying within this eclectic setting.

Guided by Benner's application of the Dreyfus Model of Skill Acquisition, nursing behaviours critical to care of the dying were identified from semi-structured interviews with twelve nurses who had been identified by peers as 'expert' in care of dying patients. Constant Comparison Content Analysis revealed nine categories of behaviours with the following themes: connecting, supporting family, providing comfort, responding after the death event, responding to feelings, responding to colleagues, enhancing quality of living while dying, enhancing personal growth and managerial support.

Mager and Pipe's Model which goes beyond education to analyze performance was used to determine rewards and punishments associated with behaviour performance.

Findings were compared with Degner, Gow and Thompson's (1991) research of critical behaviours. Recommendations were suggested for future nursing research, education and practice.

CHAPTER I

STATEMENT OF THE PROBLEM

Care for the dying has received increasing attention during this last quarter century. Participants in this process have included diverse health care disciplines as well as the recipients of care. In order to provide scientifically based educational programmes for nurses, which will enable better quality care for the dying, it is first necessary to determine what constitutes expert nursing care in the context of terminal illness.

Background

Widespread acceptance of the biomedical model of health care resulted in high expectations of health care provision, and the belief that diseases all could be cured. Institutions caring for the sick adopted goals to investigate, diagnose, cure or at least prolong life (Mount, 1976). Because professionals and the public are enamoured by the magical powers of high technology medicine, these goals of care are likely to persist (Benoliel, 1988; Nabe, 1989). In an effort to gain professional prestige and status, nurses working in hospitals identified with the dominant view of medicine. They became more technically oriented to keep up with rapid medical advances and nursing care became organized around technical tasks instead of patients (Amenta & Bohnet,

1986; Calkin, Fitch & Larsen, 1989; Conboy-Hill, 1986; Holman, 1990). Caring became submerged within curing practices (Hagall, 1989; Hoggatt & Spilka, 1978). Ironically hospitals, where tasks are intended to preserve life, are where most people die (Bircumshaw, 1993; Fulton & Owen, 1988; Hendricks & Hendricks, 1981; Lockard 1989; Parry, 1987; Radsma, 1994; Shedletsky & Fischer, 1986; Waters 1987). Studies in the 1960's and 1970's described dying patients who were placed at the end of long corridors whose calls went unanswered, and who were avoided (LeShan cited in Amenta & Bohnet, 1986). For the dying patient, consequences of treatments were rarely considered; families were viewed as hindering care, as people to call before the "failure" could be removed from the unit.

As recipients of present day health care, dying patients and their families are insistent that their needs be acknowledged and met in an expert manner; not all are willing to accept a silent role, as was common in the past. Many dying patients, or families on their behalf, are demanding individualized and holistic care. Palliative Care Units, Palliative Care Teams and the Hospice Movement developed in response to those demands. However, many people still die in acute care hospitals that are organized around a model in which the individual is categorized by a disease process, in keeping with a medical model. Several problems surface when the hospital's primary function of cure and treatment no longer meets the needs of dying patients (Corless, 1988).

Hospitals are ideally organized for efficiency, effectiveness, and productivity. Individuals who are dying want to be comfortable, want to

communicate with skilled practitioners, to have their family near, and many desire to participate in care and decision making. Despite a plethora of publications on death and dying, institutionalized values and the current organization of health care that focuses on cure, perpetuate a context in which the human and the humane side of caring is often left to chance (Benoliel, 1983; Daeffler, 1985).

A second problem arises. Many nurses are unfamiliar with death and the individualized care required by the dying. Although caregivers will have had some death education, they are not adequately prepared for situations in which death and dying are central elements. To cope with this lack of knowledge and skills, nurses keep busy carrying out physical patient care, and commonly use avoidance as a means of coping (Hurley, 1977, cited in Benoliel, 1983; Stoller, 1980).

A third problem is one of decreasing health care dollars. On many hospital units, nursing care is organized and provided based on what must be done for patient safety. Acuity of patient care often focuses nursing attention on developing technical, medically related skills (Calkin, Fitch, and Larsen, 1989). With limited human resources, the non-physical care needs of dying patients cannot compete with telemetry monitoring, multiple drug regimes and other invasive procedures that other patients may require. Palliative versus curative interventions present contradictory role expectations that are stressful for a significant number of hospital nurses. To ensure "care work" is offered to hospitalized patients, the organization has an obligation to ensure necessary resources are provided (Radsma, 1994).

Nurses are challenged to offer expert care to the dying within the constraints of the current hospital system. Educational programmes need to address deficiencies in care of the dying. To date, the effect of education on improved patient care has not been evaluated in terms of patient/ family outcomes (Degner, Gow & Thompson, 1991). Generating knowledge about what constitutes effective care for the dying is a first step in developing and testing a model of expert care.

In 1988, Degner, Gow and Thompson reviewed the literature to determine critical nursing behaviours in care for the dying. Much of this literature review came from oncology nursing literature and focused on palliative and hospice units. Research within these specialty units has indicated that in addition to symptom management, essential elements of good care include patient /family involvement in decision-making and care, a multidisciplinary team approach to patient care, support for caregivers and follow-up bereavement care for families (Scherr,1989).

Although there is increasing attention devoted to creating specialized areas or specialized teams to care for the terminally ill, the majority of patients still die within institutions (Hendricks & Hendricks, 1981) and on non-specialty units where active treatment is seen as a primary mandate.

Medical Unit

A medical unit is a broad specialty often referred to as a "catch all" for a wide variety of age groups and health alterations (Kitchens, Piazza, & Ellison, 1989). Recognized nursing specialties have become

increasingly narrow and follow those of clinical medicine. Examples include cardiovascular, gerontology, oncology, burns, rehabilitation, critical care, and long term care nursing. At any given time patients from these diverse "specialties" will be found on medical units. Nursing practice on general medical wards under the influence of medical sub-specialty practice, has become complex; knowledge once required to care for patients in specialty units is now knowledge required to care for these patients on medical wards (Calkin, Fitch, & Larsen, 1989). An expert medical nurse can best be described as an advanced generalist, a nurse with a broad rather than narrow clinical focus.

Many specialty units do not accept inexperienced nurses. Consequently, new graduates are placed on units such as general medicine. The generalist medical nurse becomes able to care for patients irrespective of diagnosis, age, or acuity (Friss, 1989).

Reason for admission to a medical ward for patients who are terminally ill is seldom reflected in their admitting diagnoses. Symptoms of disease that can still be treated, psychosocial diagnosis such as "inability to cope", or perhaps "for social admission" are often listed. The patient's terminal state is often not acknowledged and sometimes denied.

Statement of the Problem

Nurses who work on medical units become skilled in a wide range of nursing activities. One such nursing activity is care for the dying patient. What behaviours do expert medical nurses demonstrate when

caring for dying patients? When these behaviours are identified they can be compared and contrasted to expert nursing behaviours evidenced by palliative care nurses, by nurse educators, and those activities listed in the nursing literature. Knowledge regarding "expert care for the dying" on a medical unit will be identified. When the behaviours critical to care for the dying are known, they can then be considered for nursing education and practice.

Purpose of the Study

The purpose of this study was to identify nursing behaviours that were critical for patients dying on adult medical units.

Research questions addressed were:

1. What nursing behaviours of "expert nurses" made a positive difference for patients dying on medical units?
2. What nursing behaviours of "expert nurses" made a negative difference for patients dying on medical units?
3. How did these behaviours compare to those determined by Degner, Gow and Thompson's study (1991)?
4. What behaviours of nursing experts in care of the dying were "rewarded" on medical units?
5. What behaviours of nursing experts in care of the dying were "punished" on medical units?

Importance of the Study

Research into clinical nursing is essential for critical evaluation of practice, for understanding what is optimal nursing care, and for learning how best to provide it (Benner, 1984). Previous research has considered critical nurse behaviours in care for the dying from the perspectives of nurse educators and expert palliative care nurses (Degner, Gow & Thompson, 1991), ICU nurses (McClement, 1993), and pediatric nurses (Hawkins, 1995). Because the greatest number of deaths within acute care hospitals occur on general medical wards, determining expert care of the dying within that setting contributes to the growing body of knowledge describing behaviours of expert nurses caring for the dying.

Nursing care within an acute care setting such as a medical ward, is often contrasted with that on specialty units such as palliative care. Studies describe the focus of acute care to be cure and treatment activities; curing activities are relegated to a secondary position. Determining if expert nursing care of the dying is different on medical units from that care given on palliative and other units further expands nursing knowledge.

Organization of Chapters

Chapter one provides the background from which the study questions arose, the problem and purpose of the study. In chapter 2 current literature related to nursing care of the dying is reviewed. Topics considered include: fear of death, and resulting attitudes; effects of different educational strategies; effect of experience; and the

influence of the work setting. As well nursing behaviours cited in articles related to care of the dying were categorized into general and specific behaviours.

The theoretical frameworks on which the study was based are described in Chapter 3.

Chapter 4 outlines methodology including: population, sample and sample selection; data collection method; the procedure followed; data analysis; and ethical considerations.

The results of the study are discussed in Chapter 5. The sixth and final chapter consists of a discussion of the findings and recommendation are suggested for nursing education, practice and research.

CHAPTER II

REVIEW OF THE LITERATURE

Fear of Death and Avoidance of Dying Patients

Inadequate nursing care for terminally ill patients is often attributed to a nurse's own fear of death and discomfort with the dying. Fears are manifested in feelings of uncertainty, helplessness and frustration. The outcome of these fears has been observed and reported to be avoidance of the dying person (Glaser, 1965 cited in Benoliel, 1983; Gow and Williams, 1977; Kubler-Ross, 1969; Lev, 1986; Quint, 1967.) Even when patients initiated discussion, Ross (1978) found that nurses chose to avoid discussions of feelings about death by offering reassurances, denying the concern, or changing the subject. In a study identifying behaviours used when communicating with cancer patients, Wilkinson (1991) observed that most nurses used a variety of blocking tactics to prevent patients divulging their problems. Using linguistic analysis to quantify the attitudinal concept of avoidance, Mood and Lakin (1979) demonstrated nurses' verbal avoidance. Use of the impersonal pronoun "it" was greater in death related topics than non-death topics. Mood and Lick (1979) reported that nursing personnel used significantly more negative words when talking about death and dying than when discussing other topics suggesting an attitude of death denial. Hurley (1977) cited avoidance as the preferred strategy when

composure under stressful work circumstances was desired. Avoidance is not linked with amount of time spent with a dying patient. Benoliel (1988) reported that nurses spend more time with dying patients, but display more verbal and non verbal avoidance coping strategies during that time than when with non-dying patients.

That nurses employ avoidance as a defensive behaviour can best be understood when nurses are viewed as members of a society where death is not visible; nurses face death in their work situation with no more skill than their counterparts outside of health care. Milton (1984) found that 78% of final year baccalaureate students reported that if death and dying were discussed in their homes, it had been associated with discomfort, or was taboo. Societal attitudes are brought into nursing programmes and nursing programs reflect societal attitude and beliefs.

Quint (1967) believed it was imperative that nurses become aware of and deal with their attitudes toward death and dying and that they realize that their attitudes affected their practice. Kubler-Ross (1969) also suggested that nurses needed to look at their own attitudes and face them, if they were to help terminally ill patients without undue anxiety.

A moderate to strong relationship has been made between attitudes and behaviours. Attitudes are determinants of behaviour (Hill, 1981; Lev, 1986; Milton, 1984). Thanatology literature suggests that facing the reality of death makes it less fearful, and that there is increased competence when interacting with and supporting the dying and grieving

(Lockard, 1989.) Death related fears had little impact in situations where avoidance strategies could be effective, such as being near a dead body, or when providing physical care to terminal patients. Fear did, however, affect those patient/nurse interactions where there was no specific physical task to perform. Stoller (1980) concluded that nurses' uneasiness with dying patients was more than a reflection of personal death fear, and that if nurses were to be assisted to care for the dying, nursing curricula must include and emphasize strategies for providing emotional support and comfort to dying patients. Shifts in attitudes about death and dying can be influenced by education (Benoliel, 1983; Caty & Tamblyn, 1984; Lev, 1986; Yeaworth, Knapp & Winget, 1974.)

Education

The need for death education was identified by Quint (1967) and Kubler-Ross (1969). By exposing nurses to death education the assumption was that they would learn to face and deal with death more effectively. Death education research to date is not conclusive. Content of death education programmes can be viewed on a didactic/experiential continuum (Durlak & Riesenber, 1991.) Programmes can be integrated into an existing curriculum, or be elective or required courses. The presence of a clinical component with an assigned practice with dying patients varies from program to program (Degner & Gow, 1988.) Didactic programmes consist of lectures, media presentations and large group discussions. Attitude change is stimulated by increasing cognitive

awareness and understanding of death related issues. Experiential programmes may contain some didactic elements; however, the goal is to help individuals examine and discuss personal feelings and concerns about death. In a meta-analysis of published outcome research on the impact of death education, Durlak and Riesenbergr (1991) found experiential programmes produced a decrease in death fears and anxieties whereas didactic programmes slightly increased participant discomfort with death. An educational programme for nursing home staff, designed to decrease death anxiety, change attitude to caring for dying patients, and increase knowledge and skills was reported by Linn, Linn and Stein (1983). Results indicated that anxiety about death of self increased; fear of dying of others decreased. The most significant change was demonstrated in regard to knowledge and skill.

Positive effects were present and fear of death of self had subsided one year later. Lockard (1989) stated that nursing students exposed to a death educational instructional unit, with values-clarification and consciousness raising activities, demonstrated significant death anxiety reductions at completion and one year later.

After reviewing 15 evaluations of death education, Degner and Gow (1988) reported that there seemed to be a reduction in death anxiety and/or improved attitudes to care of the dying. Readers were cautioned however because of numerous problems with design, instrumentation, and data analysis. Hurtig and Stewin (1990) found 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. For students already experienced with death, the experiential component had a negative effect.

Experience

Experience with death on a personal or professional level can influence attitudes (Benoliel, 1985; Holter & Holter, 1980; Peace & Vincent, 1989). Gow and Williams (1977) found that nurses 40 years or older had more positive reactions to caring for the dying than their younger colleagues. They concluded that nurses' attitudes toward death and dying were primarily determined by personal experiences and attributes. Thompson (1985) also found that older, more experienced nurses viewed their work with the dying as rewarding and coped with anxiety by engaging the patient as a whole person.

For some nurses, personal experience with a family death was more salient than an education course or clinical experience (Hopping, 1977). Coolbeth and Sullivan (1984) found no significant attitude changes due to personal exposure or to the interaction of personal and academic exposure. In contrast, Quint (1967), Schrock and Swanson (1981), and Alexander (1990) found that direct experience with dying patients produced attitude change, but the direction of change was not determined. According to Hare and Pratt (1989), more exposure to dying patients resulted in higher comfort levels with them, but did not increase nurses' coping strategies for handling uneasiness in the work situation (Stoller, 1980). Hurtig and Lewin (1990) determined that

nursing fears are not reduced as a result of cumulative nursing experience.

A positive role model in death related matters was found to increase student comfort with dying patients (Bidwell & Brasler, 1989). This suggests that direct encounters with other nurses with positive attitudes to care of the dying influence behaviours of students nurses (Kiger, 1994; Quint, 1967). However, care of the dying cannot simplistically be tied to personality characteristics of those providing care; effects of socio-cultural and organizational factors must also be considered (Benoliel, 1988). An earlier ethnographic study showed that the working atmosphere of the unit was affected by conflicting views on treatment orientation, physician conflicts, personal crises of nurses, and reactions of patients and families to each other and the caregivers, (Germain, 1976).

Work Setting

Death can be viewed as a medical failure or as the natural outcome of the process of living. Caregiving practices are affected not only by the nature of the patients, but by the atmosphere created by the workers themselves. In an organizational culture where health care is guided by the biomedical model of disease, the individual experience of illness, suffering and dying is not considered. Instead, the patient is objectified, divided into disease categories; psychosocial data become deviations from the norm. Responses to death and dying are influenced and altered by the complex personal dynamics, and the context of

interactions and transactions taking place (Benoliel, 1983, 1988; Hendon & Epting, 1989; Holman, 1990; Martocchio, 1982.) These interactions encourage a particular affective reaction to death and dying (Billings, 1987; Thompson, 1985) and regardless of education, guide and shape attitudes towards patients and what is important in practice (Benoliel, 1988). In a British study, Field and Kitson (1986) noted that a professional nursing role was emphasized in educational settings. Within this role nurses viewed patients holistically; social and emotional problems were legitimate areas of concern. Once in a hospital setting however, the "ideals" transmitted in the school were seen as not relevant, and a more "task oriented" approach became the norm. Amenta (1986) cautioned that the depersonalization associated with large, bureaucratic modern institutions needed to be personalized by caring practitioners. Factors relating to structure and process exert powerful forces over the organization of nursing work and the constitution of nurse-patient relationships (May, 1991). The link between organizational goals and the care offered to patients on hospital units is managed by the head nurse/unit manager.

Head Nurse/Unit Manager

A literature review revealed that the head nurse is an essential and valued position in hospitals, (Hodges, Knapp, & Cooper, 1987), occupies a critical role in nursing service administration (Alidina, Funke & Thurber, 1988; Ellis, 1986) and was vital to the linking of organizational goals to unit level practice (Adams, 1988; Duffield, 1989;

Everson-Bates, 1992; Mohr, 1988). Head Nurses influence the "norms" of the particular work setting managed by them, (Darling, 1985; Johnston, 1983), including how nurses communicate with patients (Wilkinson, 1991). Perception of the head nurse role varies. According to Barker and Ganti, (1980) nursing staff view the head nurse as teacher, leader, decision maker, assistant and spokesperson. Depending on the circumstances of the day, physicians view the head nurse as a member of the nursing staff, as the person with whom they collaborate, or as the administrator to whom they communicate displeasure or give instructions to. To patients and families, the head nurse is viewed as the one who will solve all the problems; and the supervisor expects the head nurse to implement hospital policies, manage patients and staff and coordinate goals and objectives. If the head nurse supports the importance of nursing care of the dying, it will be demonstrated in the many interactions necessary to meet the sometimes unrealistic and often conflicting expectations of patients, families, nursing staff, physicians and hospital administrators (Haigh, 1990). On each nursing unit what is taught, practised, discussed, rewarded or punished is influenced by the head nurse.

Summary

The literature has suggested that nurses avoid dying patients because of personal fears of dying and that educational programmes can affect these fears. The expected outcome, less avoidance and therefore better care, has not been conclusively demonstrated to date. Work

setting and organizational philosophy influence nurses who care for the dying. Nurses become socialized to the norms of their nursing group. This can mean subjugating educational ideals to the established "way it is" in a curative setting. Death and dying education encompasses broad areas. What is required is knowledge of specific nursing behaviours that make a difference to those who die on medical units. This would enable students, and other non-expert nurses to feel confident rather than helpless when caring for the dying. Once behaviours are identified, the hospital environment can then facilitate and support rather than impede the practice of those behaviours. Developing a description of critical nursing behaviours in care of the dying is a prerequisite to developing a scientifically based curricular content for educational programmes at all levels.

Nursing Behaviours Cited in the Literature

A review of nursing literature was conducted to identify nursing behaviours described as central for care of the dying. Research and clinically based articles were included as well as fundamental nursing textbooks. Behaviours cited as important were identified; similar groups of behaviours were titled.

Insert Table 1. about here

Eight clusters of behaviours emerged. Six were analogous to the behaviours cited in Degner, Gow, and Thompson (1991): comfort care; patient feelings; nurse feelings; collegial support; patient rights; and family care. A seventh category manipulation of the environment (McClement, 1993), was identified. The category not previously cited described facilitating/coordinating behaviours. Most behaviours cited in the literature were described in broad, often vague terms. Positive nursing behaviours were stressed by nursing authors; behaviours with negative consequences for care were seldom mentioned.

CHAPTER III

THEORETICAL FRAMEWORK

Three theoretical perspectives guided this study. Quint's perspectives related to nurses learning to care for dying patients 2) Benner's application of the Dreyfus and Dreyfus Theory of Skill Acquisition to nursing and 3) a model developed by Mager and Pipe (1984) to analyze performance problems.

Quint's Perspective

Quint (1967) was influenced by symbolic interaction theory, a theory that seeks to understand how individuals take and make meaning in interactions with others (Marshall & Rossman, 1989). In an effort to understand the reason for the lack of care received by dying patients in hospitals, Quint suggested that nurses learned through their interactions with nurses and other health care professionals. Quint felt that exposure to dying patients without any education about death and dying was anxiety provoking for nurses, and led to negative attitudes towards the terminally ill, most often demonstrated by avoidance. To reduce avoidance behaviours, Quint (1967) suggested a comprehensive educational component on death and dying, that included specific education with planned clinical experience with dying patients.

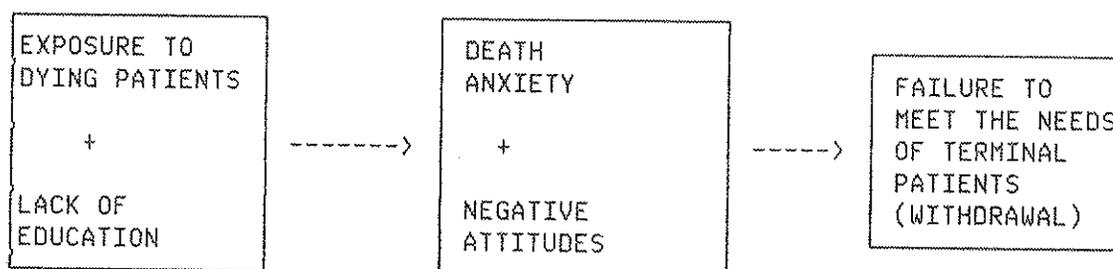
Degner, Gow and Thompson (1991) identified critical nursing

behaviours in palliative care. Their study was seen as a pre-requisite for the development of scientifically based content for an educational programme related to death and dying as suggested by Quint (1967). This replication study expanded upon their research to determine critical nursing behaviours for patients dying on adult medical units.

Benner (1984) applied the Dreyfus Model of Skill Acquisition to nursing. She demonstrated that intentions, expectations, meanings, and outcomes of expert practice could be described and aspects of nursing "know how" identified by interpreted descriptions of actual practice. Her model was the basis for identifying the nurse experts who participated, and the structure of the interviews that gathered the "know-how" of expert medical nurses.

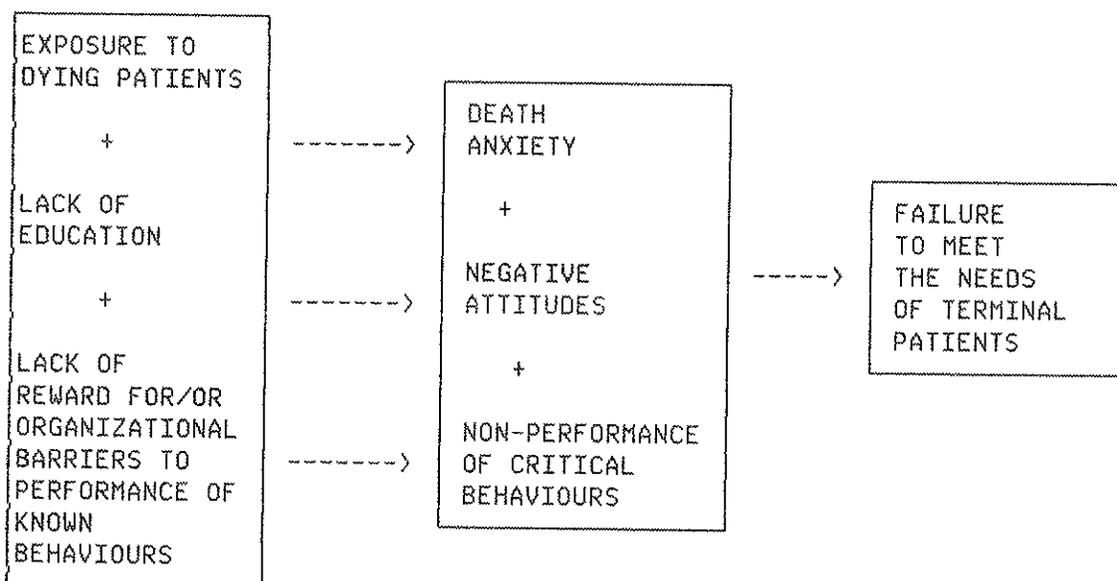
A secondary purpose of this study, was to determine what behaviours were rewarded or punished, based on a model developed by Mager and Pipe (1984). The model provided a framework for analyzing performance discrepancies. This added perspective speaks to the impact of setting and those in a position to influence nursing care provided within that setting.

FIGURE 1. Quint's Theoretical Perspective



A revision of Quint's model is proposed that includes structural conditions that affect nursing practice.

FIGURE 2. Proposed Model



Benner's Application of the Dreyfus Model of Skill Acquisition (1984).

Benner (1984) applied a model developed by Dreyfus and Dreyfus (1977) to actual clinical practice reported by expert nurses. She found that knowledge embedded in their practice accrued over time. Her study also revealed that expert nurses changed their intellectual orientation, integrated and sorted knowledge and refocused decision-making based on perceptual awareness. Less experienced nurses used a process orientation which Carlson, Crawford and Contrades (1989) described as a conscious, deliberate, analytic problem solving process .

The Dreyfus Model posits that students pass through five levels of proficiency when acquiring and developing new skills: novice, advanced beginner, competent, proficient and expert. According to Benner (1984), changes in three general aspects of skilled performance are reflected in these different levels. One is a movement to use past concrete experiences as paradigms instead of reliance on abstract principles. A second involves a change in perception of a situation from one in which many parts are seen to be of equal relevance to one in which the learner can see a situation as a whole with certain parts more relevant than others. The third is movement from being outside the situation, a detached observer, to becoming an involved performer in the situation. Thus the role of experience, the influence of perception and the perspective of involvement in situations are key concepts that are integral to this model. One assumption of the Dreyfus model is that with experience and mastery, skills are transformed and improved performance results.

As Degner, Gow and Thompson (1991) noted, the need to define expert nursing practice in care of the dying is acute. What is available in the nursing literature is opinion based and anecdotal in nature, instead of what Benner (1984) described as the well charted practices and observations essential for theory development. Benner (1984) utilized critical incidents that are situation based descriptions of patient care episodes. Critical incidents describe patient care episodes such as a situation in which intervention made a difference in patient outcome, an incident that went unusually well or one in which

there was a breakdown, an incident that was very ordinary and typical, one that captured the quintessence of nursing, or an incident that was particularly demanding. Incidents revealing what Benner (1984) described as "knowing how" are seldom found in textbooks. Farrell and Bramadat (1991) suggested that they are found in the "folk milieu" of the practice setting, in shared discussions, in the frustrations and joys expressed about particularly satisfying or tough clinical situations.

To gain access to the "knowing how" of expert care of the dying on medical units, it is necessary to listen to medical nurses described as experts by their peers. An expert, according to Benner (1984), no longer relies on analytic principles to connect understanding and action. Instead, the nurse has an intuitive grasp of each situation because of previous experiences, and is able to zero in on problems without wasteful consideration of a large number of alternate diagnoses and solutions. Experience therefore refers to the active process of refining and changing notions and ideas when confronted with actual situations and each encounter may add a shade of difference to current theory. Experience is a prerequisite for expert practice; it does not refer to longevity or length of time in a position.

According to Benner, (1984) experts are easy to recognize. They provide consultation for others, demonstrate acceptance of risk taking, and use discretionary judgement. The model predicts that a nurse would perform at an expert level in a clinical situation where experience has already been gained and where there is motivation to perform well.

Benner (1984) suggested that expert practice is usually found in practitioners who have worked with a similar patient population for more than five years. In her study nurses were selected with at least five years clinical experience, and who were currently engaged in direct patient care. Educational background was not a formal consideration. For the purpose of the present study nurses with several years nursing experience will be considered.

To facilitate identification of medical nurses considered to be experts in care of the dying, a sociometric tool, the Medical Nurse Expert Identification Tool (MNEIT) was used. (See Appendix A.). Three paragraphs describing expert practice were written from Benner's (1984) descriptions of expert nursing practice, and nursing behaviours described in the death and dying literature. For each paragraph, participants were asked to list one to three peers who best met the described behaviours. If appropriate, the participants wrote their own name. The nurses listed most often by their peers were the nurse experts approached to participate in this study.

Analyzing Performance Problems: Mager and Pipe, (1984).

Mager and Pipe (1984) posit that when there is a difference between actual and desired performance a "performance discrepancy" exists. The literature reviewed for this study supports that a performance discrepancy exists between current practice vis a vis nursing care of the dying and what is desired nursing care of the dying. If a performance discrepancy is identified, the first step is to

consider its importance by answering the following questions. Why is the discrepancy important? What would happen if things were left alone? Is resolving the discrepancy worthwhile? If nursing care on medical units does not address the needs of dying patients, a performance discrepancy exists.

The second step in this model is to determine a remedy for the discrepancy. The remedy is based on whether nurses could demonstrate the behaviour if their life depended upon it. Thus the question "could nurses give expert care to dying patients if their life depended upon it"?, determines which of two sequences for solution is followed. For some nurses, there is a genuine skill deficiency; they have had no exposure to caring for dying patients and do not know what to do. Exposing nurses to death education and practice with feedback would be beneficial. Before skills/behaviours can be taught, they must first be identified, which is the purpose of this particular research and research conducted in other clinical areas (Degner, Gow & Thompson, 1991; Hawkins, (1995); McClement, (1993).

When selecting a remedy, Mager and Pipe (1984) suggest that sometimes skills are known but, due to lack of practice, they have been forgotten. For these individuals, skill practice and feedback is effective. Research by Degner and Gow (1988), demonstrated that death education with a compulsory clinical component, which also included post practice discussion, decreased reported nurse avoidance behaviours two years after the program was completed.

The second arm of this model acknowledged the importance of the setting in which the behaviour occurs. Rather than modifying the person's skill or knowledge, the conditions or consequences associated with performance need to change. Four general causes of non-performance are suggested in this model: 1) it is punishing to perform as desired; 2) it is rewarding to perform other than as desired; 3) performance does not matter; 4) there are obstacles to performing as desired. This model suggests that if someone knows how to perform as desired but does not, the remedy is to find ways to reduce or eliminate negative effects and to create or increase the strength of positive or desirable consequences for the performer. If non-performance is rewarding, the rewards need to be altered. Is there a meaningful consequence for desired performance? Sometimes performance discrepancies exist because there are no consequences if a behaviour is present or not. Making desired performance matter is suggested by Mager and Pipe (1984) in this case. Removing obstacles to performance includes making expectations clear, and having the authority to perform as desired.

Caring for dying patients in a curative setting can cause role strain when daily task structure encourages a curative orientation, yet the expectations for nursing dying patients require a palliative orientation. Nurses are obliged to manage not only the uneasiness of dealing with interactions with dying patients, but also the aura of failure that dying carries within a curative setting (Thompson, 1985). If the "norms" of the unit reflect a curative philosophy, going against

them may be associated with few rewards and much personal and professional cost. In contrast, a nursing unit where the patient/family is the focus of care rather than a disease, where all professional competencies of expert nurses are acknowledged and rewarded and where teamwork among disciplines is the norm, a setting with few obstacles to expert care of the dying would be expected (Benoliel, 1988; Smith & Variglu, 1985; Thompson, 1985).

Summary

This study was one of a series to determine critical nursing behaviours for dying patients which could be incorporated into an educational programme on death and dying, as suggested by Quint in 1967. Benner's (1984) application of the Dreyfus Model of Skill Acquisition to nursing was the basis for identifying the nurse experts who participated and the semi-structured interview guide that was followed. The study was broadened to include a perspective offered by Mager and Pipe (1984) that analyzed reasons for lack of performance. While recognizing the importance of education, their model included recognition of other factors within the work setting that encouraged or discouraged performance.

CHAPTER IV

METHODOLOGY

The primary purpose of a descriptive study is to "paint a picture" of a situation rather than studying cause and effect relationships (Munhall & Oiler, 1986). Because there is a paucity of information about what constitutes expert nursing care of the dying in general, and expert nursing care of the dying on medical units in particular, it was appropriate that this study design was descriptive and qualitative.

Population, Sample and Sample Selection

The selection of an appropriate and adequate sample is critical and has a profound effect on the quality of research. According to Morse (1989), appropriateness refers to the degree to which the chosen informants and the method of selection fits the purpose of the study.

Sample

In order to determine critical nursing behaviours in care for dying patients on adult medical units, a purposeful sample was obtained. Twelve medical nurses, identified by at least eight peers as experts in care for dying patients, were selected from a medical ward within one large tertiary teaching hospital and one community based hospital. Previous research by Degner, Gow and Thompson, (1991) and McClement (1993) has shown a similar sample size (ten) provided maximum

information without redundancy. In purposeful sampling the size of the sample is determined by informational considerations; sampling is terminated when no new information is forthcoming (Lincoln & Guba, 1985). One criticism of purposive sampling, that generalizations cannot be made to broader populations cannot be disputed. This method was however, necessary, in order to obtain information from specific informants, namely medical nurses expert in caring for dying patients.

Nurse experts were identified using the "Medical Nurse Expert Identification Tool" (Appendix A). This tool was adapted from the work of Hiss, MacDonald and David (1978) and revised to reflect Benner's (1984) attributes of nurse experts. Attributes of expert nurses identified by Benner (1984) and categories of nursing behaviours frequently identified in the literature to be essential in terminal care, were used to construct the paragraphs that described nurses expert in care for the dying (Appendix C). The names of medical nurses matching the descriptions in the tool became the population from which the sample was selected.

Data Collection Methods

Interview Guide

An interview is a conversation with a purpose (Lincoln & Guba, 1985). Benner (1984) found that experienced nurses can readily bring to mind clinical situations that had altered their approach to patient

care. To access the knowledge of participants, a semi-structured interview guide was developed that contained an overview of the elements to be considered (Appendix B). An advantage of a semi-structured interview is that both the interviewer and the participant are free to introduce new thoughts or observations that are particularly relevant to their personal perspective as the conversation unfolds (Wilson, 1985). The interview guide was based on the work of Benner (1984), Degner, Gow and Thompson, (1991) and the literature reviewed (see Appendix B). The interview guide elicited descriptions of those behaviours medical nurses associated as positive or negative behaviours to care for the dying and the context in which the behaviours occurred. Nurse experts were asked to describe the most recent incident they could remember in which a student or colleague had made a positive difference to care of the dying: Was it something said? Was it something done? What consequences occurred? Was the behaviour rewarded? Punished? The same approach was repeated but this time the nurses were asked to describe an incident in which a student or colleague displayed negative behaviours when offering care to a terminally ill patient. Contradictory data were sought and investigated thus increasing the wealth of information available to the researcher and prevent undue bias (Hutchinson, 1986).

Procedures

After obtaining ethical approval from the University of Manitoba Faculty of Nursing Ethical Review Committee, The Ethical Review Committees of the Health Sciences Centre and Victoria General Hospital,

the project was explained to medical staff nurses at their unit staff meeting. At this time, the voluntary nature of participation in selection of nurse experts and subsequent potential participation in the study was stressed. Nurses who agreed to identify their peers expert in care of the dying were then requested to read the disclaimer at the top of the Medical Nurse Expert Identification Tool (Appendix A). Continued participation took the place of a signed consent form.

Nurses who been nominated by eight or more peers were contacted by the researcher, by telephone, at their home. They were asked if they were willing to continue to participate in the study. If they were, interviews requiring one and one-half hours were arranged at a time and place convenient and comfortable for them. Four interview sites were chosen by participants: three chose to be interviewed in the researcher's office; two in her home; and seven on their respective units. Five participants were interviewed after their eight hour shift, one before her eight hour shift and the remaining six were interviewed during work hours. At the time of interview, a consent form was given to the participant and questions about the study were answered. After participants indicated their understanding of the purpose of the study, the consent form was signed. Informants then completed the Structured Data Collection Tool including: age, gender, years in nursing, years in medical nursing, level of nursing education and other educational preparation related to terminal care (Appendix E). All interviews were audio tape recorded and transcribed verbatim onto computer discs.

Data Analysis

Interview data were analyzed using a method known as constant comparative content analysis (Glaser & Strauss, 1967). In this method each section of the interview was analyzed and coded for particular meaning which was often described utilizing verbs (Brink, 1989). The coded data were compared with every other section already coded until patterns and categories emerged and themes were established. The researcher determined similarities and differences of incidents, if the described incident was central or recurring, and if it made sense to people in the setting (Brink & Wood, 1989). According to Munhall and Oiler (1986), comparing similar incidents defined the basic properties of a category; differences between incidents established boundaries; relationships among categories were gradually clarified. Categories of emerging behaviours were described using the words of participants. Only when categories could not be described using the language of participants did the investigator assign titles to categories.

The data analysis was modified by including a procedure for achieving reliability through consensus (Degner & Beaton, 1987). The first five interviews were read independently by the student and advisor to identify critical behaviours. The behaviours were written on cards, and then compared to achieve consensus in meaning and wording. The same approach was used in subsequent interviews. Following this, all behaviours were compared and clustered into categories that appeared to provide the best explanation of the data, and operational definitions were written for these categories. Next, the interviews were coded into

the operationally defined categories. Finally, coded data extracted from the original interviews was organized under each of the final categories that emerged.

Issues of Data Trustworthiness

Persuading others that findings are worthy of attention is the basic issue in relation to trustworthiness (Lincoln & Guba, 1985). They suggest that credibility, transferability, dependability, and confirmability are indicators of trustworthiness.

Credibility (Internal validity)

According to Lincoln and Guba (1985), increasing the probability of credible findings can be achieved through prolonged engagement (understanding the culture), persistent observation and triangulation. Although this researcher was familiar with the culture of nursing, and dying patients therefore reducing the potential for distorting data due to lack of understanding, the same familiarity could bias findings due to researcher a priori values and constructions. To reduce this threat, care was taken to use the same words and examples as participants, and to continually clarify what the participant meant. A example question to illustrates was "One participant described death as ugly how would you describe it?" This technique gained deeper access to the participant's world, an example of what Lincoln and Guba (1985) described as persistent observation. The third technique to establish credibility, triangulation, was demonstrated when the researcher

verified that data from one participant made sense to other participants. Copies of the findings were sent to each participant . They were asked to review the results and indicate if the results "fit" with their experience.

Lincoln and Guba (1985) suggest that prolonged engagement facilitates the development of trust between researcher and subject, a development that reduces the likelihood that participants will distort information. Trust was established when participants were given the opportunity to influence the study. They were asked to determine if the study findings "fit" with their experiences. Ensuring and maintaining confidentiality of data and anonymity of participants was an essential element. The researcher, her thesis advisor and the individual hired to transcribe the tape recorded interviews, were the only ones who had access to the data; nurses completing the expert nurse identification form were reminded not to write their names; participants were assigned code numbers; general terms such as nurse or patient were used to prevent identification of the participants; assurance that confidences learned through the interview process, would not be used against participants, were examples that promoted trust through confidentiality. When rapport was established (when both parties trusted each other) the criterion of credibility was met.

The student's advisor checked the descriptions of critical behaviours identified in the study. As a final check on validity of inferences drawn from the data, a preliminary draft of the results of this study was distributed to participants to see if the nursing

behaviours described "fit" or accurately reflected their perceptions of critical behaviours in care for the dying, and if they were complete. Recognition of the categories indicated what Munhall and Oiler (1986) termed theory "relevance". Morse (1989) suggested that distribution of the preliminary results should be in a group setting to remove interviewer bias. Because of the logistics involved in getting all participants together at a time mutually convenient, confirmation took place on an individual basis.

Transferability (External validity)

Findings from qualitative methodology represent a hypothesis together with a description of the time and context in which they were found to hold (Lincoln & Guba, 1985). The focus of this study was subject specific, (nurses, expert in care for dying patients) and context specific, (on medical wards). The findings are not generalizable to other nurses or other settings. To have chosen a random sample, however, would have violated the qualitative principle of obtaining data from experts (Morse, 1989). Expert medical nurse participants provided "thick" information data base of their experiences at the time of interview.

Dependability

A technique referred to as "Overlapping of methods" was suggested as one way to establish dependability. In this study subjective

interpretation of data was reduced by overlapping researcher memory, with tape recordings and verbatim transcriptions of the data.

Confirmability

Interview tapes and transcribed verbatim interviews will be stored for seven years. If questions arise, the researcher and advisor have access to them. Findings can be confirmed.

Ethical Considerations

Informed Consent

Informed consent in the form of participation in the expert nurse selection was obtained when the Medical Nurse Expert Identification Tool was completed. Attention was addressed to the disclaimer at the top of the form.

Nurses agreeing to be interviewed were given a verbal explanation of the consent form (see Appendix D). Questions about the study or the consent form were encouraged. After reading the form the participant was asked if they understood. If they understood the form and agreed to participate they were be requested to sign it.

Participant Physical and Psychological Comfort

All interviews occurred at a time and location convenient to the participant. Other than satisfaction from contributing to improving care for dying patients, there was no known benefit to participation in

this study. On the other hand, participation in this study did not involve any ill effects. No strong feelings were evoked during discussions of death and dying; the interviewer was sensitive to the affective needs of the participant. Participants were given opportunities to re-schedule interviews, were reminded that they could withdraw from the study and, if the participants indicated, they could request the assistance of a support person. Participants were informed they could refuse to answer any question. Participants indicated to the researcher that the opportunity to talk about death and dying and issues surrounding nursing work had been positive. Talking about experiences in which their care had made a difference felt good.

Confidentiality

Anonymity of sources of data was assured. Prior to participation in expert nurse identification, participants were reminded not to put their name on the M.N.E.I.T. These forms were kept in a locked area separate from other materials. Persons interviewed were assigned a code number. Audio tapes, verbatim transcripts of the interviews, notes, and documents that make up the raw data of the study are kept in a locked filing cabinet at the St. Boniface Hospital Research Centre and will remain there for 7-10 years. Access to the data was limited to the researcher and her advisors. When the study was complete, the audio tapes were erased.

Summary

In this chapter sample selection, methods of data collection and analysis have been described. Evidence of trustworthiness of the findings was offered. The chapter ended by considering ethical issues.

CHAPTER V

FINDINGS

This chapter provides the description of the study findings. The characteristics of the study sample, obtained from the Structured Data Collection Tool (see Appendix E) are also described.

Characteristics of the Sample

The purposive sample for this investigation consisted of 12 nurses from two medical units, identified by their peers as "expert" in caring for dying patients. Participants, all female, ranged in age between twenty-three and fifty-four years; the average age was thirty-six and one-half years. Experience in nursing ranged from two to twenty-three years; the average was eleven and three quarters years. Medical nursing experience ranged between two and fifteen years averaging just over seven years. Eight participants had worked only on the current medical unit while four had experience in other areas of nursing.

All participants had registered nursing diplomas and one had a post diploma baccalaureate in arts. Six participants reported attending one or two conferences or seminars related to palliative care and/or oncology.

Overview

Preliminary data analysis revealed eight categories of nursing behaviours plus the category managerial support. Descriptions of these behaviours were written by the investigator using coded interview data. These descriptions were checked against the original data by the advisor and revisions were made. The preliminary draft of the chapter was given to each participant for critique as a final check on the validity of inferences drawn and revisions made. Final descriptions of nine critical nursing behaviours are summarized in Table 2.

Connecting

Medical units are truly eclectic in the sense that patients present to the unit for diverse reasons and in varying physical states. Patients who were dying were no exception. Participants explained that sometimes they knew dying patients because of repeated admissions or because they had been on the ward a long time. In contrast, some dying patients were transferred to adult medical units from emergency or intensive care units and were unfamiliar to ward nurses. In all situations nurses tried to get to "know" the patient in order to provide care that met each person's needs. The same connecting nursing behaviours were described for all patients who might die on the ward. What varied was how they were prioritized within the total care needs of the patient. For patients very close to death they were the top priority and the intense focus of nursing care. For patients with more time the sense of urgency decreased. Initial interactions were directed

towards establishing a relationship, a connection with the patient that would become the foundation for all other interactions.

Contact Behaviours that Lead to the Development of a Relationship with Patients.

In order for nurses to get to know and understand their dying patients and to determine what mattered to them, participants identified characteristics that were essential to successful relationship building. Nurses described the need to know the individual first, placing the fact that they were dying in a secondary position.

Where are you, not where I want you to be, not where I think you should be, not where your neighbour is, or what the last person experienced, Where are you now?

You have to be real, in a situation like that you can't be anything but real.

Really listening to them, the patient and what they want, what their last requests are and what you can do to meet them.

Sensitivity, empathy, humour and the ability to be a good listener were essential, as was a sense of comfort and ease with the process of death and dying.

Rather than awful and frightening you see death as a process and that there is a reason it is part of a cycle, we are all part of it. There is a special intensity about recognizing that I am alive while at the same time knowing that one day that will be me.

You start being comfortable, when you know you are doing everything for the patient and you are doing the right thing for the family. If you like what you are doing and you want to be the best.

Several participants described a trust that developed when they were able to follow through with what had been discussed or promised. In some situations such follow through was not possible, but in good relationships truthful explanations were understood and accepted by dying patients. One nurse found that developing a relationship with a dying patient was faster and easier than with other patients.

You do that quickly because you spend such concentrated times with people. Like you are bathing somebody; they are completely vulnerable, so you do get to know people faster in that situation. I think dying people have a sense that they don't have a lot of time and they are not full of a lot of garbage, they are coming right down to what they want to say. They are very much themselves, there is very little pretence.

There are no games, your conversations are deeper, your conversations are much different. They tell you things that are incredible.

Successful relationships with the dying are described as incredibly close. Inner thoughts are shared making this relationship more intimate than some family relationships. Medical nurses considered their role in this special relationship a privilege.

They will tell us things about their families, it is privileged information in the real sense of being privileged to hear. That someone would trust you enough to mention things that they felt they had to let out before they died, and yet weren't comfortable telling even the family members.

I find that very surprising still and wonderful and because you are ultimately that position of trust with people they look at you for truths that they can't get from other places.

In contrast, nurses were able to describe situations where there was no connecting, where the relationship was distant, reserved or had become overly dependent causing the nurse to "back off." Intellectually, nurses understood that there would be patients with whom

they would not or could not connect. When that happened nurses felt they had failed and met with other nurses to plan different approaches that might meet with success.

We expect people to come into hospital and just because they are the patients in the hospital and we are the people working in the hospital, to instantly create this really strong bond with us, to open up and tell us everything that has happened to them, all their deepest fears their largest hopes and that doesn't work, it doesn't work instantly. They have to trust you.

He wasn't ready to die and I found it really hard to try and get him to talk about the fact that he was very angry. He would just say, "oh never mind, don't say anything, I really don't want to hear it". The unfortunate part about it was that we were never able to get past that point and he did die. It feels like failure; it is definitely frustrating, but if they won't let you reach in, there is nothing you can do or say.

Patients reminded some nurses of family members and they were unable to get beyond feelings of personal vulnerability. The relationship suffered as a result.

Nurses can be afraid of being with the patient or family for whatever reason. It might be too close to home; it might be someone who reminds them of their husband or it could even remind them of themselves. I think that sometimes those are the kind of things that interfere with the ability to develop that intimacy.

Some patients connected with one nurse on the unit excluding the others. Other nurses could never measure up and hard feelings arose.

I have to be careful because sometimes you feel people become dependent on you. You are the only one that can do things right or something. You have to back off. I have had to back off on occasion when patients became too dependent on me. Not that I was any better than anyone else, but I spent a lot of time in there.

Barriers to establishing relationships occurred when tasks were the focus of interactions rather than the person.

He was so alert, people were afraid to look after him. He had so much machinery. They sent him from ICU as soon as they could. He was a very heavy patient. He was on isolation too. Nobody was comfortable with someone so young and so sick and needing so much attention. They focused on the tracheotomy rather than the patient that was dying.

Supporting the Family

Medical nurses considered the patient/ family unit as the recipient of their care. When differences arose between what the patient wanted or needed and what the family wanted or needed, medical nurses put patient's needs first. Everything done for and with the patient affected the family. Within family units individuals were recognized to have needs that could be different from the needs of the family unit.

Five themes emerged in this category: 1) behaviours that supported families and individual family members, 2) behaviours that responded to informational needs, 3) behaviours that prepared the family for the death, 4) behaviours that included or excluded the family from responsibilities in care giving according to their wishes, and 5) behaviours that reduced the potential for future regret.

Behaviours that Demonstrate Support for the Family and the Individuals that Make up the Family.

Participants identified the need to get to know the family and to connect in a trusting relationship with them. This included knowing who the various members were and helping them to identify and meet their needs. Nurses needed to know specific information such as the name of the contact person, and the family's desired role. When nurses knew the

family they were able to intervene appropriately. Family needs were often varied and sometimes at odds with patients needs. Good communication skills were essential when working with a number of stressed family members who each responded differently to their relative's impending death.

Family members were given the phone number of the unit, and the nurse's name. In one instance a nurse gave her home phone number in case the patient's wife needed to talk.

It is very important to get in touch with the family. And I don't mean by telephone, I mean in terms of building a relationship with them right away, making them feel comfortable and welcomed and whatever they need.

I try and get myself involved with the family as much as the patient because I think that once the patient is kept comfortable the ones who need a lot of support is the family. They are the ones who have to go on dealing with things following the patient's death.

Just reassuring and letting them know what is happening. I think that for families they want to know what is happening and they are always asking questions and just listening to them and trying to answer as honestly because we don't have the answers very often. Just being there for them. When they want to talk about how they are feeling or how well prepared they are.

Some family members found it difficult to be at the hospital all day every day but not coming made them feel guilty. Nurses supported families by recognizing all their efforts and in some instances by giving them permission to stay home. Understanding how difficult one woman found coming to the hospital, the nurse continued to support her by telephoning to make sure she was alright. Some families felt threatened and overwhelmed. They were unsure of their role and needed to know if they were "doing" the right thing. Nurses gave positive

feedback to encourage continued family involvement. In some cases this meant explaining how important touch was.

Telling her that you are there if she wants to talk, letting her know that she didn't have to feel guilty and that she was doing wonderfully. Helping her to feel comfortable. She would phone in and want assurance that she wasn't a bad person for not coming in and I felt I owed that to her.

How are you feeling, are you tired? Are you talking to him? You need to talk to him, he can hear you. Whatever part of him is him can hear you wherever that part is, so you need to be comfortable in doing and saying the things you need to say.

He would spend hours talking to his dad and rubbing his feet even after he became confused and was no longer talking. He wondered if it was getting through if it made any difference. What I did was assure him that the talking and the touching was communicating his love, that his dad would feel his love wherever he was, wherever he was going.

Nursing presence was important especially in situations when families seemed closed and defensive.

I think that the nurse's physical presence is so important. One of the things that happens in those situations where you have the family that is defensive and whether it is defensive about the family member dying, or about care they are receiving or anger towards physicians that may be totally unrelated to the dying person, I like to call that a kind of siege mentality, where the family walls themselves off in room, the door is closed, and everybody is huddled in there. Usually your response is to run in and do whatever there is and then get out, because it is really tense. I think if you make yourself go in there and plunk yourself down like you are part of it, you can start with them. They will start to see you as one of "us" as opposed to one of "them".

Responding to the Family's Need for Information

Family anxiety was reduced when they trusted that health professionals were sharing information with them and when families felt their knowledge and concerns about their loved one were listened to and

valued. Current information facilitated family grief work as well as enabling them to provide support to the patient and each other in their own way. When the individuals within the family unit were known, the nurse could gauge the timing and amount of information as well as identify the family member with whom to speak. Nurses needed to be sensitive to family responses and not go "overboard". Information allowed family members to continue to make choices, such as staying the night or going home.

They like to hear the truth and honesty in information. I think providing people with honesty and all the information that is available is the best thing you can do, if they are wanting to hear it. Some don't want to hear it and some aren't willing to listen and that's fine too. But people who are asking questions, I think have every right to know every bit of information that's there. And again, depending on the family, if I know them I might call and say you know, Dad's not the same today, I don't know what it is but he's just not the same. And if I know them I will call them and say these things and they will come in. They respect that, especially if they know you. They will say, oh, I trust her judgement. She has looked after my Dad quite a few times and maybe we should go in.

Nurses often found themselves translating what doctors had said or what the consequences of events could be. In some instances this meant that nurses were the ones who presented a realistic scenario and then worked with families to help them cope with reality. Information often needed to be repeated.

You have to be open and up front with them and if things aren't going good maybe it's not up to you to tell them but you have to ask the doctor to at least and even if he doesn't say much, I sometimes will stick my head in. If he sort of just, he figures he has said something but if it is not what I know they needed to hear...I've gone in afterwards and explained exactly what he meant.

I think being able to tell the family member that what they are seeing is happening that it will not somehow go away is really important.

As far as explaining a "do not resuscitate" or a "no codes" order, I have heard them explained terribly. You know, the doctor comes in and tries to talk to them about it and they leave and they will come back and say yes they want full calls. I thought, they haven't got a clue what you are talking about. They don't take the time to explain things in layman's terms. They certainly don't give them the opportunity to give them the idea of sort of the quality vs. the quantity; like this will work for a little bit.

The fact that some nurses did not make themselves available to speak with families did not sit well with participants who felt that it was important to be available to answer questions even if there was no definite answer.

To be available to answer questions even if the answer is I don't know. That is another thing that some nurses don't respond to well, they are always asking questions. I see that as a really big role of nursing. That doesn't mean you have to have the right answer or that you know the answer, but almost always you can find out the answer, even if the answer is nobody knows.

Within each family, roles and dynamics are unique and in some instances very complex. Nurses attempted to identify one or two family members who became the main contacts for the family and to whom health professionals directed their communications. When families were large this was particularly important to ensure there was time to care for the patient as well as communicate with family.

Usually if there are large groups of family it is good to find out, and there is always one, who is the spokesperson or the main contact for the family. You go through them as far as establishing what they know or have been told, what they think is going to happen, how they want it to happen, do they want to be right here in the room, do they want to be phoned are they going to sleep over, do they want to sleep in the bed?

Family members were more comfortable with the care given to their loved one when they understood exactly what was happening and why. This was not always easy because family members did not always see events from the same perspective and at times seemed to be pulling in opposite directions. Excellent communication skills were demonstrated as nurses facilitated clarification of patient and family goals with the care being offered.

If you increase the rate on the machine delivering the medication, or if you discontinue the intravenous explain why. If you communicate to the family what you are doing all the time they feel comfortable, they gain confidence in you.

They may be a close family or not. One may think totally different from the other. They may have the same goal in mind but both looking at it from such different angles. If you aren't listening you might think why is one bucking against the other? But they aren't bucking against each other. It's just this is how they have heard it, or this is how they have been told. All they want is for Mom to be comfortable.

Nurses described situations where the family insisted upon a course of action that was unusual or not in the patient's best interest.

They wanted us to transfuse him so his apnea would be reduced, which I thought was totally bizarre. However, at this point, it would not have been detrimental to the patient and it was something that family really needed, so that kind of advocacy was important. If the physician had said I refuse to do that, that is ridiculous, I would have said, I know it is strange, but I think it is something that they need, I don't think it is a big deal.

The family was in and we went over and over what would happen. I had taken them aside outside the room and explained that he could go at any time and they still wanted everything done and I went through what would happen when his heart stopped and what they would do and they still wanted everything done .

The nurse wanted to increase the morphine but the family kept saying no, she's alright; all she needs is us to be here. The nurse who was explaining to them is a wonderful nurse, tried to

explain to them that the patient was asking "help me, help me". I think she feels awful today. She feels awful because she feels the family is probably going to blame her because she did increase the morphine and the patient died that evening.

One nurse found that giving examples of similar situations helped to allay fears and assist families in decision-making.

I have often said, I have worked here a number of years and I have seen patients like your Mom and none of them suffer because there is no intravenous or anything. I had a patient and this is what we did and she was so comfortable and that is sometimes what they need to hear. About somebody else and that is exactly what was done, and then OK that's fine, it's not that you are making my Mom a guinea pig, that you don't want to do this, and you are going to make her suffer.

Including or Excluding Families from Responsibilities in Care-giving According to their Wishes.

Not all families wanted or were able to participate in caring for their relative. Nurses became adept at interpreting clues such as body language to gauge if they should involve the family in actual nursing care and if so, to what extent. Some family members felt comfortable assisting the nurse, while others wanted to do everything. Nurses tried for a balance between what was good for the patient and what was beneficial for the family. Families were taught necessary nursing skills that would make the patient comfortable.

You assess the family. You say would you like to do this? This has to be done every two to three hours. Are you comfortable doing it? Some of the family will say no, and right away you say that's fine. You don't want them to feel guilty. You hope they will do it, but if they don't you don't ever make them feel guilty.

So with the families you know want to be involved, because they feel there is nothing more they can do and they want to help; then

you get them to do as much as you can. They feel good about it and they like it and it's good for the patient.

Some families attempted too much and nurses had to intervene to allow the patient to rest or to prevent family burn out.

They stayed all night because they felt they should but they got worn out. I let them know that I would look after her and call if there is a change. They need to look after themselves.

Reducing the Potential for Future Regret

Nurses helped families identify if there was something that needed to be said or done before their relative died.

Once you know the family a little bit better sometimes you delve into what do you think the person would have wanted. If the roles were reversed, would that person want you laying here uncomfortable or would that person want you to be comfortable? And I have often used that sequence putting the family member in the patient's position, and saying now what would you want if you were in that position?

Most nurses thought that families experienced less guilt if they were present during the death scene and they tried to facilitate this happening. Even when patients and families had decided otherwise, nurses would contact families to give them the opportunity to change their minds on this one time event.

I asked her if she wanted me to call her husband and her children to be there with her. She didn't want them to be there. And later on that night when her husband did call in the middle of the night he didn't want to be there. I guess this was something they had decided before. We also make sure the family knows, if they wish to change their minds. just to let them know so if they have anything left they wish to, any last words or if they wish to change their minds.

I didn't realize that he didn't want to see her. He didn't want to be called, he didn't want to be here when she passed away. Maybe we should have done something, like talk to him more, tell

him that he might feel more comfortable, maybe she would like you to be here, just to hold her hand, or something. We all felt it was the wrong thing because he could have accepted her death easier if he were there. As it turned out, I think he arrived within minutes of her death and he was heard to tell his doctor why...now he is blaming her.

Even when patients were no longer responding, the nurse's work with the family continued.

The relationship I had developed with that patient at that point was really non-existent, like there wasn't anything to relate to. The nursing time I spend is with his daughter and that to me, you see I'll spend half an hour with his daughter and I'll charge her up so she can spend three hours with him.

And I often thought about all the anger that his wife is still living with right now that never really got resolved. It never worked itself out. I worried about him, but I am more worried about her right now, how she is functioning. He was so angry at his wife like she was to blame. Yet she never took it personally. She never said anything when she was here, but I imagine she went home with a lot of grief.

Nurses also tried to ensure that wishes of the family were met.

She wanted him to die at home. He was on IV analgesics and we weren't sure how we were going to get that set up because we don't have an IV team here. So we got Home Care involved and we managed to get Medox and he was home for three days before he died. She was in contact with us if she needed anything. We showed her how to give him something in case he ran into difficulties. She said it was nice to be at home. She said she spent the last few days as his wife, not his nurse or bedside maid.

We did get it together and the patient managed to see all of his family. Not all at the same time, mornings were for certain family members and afternoons for others. He did get to see his grandchildren. I was able to say that he went knowing that he had seen all his family members. I think the family members, even though there was some rivalry and some anger amongst them, were able to say that they did what he had wanted. They weren't left with feelings of guilt that maybe I should have done this or shouldn't have done it. And that's a good feeling.

Preparing the Family for the Death Event.

Nursing behaviours during the actual death event were based on prior circumstances. What had the doctor told patients and families? Was this communicated to nurses? Was the event expected or unexpected? Was the family known to the nurse, were family present, and was the patient to be "coded" or not? Participants believed that someone should be with the dying patient at the time of death. Ideally a family member should be present but if that was not possible, nurses made a special effort to be present. Continued support for families during this difficult time was identified.

I am always relieved if they have a "no resuscitation" order on a dying patient. It makes a great deal of difference. Not specifically to how we care for that patient but it makes it easier for everybody to cope with the fact that they are dying.

Sometimes patients were transferred from the intensive care or emergency unit to enable family to be with their loved one in a more dignified setting. When this happened, nurses on the receiving medical units attempted to connect with the patient and family immediately.

If it is something that looks like it is going to be imminent, you want to get as much information from them about their family, or what has been going on with the family up there, if the family is aware, if they are around, if they want to be there, if they are not there do they want to be called?

If there was no family present, the nurse made a concentrated effort to spend more time with the patient because they did not want patients to die alone. This often meant that nurses spent their breaks with dying patients.

I don't think anyone should die alone. They didn't have a lot of family; he only had one visitor in three days when he looked really poor. I felt really guilty, no not really guilty I just felt sorry for him and I felt that I wanted to go into the room a few more times. I'd go in and just hold his hand even though he wasn't responding and he looked terrible, just because I didn't want him to be alone, it felt awful, no one should be alone at that point.

Any time I had, lets say every 15-20 minutes; the night of no breaks, as you say. Maybe a break to go to the bathroom, run up and get a sandwich and just spend some time with him talking. There has to be something pretty pronounced to get me out of there, like it would have to be an emergency to get me out of there.

Difficulties arose when families seemed unaware that their relative was close to death. Nurses described families who had come running from patient rooms screaming for something to be done trying to pull the nurse into the room while she was trying to calmly and directly explain that there was nothing more that could be done. When families were insistent, nurses would institute modest nursing measures such as starting oxygen or gentle suctioning. In some instances, a "slow code" was called.

I thought the doctor had prepared the family. Whether he did or whether it didn't sink in is two different things too. They turned on me and started screaming and swearing and saying "Why aren't you doing something"? Meanwhile I was trying to hold their hand and trying to prepare them and ask them if they felt comfortable to come around and touch him if they felt comfortable. They took a different reaction and became almost violent. Throwing their bodies on top of him and crying and asking me to do something. So I put the oxygen on and I went out and called for some help. I said to the girls, "Do you want to get the medical officer up"? I was calling a code but it was not fast. But there are those situations that no matter what kind of care you are giving to somebody, there is always that underlying guilt, that, look what we have done. Nobody should have to go through that. Nobody should become like that and yet we've done that to this poor soul.

Sometimes, after an unsuccessful resuscitation the patient is not yet dead. The nurse has to quickly decide whether to create a dignified bedside scene or bring the family member to the bedside before the last breath is taken.

The thing was, that he was definitely drawing in his last few breaths and for her to be there with him when he passed away, there wasn't time. He was going to go and he was going to go very quickly. This is a hard trade off. That was not a comfortable thing to do, it didn't feel right.

I had taken his wife into the conference room and had her sit down because they were still in there finishing off, gathering up their supplies. The resident wanted me to bring her into the room and I said I would take her down but I wanted to go down there first. You never know how they are going to leave it and how you are going to find it. At this point this man was next to gone, but he wasn't, he still was breathing sporadically, he still was. I went in and they had left him tubed, not bagging, not anything, just tubed because they had put it in but they didn't continue with the resuscitation. I remember trying very hard to get this resident to pull that tube out before I took her down. He said "if you take the tube out he will go right away". I said "well he is going to go regardless, that's the last time she is going to have, that is the last thing she will remember, the last thing she will see".

Families needed a concentrated effort of support as their relative approached death. It was the nurse who was present when changes occurred that indicated the patient was about to die. Nurses viewed the death "event" as the end point of the process of dying. What support was needed and how support could best be offered was dependant upon the individuals that made up each family.

His son was really quite a remarkable young man, in that he was almost like he was a student in the process. He wanted to know everything I knew, he wanted to know what all these things meant, he wanted to spend time with his Dad.

It gives you an opportunity again to talk about the process not the event. I think that the actual event when a person stops

breathing is less significant in a way. It's significance is only in how you as a family member have prepared yourself or been prepared. And you know, sometimes people can't be prepared, you can try but their defences are so heightened that it's not possible.

Sometimes families had not accepted the reality of their loved one's death even as the last breath was drawn. Situations where nurses tried to gather family around to say their goodbyes, while family was insisting that nurses "do something" to prevent the death were described as being at "cross purposes" and "were the worst". Sometimes family members missed the opportunity to be part of this important event because they were unable to get beyond the words spoken by health professionals who offered false hope instead of the realities of the situation. Nurses had strong feelings about this:

I think nurses must somehow always give out hope instead of talking about the realities. I don't think people are stupid and I think they sometimes need the hard reality and it is not that they will be unsupported in their grief. But it doesn't do anybody any favours to pretend that what is going on is not going on.

I felt like I was in the dark. I thought don't they (the family) realize what was happening? Don't they realize that their loved one has a terminal illness and there is nothing more we can do? I thought they were prepared for this and they weren't and this was the worst feeling.

He died, he was resuscitated, he was maintained. They had weaned him off the respirator and he was in a sinus rhythm when he came from ICU but there was nothing there. That's again my feeling, because there is a big difference between someone who has slipped into a coma and someone whose body has been kick-started. That's what I believe happened in that case. He died and then he was kick-started, he was jumped like you would jump a car. Everything started up except his soul escaped on us. That's my perception of things but it made it really hard for his daughter. In some ways he was like a zombie from the movies.

To make the process of dying less frightening for families, nurses explained the physical changes that families could or would see. The reality of death was not hidden.

I think you need to talk to them about it. I think you need to be physically close to them and I think you need to say those words directly. I think part of the problem is that we use too many euphemisms and try and stay away from that subject when it is very obvious what is happening.

Providing Comfort

The dilemma for me, is when your decision by virtue of nursing process is altered or stopped by either a family that says I don't care if he wants to die, we want him to live; or when you know the entire family and the patient have had it, but you have a physician that says live, and I'll chemo him to death virtually. I've seen that done, and I think it is horrendous and inhumane and not respectful; death is something that happens and it can't be prevented forever.

Providing patient comfort was a nursing priority for all participants. Planning ahead, or anticipating potential needs was a skill nurses developed. Themes that emerged were: 1) behaviours that reduce or prevent physical discomfort, and mainly included pain control 2) behaviours related to prevention of unnecessary treatments including resuscitation and 3) behaviours that maintained personhood and spiritual comfort.

When you are dealing with people who are dying and they have pain, you have to remember your ultimate goal is to alleviate this pain so they are comfortable. But some people would rather have a little bit more pain and be awake, and other people want to be free of pain and would like to sleep, so you have to deal with that too. Sometimes you have to deal with the doctors because they don't want to order as much medication as you think is needed. Especially, if they don't deal with cancer patients all the time like an oncologist. Some doctors don't realize how much pain a patient can have. And then there is the family. Sometimes

they don't want the patient to have the pain medication, they want them awake so they can talk to them.

Reducing or Eliminating Pain

Nurses wanted patients to be physically comfortable and reported feelings of anger, frustration and inadequacy when pain control was not achieved. Participants related situations where pain had not been controlled and found it was a powerful motivator to do anything to prevent another situation like it. One nurse described a woman with a weeping sore whose position could not be changed without her cries being heard all over the ward. Nurses were unable to effectively control her discomfort even though they tried several alternative medications. Another nurse related her attempts to help control her patient's pain:

He is the reason I want my patients to be comfortable. We tried everything to get this man's pain under control. Absolutely everything. He had an epidural catheter put in and we were trying to give him morphine and all kinds of pain medication. The man would scream starting at 10:00 p.m. and would not stop screaming until 6:00 in the morning. The doctors were trying everything but it wasn't good enough for us either. They were "Why don't you do this why don't you do that"? He ended up having a Dilaudid sage but he was still screaming he was in so much pain. It was such a fight to get high enough dosages to get this man's pain under control. We were working one night and he was screaming and we were doing our other work and he had his family with him and his screaming stopped; he died.

To prevent scenarios like the above, nurses learned to anticipate potential comfort needs and to have orders on board so crisis situations could be prevented. Gaining control of pain seemed to go more smoothly when there was a sense of trust between the nurse and doctor.

Individual physicians managed pain control differently; nurses tailored

their interactions with physicians to get what they needed for their patients. All nurses identified that doctors acted on objective data and that subjective descriptors of pain were useless. Consequently, nurses provided very objective data. Patient information such as how frequently medication was given, how long it lasted, numerical pain assessments, patient activity level in comparison to what it had been or what it could be was reported in a calm manner. Doctors were reminded of alternatives that had worked with other patients in order to facilitate changes in orders.

I always have a plan in my head, what I want, how I'm going to get it out of them. They won't tell me no and hang up because I have all the reasons why and all the clinical data and I have what I want in my head.

Examples of successful situations with other patients were used to prompt doctors to increase or change medications to control pain.

I will often suggest that the analgesic they are on isn't working and maybe we should increase it. And if not I would give them another circumstance and say that this is what we did and it seemed to work, maybe it would be worth trying. And a lot of them are willing to give it a try because some times they don't know exactly what to do.

Actions directed towards achieving optimal pain control often required a strong advocacy role. Nurses sometimes had difficulty advocating for pain control with medical staff who were unable or unwilling to increase or change medication orders.

We try to teach all new people that we are fairly liberal with analgesic control. Our objective is that the patient is kept as comfortable as we can possibly keep them. A lot depends on who the physician is.

The standing order for comfort measures was insufficient to make this lady comfortable so I became more of an advocate for this patient at this time. It was difficult having to deal with an intern who wasn't sure, a little bit insecure and lacking confidence in prescribing necessary comfort measures.

Sometimes you have to deal with the doctors because they don't want to order as much as you think. Especially if they don't deal with cancer patients all the time like the oncologists. They don't realize how much morphine and how much pain a patient can have.

Nursing colleagues were also uncomfortable giving adequate analgesia.

Comfort and pain control, I've been frustrated to no end with those kinds of things. I have fought tooth and nail over things and I've heard from other nurses, well they will give a parameter of analgesic to give, but they don't want to give that much because the patient could stop breathing. Whereas this person is having major amounts of pain.

Connecting with families rarely occurred if the patient was in pain. Families often assumed an aggressive advocacy role for their loved one until an acceptable comfort level was achieved. In some cases there were differences between optimal pain control for the patient and what the family viewed as hastening death.

Pain control is the number one thing for the person in the bed and in a way you treat not only the patient, but the family too. The family will not be able to cope if that person is in pain.

Patients and families also determined the level of pain control.

When a patient was no longer verbally responsive one nurse told the family that she thought he was still having pain. She asked the family:

What is more important do you want him to be uncomfortable and maybe still be able to talk with you or do you want him to be kept comfortable. Just about everybody whether they want them to go or not, because many don't want their loved one to leave, but they don't want them, if they realize they are leaving, they don't want them to be in pain.

In addition to pain control other comfort measures such as mouth and skin care, ensuring cleanliness, position changes, and some procedures such as catheter insertions were identified. Normal daily activities such as brushing teeth and combing hair were continued.

She was having a fair bit of discomfort...and it was backrubs she craved. She wanted somebody rubbing and rubbing. And I remember sitting there for ages every time I could get away from other things I was doing to sit and rub her back. It is a very intimate thing rubbing somebody else's back, with the lotion and it is dark and quiet and she would talk and talk about him and it was a good one, it was a real good one.

When patients were familiar to the ward, nurses recognized individualized comfort measures and provided them as a welcoming measure.

The things that made her most comfortable were her ice and her oxygen. When she came down from ICU they had a face mask on her and that was not what she wanted. So we gave her nasal prongs and she was quite content with that. She was very tiny and was basically skin and bones so putting that foam on her bed just made her all the more comfortable and rather than rolling her over that big lump, she was so light two of us were just able to hold her up a little bit, to keep her more comfortable.

Preventing Unnecessary Procedures Including Resuscitation.

When someone is dying you want to give them the best care. You are comfortable with their dying, they are comfortable with their dying, and boom, you are in the middle of a resuscitation because you don't have an order. There is no dignity there. What could be beautiful is awful.

Nurses identified that unnecessary treatments, some of which were invasive, caused discomfort to patients. Daily bloodwork, weights, and tests that took the patient away from the unit for long periods were challenged when it was known that results would not change care plans

and had no positive effect. If nurses did not think an ordered treatment was comforting, they resented doing it.

I do the things that I need to get done, even when people are known to be dying, you might still be doing things that could be defined as active treatment. In some ways I resent doing those things, like antibiotics and that sort of thing, unless I can truly believe that it has to do with the patient's comfort, with that person's gentle passage.

Professional nurses assessed the reason for procedures and if there was no sound reason to "do" a procedure, they did not carry out orders.

We will strongly start advocating against daily bloodwork, weights, extra tests that aren't necessary. They aren't going to do anything, they aren't going to give any information that is going to be able to fix anything. They may give information that it can't be fixed this time. That is no problem, we have had lots of different discussions with physicians about extra invasive procedures that aren't necessary. And it is the same as anything; some of the physicians are good and will listen and pull back, and others will just stick their heels in and not pull back.

All patients admitted to hospital are resuscitated unless there is written direction to do otherwise. Nurses did not want to participate in this painful procedure with patients who, in their view were in a dying state, an expected outcome of disease or age. Nurses carefully assessed patients.

I have had a few patients where I've seen they are deteriorating and I know they are going to arrest, and I've phoned the house officer before and I've explained the situation and said "this patient is a terminal Ca they aren't going to make it. Do you want me to do it? I don't think we should be calling a 99". They come up before it happens and assess the situation and have said "definitely not".

Many participants recognized the difficulties faced by physicians around the code/no code issue. They still initiated discussions and

pushed for a decision. Several participants acknowledged the importance of timing discussions. When the nurse and doctor have an established rapport, initiation of discussions about coding were easier. Responsibility for code-no-code decisions, however, always rested with physicians.

Say somebody came into the hospital and was dying, had a terminal illness with mets all over. You knew this patient was dying, and you didn't have a no code order. Legally you are supposed to resuscitate, but I think I'd use my nursing judgement. The family was there and we knew that they just wanted support. I'm sure that I wouldn't call a 99 on this patient. It would be very unfair to the family and the patient.

I said to the doctor, "I hope you are going to put him on DNR". He looked at me because they were friends, and I said that would be a terrible shame if he died and somebody resuscitated him because there was no order. What will you resuscitate to? There are certain things that you have to speak openly about. Sometimes it's more difficult for the doctor than the patient.

You can sense Dr. -- when he comes up on the floor some days too, and if he's not in a good mood you just don't approach him with certain things. It's not the time to deal with it.

One participant recognized that sometimes the request was premature or based on assumptions not data.

Usually when we get a terminal patient, many of us, actually probably I find sometimes we ask too soon. Sometimes we ask too soon because the patient is older or whatever, not necessarily a terminal patient we will ask the doctor if the patient should be on DNR.

Maintaining Presence and Spiritual Comfort

Participants agreed that it was important to be with dying patients. One nurse described it as "being present" which meant physically being present in the room as well as establishing a trusting

relationship with the patient that communicated that the nurses saw a person rather than a disease.

I like to be in the room physically with the patient, I like to be there to turn the patient, even if the patient does not appear to be conscious, I like them to know I am there, and who I am and what I'm going to do for them. Even if you aren't doing something that is specific in terms of task oriented, you know we are going to turn him or lift him....I think it is important to maintain a meaningful touch to let that person know that they are still a human being.

I had to remind myself when I went into his room. I'm not going to look at the tracheotomy, I'm not going to get all caught up with central lines, I'm not going to be overcome by that terrible odour, I'm not going to be taken in by that awful physical appearance. There was a person inside that mass of flesh.

Not all nurses demonstrated caring or presence.

One of the nurses came in, she's a good nurse, gets her work done. She came in and very flippantly said things couldn't be much worse. I've had a terrible day; I got the prize patient. How could anything be worse than this? He was crushed; he didn't let it show, he was protecting her, he didn't let it show!

Spiritual needs were addressed by formal support systems such as pastoral care workers or chaplains who routinely spent quiet time with the patient. Nurses initiated chaplaincy visits based on nursing assessment or patient request. Some nurses provided spiritual support themselves by praying with and/or for patients and by participating in religious services and readings.

One of the questions on the admission sheet is religion. I usually pick that up if someone is dying. Number one I want to know if they are Roman Catholic, I always ask if they have their own priest or someone we could notify. That is a good thing because they can answer that question and some of the answers are I wouldn't want a minister near me, ok, then you know.

I have been with the group when their minister has prayed and they have asked me to stay and that's fine. Yes, I read from the Bible if they ask me, I couldn't recite a passage, but yes I would read

to them. And I have had patients that say would you pray for me, and instinctively I say yes and then I will go home and pray for them. I'm not a praying person, but if I have said yes, I will follow through with that. And sometimes they will ask you if you prayed for them and yes I actually did!

Enhancing the Quality of Living While Dying

Medical nurses identified the need to create a space on the unit where patients and family could feel comfortable to do what they needed to do. A private space was identified as the ideal; other patients were sometimes moved to accommodate the dying person and their visitors. Participants described the dying process as a special time for patients and their families. Themes that emerged included: 1) creating an environment conducive to patient/family interactions 2) promoting choice/control, and 3) promoting personhood.

I always look at it as a special time for them. I am going to do everything I possibly can to make it as pleasant and comfortable and easy for them as I can.

Creating an Environment Conducive to Patient/Family Interactions

If patients had to die in hospital, nurses attempted to make the setting as home-like as possible. A private space was thought to be ideal but was not always possible on active wards where space was unpredictable. By adding chairs or a cot, single rooms were most easily modified without intruding into another patient's space. Moving several patients to meet the needs of dying patients and their families was not uncommon and occurred any time night or day. Patients and families

familiar with the workings of the wards sometimes viewed the move to a single room as a sign that death was imminent. Nurses diplomatically discussed benefits of a private space; sometimes the benefits were for the other patients on the wards.

Being able to start to create the space and the atmosphere of home for them, even if it means moving beds, adjusting things, making explanations to other patients who may be in the room and making sure they feel comfortable, and that they are given the opportunity to participate in this.

Large families were always challenge. Nurses were creative as they searched for ways to accommodate everyone. Most visitors did not stay the night. Consequently visitors of dying patients were encouraged to stay. Common spaces such as lounges and the cafeteria were available, and nurses had more time to spend with them during the night as ward activities slowed down. Visiting hours were open and flexible.

On nights it is so much quieter, more peaceful. The family can go into the lounge without being disturbed. We have time to make them coffee or offer them orange juice. It's not as hectic and people aren't running around, nights seem more relaxed.

They have large extended families, and everyone wants to be there, like it's not two people coming at a time, everybody had to be there. We closed off private rooms and I had 15 people around this dying person. I have seen it a problem in the 4 bed rooms, but there is usually some kind of shifting you can do about it.

Promoting Choice and Control

Because death itself was beyond control, nurses assisted dying patients to maintain control over as many other aspects of living as they wanted. Nursing care was organized to meet patient time tables and

wishes. Routine activities such as baths and treatment times were rescheduled or sometimes not even done.

You don't want to get up at 6:00 am, that's fine, we'll get things adjusted so you don't wake up at 6:00 am.

If patients wanted more active treatment nurses advocated on their behalf by making doctors hear what the patient wanted. On the other hand, when patients wanted to stop treatment nurses insisted that physicians listen and act on the patient's request. In one instance the patient was continuing treatment because of the health team.

"I want to ask you something. I want you to give me permission to stop. If I stop it means I am giving up on you guys". He figured he was letting us down as a team. So we did stop everything and he was very, very comfortable with the whole thing, and he passed away probably within three days and the death was very peaceful. Really he was holding on for us, believe it or not. He wasn't letting go because of the staff.

I've sent a doctor back in the room and said that is not what the patient wanted and will you please sit down and discuss with them because this is what they have said to me in private. The good ones will go back in and I have had them go back in and talk to the patient and then they have seen it the way I described it.

Promoting Personhood

Participants accepted each person's right to be who they were and to want whatever they wanted. This involved being accepting of each person's management of their death.

So anytime anybody comes in they all have different needs, whether it is to be with family, to be alone, to be not as pain free, that's up to them too.

Nurses made sure patient requests were communicated to colleagues verbally and through documentation. In order to honour patient requests, participants might bend hospital policies and procedures and/or not

follow orders. Honouring requests could be as simple as "sneaking" a special treat onto a patient's tray, trying to transfer patients with complicated care needs to their community hospital, or might involve time consuming arrangements for special visits. One nurse described the many telephone calls required to get an invalid mother to the hospital to see her dying daughter. The nurse kept phoning until one company agreed to bring the mother to the hospital. One nurse organized a complicated family meeting and another made arrangements for a patient to see his dog one last time.

He was separated from his first wife. He had remarried and there were some children involved and they were still with his first wife. I know he wanted to see the kids before he passed away. We did eventually get together and held a family conference. There was a little bit of bickering amongst present and past family members but...

It was important for him to see this dog again. So we arranged for the wife to bring the dog to the front door and we had him there in a wheelchair. Well we had interference from security that the dog had to be removed from the foyer of the hospital. The patient at least got to spend some time, but I think it could have been more meaningful if it hadn't been interrupted.

Responding to individualized needs was not easy and could be emotionally draining.

I looked after a young fellow who was dying of cancer. And he sort of cut off the cord of support from his friends and family; at the end he refused to visit and see anyone. We respected those wishes and denied anyone access to the room to see him. But what they asked of myself to do was to relay messages, read letters, read cards, to him. I found that very difficult, emotionally.

My patient asked me to describe exactly what would happen to her once she was dead. Like, that was something she wanted to know for herself. I was pretty uncomfortable with it because it is pretty clinical and cold and an awful way to think of the end. They wrap you up in a plastic bag and throw you in a cooler.

There are not a lot of ways to really soften those type of things. But this woman really wanted to know exactly what we would do. That was probably the hardest thing I had to do as far as sitting down and talking very clinically about something that was the really ugly part of the death experience.

Responding After Death has Occurred

Nursing care did not end with the death event. Four themes were identified within this category: 1) behaviours that continue to support families, 2) behaviours that created a dignified bedside scene for survivors, 3) behaviors that ensured respect during post mortem care, and 4) behaviours that responded to other patients on the unit.

Demonstrating Continued Support for Families

Whether the death was expected or not, its realization and finality was stressful for most survivors. Nurses continued to support by identifying and responding to family preferences. They helped to inform relatives who were not present, and make arrangements for them to come to the hospital. Sometimes the police were called when there was no telephone or means of contacting relatives. Nurses carefully assessed and offered choices to families on the unit. The nurse could accompany a relative to the bedside and stay with them or let them spend time alone with their loved one. Whatever the decision, nurses kept close contact with family checking if they needed anything or anyone. Nurses made themselves available to listen and share memories and stories with families.

You would just make sure she doesn't go in the room by herself; ask if someone is coming with her. I didn't want her to be alone so I stayed with her. When she said she wanted time alone, I left her alone. I gave her a hug. I gave her time alone and then I came back to see that she was OK. I came back and spent time with her, she wanted to talk.

The family sometimes will stay for hours and hours and you judge whether they want to be left alone or to be with someone. Usually they want some company.

If the patient had never been on the unit before and died, nurses did not know who the family were and what to expect.

It's awful because you don't when you are seeing family you don't know what to expect you don't know what they look like. Sometimes they are hysterical, it is really a bad situation. Sometimes you don't know who you are waiting for and you have a sign on the door "please stop at desk" that's the kind of....Like were they close, do you give these people the deceased person's belongings or..?

Creating a Dignified Bedside Scene

Nurses wanted to present a dignified last scene for family to remember. The ideal picture included the deceased looking at peace, seemingly asleep in a clean bed free from hospital equipment.

What I do is I just make sure they are clean. Like sometimes when they die, they might be incontinent or something, I make sure they haven't been. I clean them up, make sure their bed is down, they look at last at peace. The sheet is pulled up around and just make sure they look good so that the family can come in. If they have teeth we put them in them.

When there had been a resuscitation, a sense of peace was more difficult to create in a space nurses described as a "war zone" or "carnage". Family members wanted to get in there and there was seldom time to prepare it properly for the family.

Families come in and you have tubes everywhere, this is awful. You can't bring little kids in to see the terrible mess or they

will have nightmares for the rest of their lives. What a terrible end sometimes. Especially for older people; what an awful way to go.

Demonstrating Respect for the Body During Post Mortem Care

Care of the body after death was not directly performed by nurses. On these medical units the wrapping of the deceased and the transfer of the body to the morgue was performed by other hospital staff. Although others were involved in direct after care, nurses accepted the responsibility to make sure that dignified caregiving to the body continued. Certain behaviours were not tolerated even though they were recognized to be a form of stress relief. It was unacceptable to joke or talk disrespectfully in the presence of the deceased.

If anyone would ever be disrespectful I think that would really bother me. Don't you talk about things like that. Please be respectful!

I treat them very respectfully and God help any porter who doesn't treat them respectfully.

Nurses described how they said goodbye or "closed" a relationship that was over. The majority of nurses "finished" by reflecting on the person and their death, usually after working hours, often at home with a member of their own family or a professional friend. This was particularly important if the death had been what one participant described as "ugly". Others found a few moments in the day to think of the deceased and evaluate their nursing involvement. One nurse made a special point of paying her respects even if she had not known that patient. On occasion nurses attended their patient's funeral.

If it is somebody I've been very close to, I like to go in and have my own goodbye. Just being in the room and having good thoughts about them and remembering. I think I sort of remember what they have said to me and if it's what you would consider a good death. Just feeling that I did everything I could to make them comfortable.

I always feel that's a part of finishing, putting the teeth in and closing the eyelids. And sometimes you say a little goodbye. Especially if you didn't know the patient, but as a kind of, just somebody cares, I care, we care that you aren't here anymore. You are in the room by yourself, that is something, a very private thing, there is nobody sharing that with you. I think that is a good thing to remember. Maybe they are watching and that makes quite a difference in how you respond and what you do.

Responding to Other Patients

For many different reasons patients and their families become attached to each other and develop an informal support network. Whether the patient is behind a curtain in a semi-private room or down the hall in a private room patient members of this network see and hear what is happening. The majority of nurses recognized the patient support network and acknowledged a member's need for support when a patient died. One nurse described how important it was to find a quiet time to share a patient's death with a long time patient. This nurse informed patients even though some nursing colleagues thought she was upsetting them.

They are not stupid, they know exactly what's going on. I will still go and search them out and explain what happened.

You will come in the morning and ask your patient how he slept. He says "terrible because of the racket across the hall". I find it is helpful to tell the patient that the man across the hall died last night. It was unexpected and we tried to help him.

Participants agreed that including other patients was a skill that developed as they learned to be more comfortable with the dying process. Patients were most often their teachers.

It is in a 99 that it is really bad. Every patient in a room after a 99 has to be debriefed, especially if it is in the middle of the night; you just clean up, the patient goes out of the room, to ICU or the morgue or whatever, lights out, and there is a carnage in there. And then there are these three guys lying in there in the other beds, going "it could have been me". So I think it is important to speak to all those individuals and as the nurse in the room they are your patients as well as the one that went upstairs.

I always go and tell the other patients what is happening. Now I have gotten flack for doing that from other staff who think I shouldn't have told them, because now they will be upset.

Responding to Feelings

Strong emotions surfaced when caring for the dying. Feelings of anger and guilt were frequently cited. Anger from patients, families and physician colleagues was directed at nurses. Nurses experienced feelings of anger and guilt, most often in relation to what they felt was a cruel indignity for the dying person to endure; resuscitation. Nurses were able to suggest ways to deal with their feelings. Nurses did not take the patient's or family's anger personally and felt that an empathic and sensitive response was required.

I have often said to someone in any situation where there is unhappiness, you can yell at me or feel angry. Even talking to a patient that has just been told they have a terminal illness that it's OK to feel angry.

I came in and he was angry and he said he wanted someone to give him some help. "No one has been in all day. I'm left here and no one cares." Your human side wants to say don't yell at me, but at the same time, knowing what I did, I took it in the sense that he was not yelling at me, he was just angry. So I said "I

understand. Let me know what I can do now. I'm here now and will be glad to help you". That totally changed his thought processes.

Nurses worked hard to maintain their professionalism to not respond defensively when anger was directed at them, regardless of source. This was not easy and nurses found they had to control natural automatic responses.

I get so angry, I could pull them into another room and say, Do you know what you just did, like do you have any idea? Unfortunately you can't do that, you have to be a professional...

But if I turned it around and said why are you yelling at me? I'm out of here; I don't have to take this. It would have made the situation worse and his real needs wouldn't have been met at all. I don't think he really wanted anything, he felt awful and I walked in.

This person just lit into me and he said I want to know why he's not on antibiotics. He was attacking me at the time but it was really the ward, the staff, and the doctors as well. I thought to myself, I can deal with you. You are making us look bad and I'm trying to look after this patient. I knew what I wanted to say to him, but I couldn't.

One patient said to her, "it's your fault, you should have come sooner. What a terrible feeling to put the nurse in a terrible position to make her feel that way. But then we had to understand this is the way this patient deals with things.

Participants often directed their anger at physicians and in most examples the reason for anger was un-met patient needs. Poor pain control and preventing a dignified death because of resuscitation were the main areas of contention.

Trying to explain to the physicians that death and dying is quite natural at the age of 92 with chronic diseases. That somebody could just die in their sleep is unacceptable to them and they will keep them on calls. If they die in hospital, we resuscitate them. That's a crime.

He was of course on calls because no one wants to deal with the fact that people die in life, you know. You would want to bring them back my goodness to what I don't know. So he was resuscitated and I remember this was a resuscitation in the middle of the night..the student doctor was yelling, "this is a full call, full calls, we have to be really aggressive, this man was doing really good". And I thought where have you been? Where have I been? Are we talking about the same person?

Nurses described experiences in which anger from other team members was directed at them.

The Nurse fought with that doctor for two and one-half hours to get some extra pain control but he wouldn't give it. So she got the order she wanted from the attending doctor. The other doctor got very mad at her and wouldn't talk to her after that.

Various ways of dealing with anger were suggested. Some nurses removed themselves from the situation.

If everything has gone bad and wrong, and I am totally unhappy with the situation I need to get off the ward. I get angry. I get very angry at whoever stopped me from doing what I wanted to do. So I leave. I take a breather. I need to get out.

I had to leave the ward for a while and just gather my own thoughts and deal with my own grief, because I was grieving myself at the time. I was very involved with this person. I did not immediately jump back and start caring for other people. Eventually I had to and I had to deal with his death eventually. Sometimes it is necessary to step back and collect your thoughts. If it is an emergency, which nine out of ten times most things aren't, things can usually wait. I guess second sense takes over and you do what you have to do. Put it away for a moment, but most times I allow myself some time to think.

Responding to Nursing Colleagues

The participants recognized their own need for support as well as the need to sensitively support each other. Participants described their working relationships and their colleagues as "unique" and "special". This did not mean that everyone always got along but rather

that they were able to express their feelings and ideas to their colleagues who would listen and respond in a supportive manner. Support was offered informally, by encouraging colleagues to talk and express their feelings. Most often this happened during coffee and lunch breaks but on occasion, discussions were formalized and part of staff meetings where other disciplines could be involved.

If we are having a little difficulty we often talk on our lunch breaks or coffee breaks. We are always talking. Maybe we're not sure what we should have done or what we did do. We get a lot of support from our peers at our breaks. We all do it and I think if we didn't do it would certainly be more harmful to us than not. So often all you have to do is go down and say "yes, you did do the right thing or maybe I would have done it that way". And if you think about it and maybe you go back and try it that way.

We had a couple of unit meetings because the problem was nobody would look after this patient, nobody wanted, very few people would go in and care for him. He was such a heavy patient, number one and we talked about it. Our chaplain was very involved. But even talking about it you reach a few but there are still those that avoid the situation at all cost.

Nurses had learned how best to respond to individual colleagues by "reading them". In some situations with some nurses, support was demonstrated by a gentle hug while in others nurses recognized that their colleague needed to be alone. Participants respected their nursing colleagues and suggestions and comments were valued and strongly influenced nursing practice with dying patients. Participants informally sought and offered feedback.

A nurse told me about a situation where a patient told her he was going to die. She said "oh no, you're not, you are doing just fine". She said that is the worst thing, and to this day she feels guilty about it because she said she didn't listen to him. He told me he was going to die and I didn't believe him. She was excellent for telling me that story and now when someone tells me,

I remember that. I will never forget that story because I don't want to feel guilty for not listening.

One nurse described a situation where she had been ill-advised.

My patient hadn't been doing well for a while. I could tell that night things weren't right. Not knowing the family very well at all, I spoke to a couple of nurses on the ward, to try to get some advice as to what to do. Whether I should phone the family to come in right away or wait a while. The other nurses talked me out of contacting the family. I guess the advice I got wasn't what I had wanted to do. I ended up going for my break and when I came back she had passed away and that left me with a lot of guilt.

When nurses were aware of events, they offered assistance without being asked. In some situations in order to meet the needs of dying patients, nurses delegated the care of their other patients.

If you are in a situation where maybe the family, the patient has passed away and the family needs something, they will be there to help you make the coffee or they will be there for the little things. They are there for you, whatever you need.

If they know you have a terminal patient and they know you have gotten very close with the family and the patient and you are spending an awful amount of time with them they will pick up your work and do things for you while you spend that time with the family.

Participants set high standards for their nursing care. If a nurse did not meet the expected standard, they responded by speaking obliquely with the nurse through questions and suggestions of other ways of doing things. Nurses were told stories about similar situations and what had worked in those cases. New nurses or those not measuring up to the standard, were supervised closely. If nursing care did not improve, participants assumed care of the patient themselves.

I think it's done mostly peer to peer. You can't always go up to the person and say I don't like this, or this is what you've done, or I don't know why you are doing it this way or that way. But

sometimes just through things like you suggest that this is how I might have done it, why are you doing it this way? And sometimes you learn a little bit from them. You learn that perhaps the way they are doing it may be better than the way you are doing it.

I check on their patients more. I say, you have to use your diplomacy because you can be a real nag and I've probably been known to do that with people. But quite often when people work with me now, they know what I expect from them, so they will try. But if they don't, if there are certain things I don't like what they are doing, I'll try to use my tact in telling them, to draw their attention that I know what is happening sort of thing. But you have to use your tact, but I don't think it should be let go.

Speaking with colleagues was not always easy and was open to mis-interpretation.

Sometimes I'm concerned about the flippancy of what people say. Everybody can say something or make a mistake and say something foolish, that is understandable. But I guess if someone is flippant, cold, uncaring, there is no excuse for that. That bothers me. And yet those are the kinds of things that you can't change in people. If someone was flippant and callous, and I went and said I don't like the way you were talking, you haven't changed them, they just resent the fact the fact that you have drawn it to their attention. They don't agree with you because they weren't being flippant and callous, they believed they were being perky.

Several participants described situations where their individualized care for patients was not supported by colleagues who perceived going that extra mile as "spoiling" patients.

My co-workers often get angry with me because I spoil my patients and then it is harder for them to look after them. I don't see it as spoiling them. If someone is thirsty and wants a drink of water, ice water, I might make that extra trip to the kitchen, or to the hall to get ice water. Someone else will go to the tap and just get water from the tap. They call me down for making that extra trip, they prefer not taking care of my patients.

Participants acknowledged that some nurses had difficulty working with dying patients. Strategies to ensure that care of the dying patient met expected standards ranged from teaching and coaching to changing

patient assignments. Some nurses helped colleagues identify and then remove barriers to effective care for dying patients.

Often we find some people are uncomfortable especially new grads or people who are not familiar with the terminal patients. If they are having a hard time dealing with it, we will sometimes say, well I know the family quite well or I'll stay with them or do you want me to go over exactly what we know of the family of the patient, what their likes are, what keeps them more comfortable?

Maybe they have never been around death until they come to work here. Everyone copes with it in their own way. I've heard lots of inappropriate joking or silliness and that doesn't sit well with me at all. You wouldn't be doing that to the person in the next room, so just because you aren't sure if they can hear you or see you or respond to you, you shouldn't be doing it to them. I think people they just don't know how to react so if you mention it or say something to them it is probably the last time they will do it.

On the other hand, some participants changed patient assignments based on the belief that if a specific nurse didn't like caring for dying patients the worst possible thing for the patient would be to assign that nurse to perform their nursing care.

We have a lot of good nurses here that give excellent care, never miss a coffee break, they are always on time for lunch and out of here. They are good nurses, charting is excellent, their care is good. I'm not so sure sometimes about the caring. If they're not caring, I wouldn't say they shouldn't be here because we need them, but they shouldn't be looking after dying patients.

Enhancing Personal Growth

Participants reviewed their experiences with dying patients in terms of personal learning and self-worth. Medical nurses felt privileged to be involved in this special event. Identified as central

to learning were three themes; recognition of death as a process, the realization that dying was not always a negative occurrence, and the importance of perceiving the person as living until after the death event. Realization of the positive part played by the participants in the death process was acknowledged. Nurses enjoyed the eclectic milieu of a medical unit and felt it enhanced their practice.

The family taught me two really important things. That it is natural to die and that it is not necessarily grievously wrong and something to be railed against. The other thing that is more important is that it taught me that death is a process and not an event. It is something that has served me well in understanding and helping other patients and families. It is a process, it doesn't just kind of happen.

Sometimes learning was a painful process particularly when nurses were unaware of their own limitations.

I think people have to go into those types of situations with the right frame of mind; you know, they can only do certain things and that their role is there to make the patient or family or next of kin as comfortable as possible in whatever the situation might be. And you see that with new grads. They are very terrified, they are upset when a patient takes a down turn in their health. The expectations they have is that patients will do well. When the interventions don't work, they become saddened and upset because the patient's health is taking a down fall. Most times they see that as failure on themselves and the medical team.

I used to live with such guilt. It took me a while to see that if I am going to survive, if I'm going to be useful and giving to my patients, I can't carry that guilt around with me. I cannot be everything; you just do the best you can. Patients know that.

Participants were able to recall and value their work. They verbalized their satisfaction to students and other nurses who did not understand how medical nurses could work with dying patients on a daily basis. Participants felt that their work with dying patients and their

families was a privilege. They felt honoured if they were the one to offer the last sip of water, or to give the patient his last bath.

It is a privilege; it is special. There is some special reward, feeling, that you get even when the place is in shambles. It is special, maybe that is what I am here for; I feel that I contribute something that adds to part of your being. Like what other job would you get the opportunity to be with someone who is dying? There are people who go through life without ever seeing a dead person, except for the TV, you don't get the feeling. But there is a very special intensity about recognizing I'm alive and at the same time knowing that one day, i will die too. But right now it is nice being alive and to be part of the process. You see the process, especially as I'm getting older, you see there is a reason and there is a cycle and you feel more part of it. I think that is what being with someone who is dying does.

The dying process, the death event and the circumstances surrounding it were all considered when participants reflected on their experiences. They were able to get beyond the common view of death as failure. Participants related discussions with others about their own death and saw death as a natural outcome of living.

I wonder if it is not so much the number of years as maybe the growth that you've developed in your practice and your understanding of what your work is. And your ability to say, yes, he died. Not as you said before, this isn't the end of the world, and the worst thing that could happen to somebody. Some people might feel that, but you know, I feel really good about this person dying. Because I think particularly with our oncology patients, you have watched them work really hard and their work is done now, the drugs have stopped all of this and they had a different work that was hopefully more peaceful and now it is done.

That's what I find my family and friends don't understand this. How can you say someone died and it was a good experience? I think only a nurse can understand that. Most people view death as something awful and sad and never can understand how it can be good for a patient or family etc. I think that is just something you learn in time.

And I remember when he finally, finally died and it was weeks, it was just amazing. It was like he died, that's great. I remember

being in the conference room that day, everyone literally cheering that he had finally died. He was successful, great!

Someone said to me once, oh you must get used to people dying and I don't know, I find it a remarkable thing. It is amazing how someone can be alive even in that very peaceful state and then be so incredibly dead.

Participants valued the diversity of patient care needs on medical units and felt it enhanced their practice.

As far as I'm concerned I can have two beds in a room and I can have two patients same age, same pathophysiology and by virtue of let's say intellectualizing nursing and applying nursing diagnosis, I can provide for a dignified death right next door to someone that I am actively attempting to pull out of a serious situation. It doesn't require a huge mental leap. To me it's a natural way of looking at things. This man is at a point in his disease where he still has things to do and he wants to get through this and I am going to help him. This man has had enough, this is his decision or the decision that is made on behalf of him by his family, and I can work with him as well.

I think your practice has to be balanced. If you don't know what pain and sorrow is how can you understand what happiness is? And so if you don't have that experience with death, you won't really understand the value of life or a cure or those things. I would feel really cheated if I did not have those opportunities, if all I did was check people, fix them up and check them out. I really want to be there when they go through that process.

Managerial Support

It is important to accept an individual wherever they are in whatever process they are in. If you work in an environment that does not support that kind of thinking you may practice more according to the medical model where the most acute person gets the most attention. The person who is dying, well you don't worry about them.

Participants agreed that managerial support influenced their ability to meet their personal standards of care for dying patients and their families. If nurses were to offer expert care for dying patients, they needed managers who recognized and promoted nursing practice.

When a physician comes up to me and says "I ordered vital signs QID on this patient" I will look at him and say "This patient is dying, I don't think pumping the arm up with a tight blood pressure cuff every six hours is going to make him comfortable. I don't think you are going to do anything if the blood pressure is up or down". I make those assessments and feel comfortable with them. The head nurse will back me up, she taught me.

Nurse managers recognized and encouraged some nursing behaviours and seemed to ignore others. Several nurses suggested the manager was not aware of what they did when they cared for dying patients. For some participants meeting the expectations of managers in one performance area meant they were unable to meet their own standards of care for the patient who was dying. Several nurses consistently worked into the next shift because they would use time at the end of the day to spend with their dying patient and their family. This created a problem for some nurses who were aware of the added costs of working overtime and who knew that leaving on time was thought to demonstrate a nurse's ability to organize patient care, a behaviour that was rewarded by management.

If I'm late getting off, to me, that's not the end product. They don't see you giving that extra five minutes to someone. I don't claim overtime. If I did, I would be out of a job because they would think I was incompetent.

There are lots of caring people, but they're not always the people that you single out to be the best nurses. Sometimes administration will look at somebody, oh isn't she good, charting is perfect, always home on time, no overtime... they can articulate but they are not caring.

One participant questioned whether her care was good nursing care or, as other nurses thought, over involvement.

You know you hear all this marvellous stuff and yet sometimes when you do what you are supposed to do, it's the wrong thing, "pull back, you are too committed, you are too involved".

Nurses needed their managers to recognize and appreciate their work while empowering them to determine exactly what that work was. Nurses described situations in which they were seen just sitting with a patient. In most instances managers and colleagues acknowledged this behaviour as work and did not assume that the nurse was "just having a break". Nursing colleagues would only interrupt in emergency situations. Nurses found it frustrating when they had to put care for the dying in a secondary position because of other ward events even if they were emergencies.

Some of the patients are just ready to tell you something and you have to leave, there is some doctor waiting on the phone, somebody is falling out of bed. That is a really big problem. I don't think they have the same problem on palliative care. I think that is where they have an edge. When someone is ready to talk you can sit down and you can listen.

We can get very task oriented and in a way we have to be; there is a lot to be done in a very limited time. If you don't have a sense of organization you just wouldn't cope, you would fall apart. So there has to be some sense of organization and some control over your time. I think you have to be flexible enough that you aren't going to worry if you take a few minutes just to talk or just to listen. It has taken me a long time to get me to that point.

I might say I am going to work really hard this morning so I can spend time in there this afternoon. So I work really hard, all my work is done and we have some cardiac arrest or something. That's really frustrating.

Nurses valued their responsibilities but wanted to know that their manager would stand behind them, be an ally and would advocate for them on behalf of the patient when conflict arose between nurses and physicians over necessary care requirements.

If we are wrong, we all learn from our mistakes. We talk about it and we learn to be better. She is also there as an advocate for us

and supports our decisions, hears our rationale. You always know that she will stand behind you.

You have to go to your manager and say that you aren't comfortable with this patient's level of comfort. I think the patient should have more. Sometimes, depending on the doctor she will discuss it with the doctor.

Participants recognized and appreciated the direct and indirect supportive behaviours of their managers such as the timeliness of a hug when a patient died or the granting of a "time out" when she saw a nurse had enough of death and dying for a while.

She is very supportive in pretty well every aspect or anything that you do there. There are lots of times people will cry and she will always come and cry with you. Always she is right there with an arm around you.

She didn't provide LOA's for her staff before. Now she is more accepting. She knows you are not going to be good for anybody. The majority of us have families and children, so we are still going at home until 10 PM. Then you come back and are facing all these dilemmas and you can't shut off the 99s.

The difference between manager's work and nursing care was appreciated by participants. They identified the strong peer support that had developed within the staff nursing group. One nurse felt empowered because she was responsible for the nursing care decisions that made a difference in her patient's care.

Conclusion

Twelve nurse experts provided information about nursing care of dying patients and their families on adult medical wards. Analysis of data revealed eight categories of nursing behaviour. A ninth category described managerial behaviours that influenced the nursing care of participants. A table of operational definitions was developed from the

detailed discussions of each category. The next chapter will include a discussion of these findings and implications for nursing practice, education, administration, and research will be suggested.

CHAPTER VI

DISCUSSION AND CONCLUSIONS

This chapter includes a discussion of the findings from chapter five as they relate to the theoretical framework of this study, and the four research questions posed. The critical behaviours identified in this study are compared to those identified in the previous work of Degner, Gow and Thompson (1991), McClement (1993) and Hawkins (1995) who used a similar research protocol to study critical nursing behaviours in palliative care, ICU and pediatric settings respectively. The behaviours that were rewarded and punished within medical units were identified. The chapter concludes with recommendations for nursing education, research and practice based on the findings.

Relationship of the Findings to Theoretical Framework

The theoretical perspective of Quint (1967) proposed that without educational support and positive mentored practice, nurses would model the behaviours of those around them and care for the terminally ill would be limited. A longitudinal study by Degner and Gow (1988b) demonstrated that after a "high dose " of death education coupled with clinical practice, the nurses in the experimental group had significantly better attitudes to caring for dying patients than a control group. In an effort to start a beginning list of critical

nursing behaviours that would become part of a research generated knowledge base Degner, Gow and Thompson (1991) described critical nursing behaviours essential to care for dying adult patients and their families on a palliative care unit. Nurse educators and palliative care nurses described essential nursing behaviours for terminally ill patients and their families and a comparison was made with behaviours described in the literature. McClement (1993) expanded on the work by Degner et al. and described critical nursing behaviours for adults dying in an Intensive Care setting. This study further expands the knowledge of critical nursing behaviours for care of adults dying on medical units.

Based on the Dreyfus Model of Skill Application, Benner (1984) identified nurse experts and through semi-structured interviews discovered the common meanings within their nursing practice. In a similar manner, Degner, Gow and Thompson (1991) identified nurse experts in palliative care and analyzed their stories about care for terminally ill patients. Nursing behaviours that had made a positive and/or negative difference to patients who were dying were analyzed and clustered to determine critical nursing behaviours in palliative care nursing. McClement (1993) selected nurses from intensive care settings. In this study Benner's methodology was followed to identify twelve medical nurses who their peers identified as expert in care for the terminally ill. Identified experts described incidents from their clinical experience that made a positive difference in care for the

terminally ill. Albeit with more difficulty, they also described behaviours that had negative results.

A third perspective in this study was based on a performance model described by Mager and Pipe (1984) that identified the influence of consequence of behaviour on that behaviour's occurrence. Specifically, behaviours that were rewarded would occur more frequently than those with either no consequence or consequences that appeared to be punishing. The model also recognized the influence of organizational obstacles to performance.

Overview of Similarities and Differences

Five of the seven categories of behaviours identified by Degner, Gow and Thompson (1991) were also identified in this study. In several instances operational definitions were expanded or addressed elements of behaviour that had not been identified by nurse educators or palliative care nurses.

The behaviours Degner, Gow and Thompson (1991) labelled "Responding to Family" were categorized Supporting the Family in this study. The operationalized definitions fell into three functions of support; esteem support, informational support and instrumental support.

The category "Responding during the Death Scene" did not emerge as a separate cluster of critical behaviours for medical nurses. Nurses on medical units identified Responding after the Death Event as McClement (1993) had identified in an ICU setting. Behaviours similar to those identified by Degner as responding during the death scene were

categorized as behaviours within the category Supporting the Family within the dimension Preparing for the death event.

Nurse managers influenced the environment in which medical nurses worked. Behaviours that facilitated and rewarded the care medical nurses offered their terminally ill patients, were nurturing behaviours categorized as Managerial Support. Managerial influence on practice was not identified in previous studies.

Connecting

Central to all nursing care for the terminally ill was the trusting, caring relationship that developed between the nurse and the patient. Davies and Oberle (1990), described a supportive role of nurses in palliative care. One dimension, a connecting role, consisted of three types of behaviours; behaviours that made contact, behaviours that sustained the connection and at an appropriate point behaviours that ended the connection. According to Davies and Oberle (1990), when nurses "got in touch" and "entered" the experience of their patients they were connecting. Successful connecting led to increased awareness of the person as unique. "Knowing" the patient is fundamental to individualized nursing care and as May (1991) stated is central to professional nursing. Hawkins (1995) identified that connecting was the essence of the relationship that developed between dying children and pediatric nurses. Reid-Ponte, (1992) and Tyner (1985) described elements of empathic care with similar attributes including unconditional acceptance and acknowledged the use of active listening to

discern the meanings of events to each patient. Connecting behaviours were pivotal to the intricately interwoven dimensions of all caring nursing behaviours for the terminally ill and their families. Caring has been described by Leninger (1984) as crucial and an essential ingredient for human development, human relatedness, well-being and survival. Elements of connecting behaviours often were found in the literature categorized as feelings, either those of the patient, the family or the nurse. Nurses in this study identified situations in which personal factors such as fatigue, lack of concentration, and work assignment negatively influenced their ability to establish and/or sustain connections.

Medical nurses recognized that when they and patients connected they were better able to meet patient needs; they felt good about their nursing care. This observation is not unique to medical nurses, and as Malin and Teasdale (1991) have stated, when nurses meet patient needs they are living out one of the basic values of the nursing profession, that of caring. Nurses were reflecting an ingrained understanding of the basic source of their legitimacy within the patient/nurse relationship as patient expectations and reactions can be ignored only briefly or at considerable risk (Friss 1989). Benner (1984) noted that meaningful work was essential to expert care.

Nurses were seldom overtly rewarded for their connecting behaviours; the sense of accomplishment, of reward was personal. This view is supported by May (1991) who found that "knowing" was oriented around reciprocity and exchange encounters that resulted in a more

satisfying milieu in which to work and was a form of relief from mundane tasks. It offered a connection between nurse and patient that was both particular and meaningful. Nurses in this study became close, shared inner thoughts and were able to enter into the experience of their patients. On occasion this often invisible work of connecting was viewed as "over-involvement and spoiling" by colleagues. According to Mager and Pipe (1984), negative consequences or no consequences for practised behaviours influence performance. The unit manager was in a position to facilitate connecting through creative nurse/patient assignment and by rewarding connecting behaviours and by actualizing a holistic philosophy that included nursing care beyond only visible tasks. Supportive managers recognized the importance of finishing or breaking connections by facilitating nurse attendance at patient funerals and bereavement follow-up with families.

Connecting was not identified as a distinct category of behaviours by Degner, Gow and Thompson (1991) and McClement (1993).

Supporting the Family

Cobb (1976) conceptualized support as providing information that another was cared for and loved, esteemed and valued and belonged to a network of communication and mutual obligation. Norbeck (1985) more succinctly described support as providing positive affect, affirmation and aide. Behaviours identified by Degner, Gow and Thompson (1991) and McClement (1993) as responding to the family are analogous with sub-sets of family supportive behaviours identified in this study. Nurses in this

study provided support by being available to families and listening to them, sharing personal experiences and avoiding criticism of the family (Barker, Burstein & Goodman, 1982; Cowen, 1992; Jassak, 1992; Reimer & Davies, 1991). Informational support was provided when nurses explained procedures and events. In helping interactions, esteem enhancing behaviours and advice giving typically occur together and have a high correlation, perhaps because provision of advice may be perceived by the recipient as an expression of caring and concern and interpreted as esteem support (Norbeck & Tilden, 1983). Instrumental support, also called aid, was tangible or material support and included assisting the family with practical tasks such as, organizing their transportation to the hospital or assisting with funeral arrangements. Supportive behaviours were woven throughout all aspects of family care.

Central to supporting families was the degree of connecting that occurred. In many situations nurses connected with patients and families at the same time. Being available, spending time and establishing trust, were "connecting" behaviours (Davies & Oberle 1990) and describe supportive behaviours. When a trusting relationship with the family was established, the nurse was able to enter into the experience of the family, learn what was important to them and intervene to meet their specific needs.

Behaviours that responded to the family's need for information were analogous with those identified by Degner et al. and McClement (1993) and were identified in the literature as essential to family care (Chekryn, 1885; Hull, 1989; Kristjanson, 1986). Benner (1984)

identified providing emotional and informational support to families as a component of nursing within the helping domain. Medical nurses identified that they also needed information from families if they were to meet patient's and families' needs. This two directional description of informational needs was not identified by Degner, Gow and Thompson (1991). Knowing a patient included knowing everyday habits, practices and preferences; nurses relied on family members to help them recognize subtle changes that might influence care. Nurses in this study identified that they actively listened to the family, offered explanations about equipment, shared information by translating what others had said, and reinforced information that had been given at another time. Two way communication between nurses and families was established when there was a connection with the family. Nurses were able to identify which family member to speak with at what time in which way. The manner in which information was delivered was an indicator of quality patient care by Kristjanson (1986) and Jassak, (1992).

The critical behaviours identified by Degner, Gow and Thompson (1991) as "including or excluding the family in care" were also identified in this study. As with meeting informational needs, when the nurse and the family had connected it was easier to determine the role that family/individuals wished to assume and then support them as needed. As one participant said "I plunk myself right down in the middle and become one of them". Communication was straight forward and relatives could determine their own behaviour without feeling they were being judged. Critical nursing behaviours included reassurance and

positive feedback for the good work done by the family, and giving permission for family members to take time off; to stay home.

Behaviours that "reduced the potential for future regret" were first identified by Degner, Gow and Thompson (1991) and supported by McClement (1993) and this researcher. These behaviours were illustrated in this study when nurses assisted family members to define and then follow through with activities that were identified as a meaningful to them. Nurses encouraged and assisted family to communicate with each other. When the patient was no longer responding, nurses assisted relatives to do what they identified to be important.

In this study, a category of behaviours called preparing the family for the death event, was identified. This too was a sub-set of behaviours within the dimension of supporting the family. Drawing on expertise, medical nurses recognized patterns of dying and could, as death drew near, concentrate supportive efforts by describing the physical changes that were occurring in a realistic manner. Emotional support was offered by listening to families and accepting family responses without judging. Medical nurses also assisted family members to support each other through the dying process and with their grief (Chekryn & Davies, 1991; Davies & Oberle, 1990; Samarel, 1989). The actual death event was an extension of the supportive connecting behaviours that were woven throughout all family care. Most nurses did not describe a death scene.

Preparing the family for the death event included behaviours similar to those identified by Degner, Gow and Thompson, (1991) "during

the death scene". In the milieu of a palliative care unit, death is an expected outcome; on medical units active interventions that postpone death (such as resuscitation) occur. Patients on medical wards were seldom identified as dying; therefore it was not possible to prepare a death scene. Families were not part of resuscitation. As in the ICU (McClement, 1993), families were ushered into waiting rooms to await the outcome of the resuscitation. For those patients not resuscitated, a calm dignified scene was desired. If no family was present, medical nurses attempted to be there.

Rewards for nurses that connected with families were similar to those when nurses connected with patients; they were intrinsic rewards that resulted in feeling good about work performance. Positive feedback from peers, other team members and the unit manager was appreciated. Nurses felt rewarded by families when they were comfortable to ask questions and felt welcome on the unit at any time. The consequences of including families were mixed; families were appreciative, other patients and some staff sometimes were not. Large families required more space than the unit could accommodate. The resulting overcrowding interfered and frustrated other patients and some staff who complained, an outcome that was interpreted as punishing. When unit managers encouraged, supported and rewarded creative problem solving, nurses were more likely to accept the patient / family as the unit of care and continue to support them.

Responding After the Death Event

Nursing behaviours that occurred after the death event were not identified by Degner, Gow and Thompson (1991). McClement (1993) identified that nurses in intensive care units created a dignified bedside scene for families to return to because families were not part of the death event when resuscitation occurred. This was a common occurrence on medical wards as well. This was particularly important when there had been an attempted resuscitation and the room was in disarray or as one nurse described, "looked like a war zone". Medical nurses created a calm and dignified final scene for the family to remember.

Post mortem care was not mentioned by Degner, Gow and Thompson (1991). However McClement (1993) identified that ICU nurses stressed the importance of handling the body in a respectful manner as did medical nurses. On these medical units, nurses did not care for the body after death. Support staff wrapped and transported it to the morgue under the careful supervision of nurses who ensured respectful after care. Wrapping the body is sometimes felt to be a closure activity (Smith, 1992). This was not identified by any of the participants as part of their care or needs.

In addition to offering continued support to the family of the deceased, nurses on medical wards supported other patients on the unit by acknowledging the death event and responding to their particular needs for support. Including other patients and responding to their needs after a death was not previously identified by Degner, Gow and

Thompson (1991) or McClement (1993) although Benner (1984) had identified interpreting events on unit to other patients as a nursing competency. Because of previous admissions or length of time on the ward patients and families knew and often supported each other. When a member of this network died, (sometimes in the same room), members required support and received it from medical nurses. Degner and Beaton (1987) observed that staff tried to shield other patients from the resuscitation, however they did not identify what happened after the event.

Providing Comfort

Providing physical comfort to terminally ill patients was the most common nursing behaviour identified in the literature (Hesslin, 1989; Kristjanson, 1986; Magno, 1990; Martocchio, 1986). Patients had to be physically comfortable before other needs of the patient or family could be met (Fleming, Scanlon & D'Agostino, 1987; Kristjanson, 1989). Degner et al. (1991) described behaviours that reduced physical discomfort and McClement (1993) expanded the comfort dimension to include behaviours that reduced physical and psychological pain. Benner (1984) identified several nursing competencies that involved pain control. Providing comfort measures and preserving personhood in the face of pain and extreme breakdown was within the helping role domain; anticipating problems that might arise and thinking about what they would do was identified within the domain of diagnostic and monitoring function. As with the palliative nurses in Degner et al.'s (1991) study who "bucked

the system" medical nurses described situations in which physical comfort had not been achieved and/or when extraordinary measures were needed and nurses had to "fight for orders". On medical units this was attributed to working with less experienced medical staff. Medical nurses described strategies that were effective to ensure pain was managed adequately, including anticipating needs (Corcoran, 1986; DelBueno, 1990; Mosely 1985). Benner (1984) identified as getting appropriate and timely responses from physicians within the domain providing a backup system.

When the patient and family were comfortable, the nurses felt a sense of accomplishment for a job well done; their efforts were rewarded. On occasion when a high dosage of analgesic was necessary, some nurses felt uncomfortable and fearful of potential side effects; they withheld analgesic. Expert nurses did not reward this behaviour. They taught and reinforced the need for pain control. Achieving pain control sometimes involved what Degner called "bucking the system". Some physicians rewarded behaviours that ensured adequate relief from pain; others did not want their decisions questioned (Kelsey, 1992). Unit managers supported nurses as they attempted to achieve control of their patient's pain; their fight for appropriate control of pain and their assertive behaviours were rewarded.

Preventing unnecessary procedures was a comfort category not identified by Degner, Gow and Thompson (1991) or McClement (1993). Invasive procedures are minimal in palliative settings. In the ICU setting they are essential to monitor the critically ill and can be the

reason the patient is in ICU. On active medical wards they are required for diagnosis and treatment. Resuscitation was viewed as an unnecessary procedure for those patients who medical nurses identified as dying. Interventions described by nurses to prevent resuscitation were advocating and anticipatory in nature. When nurses were unsuccessful, they became angry and this was a negative consequence for nurses.

Lindley-Davies (1991) suggested that nurses on acute care wards had difficulty "letting their patients go" because of an overriding need to see their patients cured. This was not identified by medical nurses in this study. In contrast, medical nurses viewed unnecessary resuscitation as causing pain and interfering with the dignity of dying, a finding similar to Candy (1991). The resuscitation dilemma was included in the theme "responding to anger" by Hawkins (1995) who described behaviours to promote resolution when anger occurred in the health care team as a component of responding to anger. McClement (1993) included active treatment issues with advocacy behaviours within the category "enhancing personal growth" and they were described as a developmental nursing role.

McClement (1993) identified as one nursing behaviour reducing psychological pain, demonstrated by listening and talking to the patient about their concerns in a non-judgemental fashion. Medical nurses in contrast maintained personhood by what they described as being with dying patients. Benner and Wrubel (1984) defined presencing as "being with a patient in a way that acknowledges shared humanity, being in tune and aware of a unique personhood, by addressing the uniqueness of the

person not the disease." Being with was illustrated when nurses were comfortable sitting with patients in silence, seemingly doing nothing (Conrod, 1985; Sytles, 1990). In the context of an active medical unit where the dying patient is one of five to ten patients being cared for by the nurse, presencing gains significance. It involved organizing work in such a way that there was time to include just being there. When caring for the dying patient, the nurse has to overcome the medical model mind set established by specialists attending to medical patients. Instead of doing for and curing the patient, they contribute to and facilitate the patient's sense of personhood, meaning and dignity. Being present was similar to elements of supportive behaviours that Oberle and Davies (1990) called valuing.

The decision to code or not is a physician responsibility. Many doctors did not appreciate nurses reminding them of their inability to cure or prolong life. Initiating this difficult decision making process and dealing with the feelings of frustration and anger that surround it have negative consequences. In many instances it was easier to avoid, to not initiate the discussion if the risk was one of antagonizing the physician. When unit managers promoted and facilitated multi-disciplinary team decision making, they were supporting nurses as contributing members of the team.

Promoting spiritual well-being was not identified as a critical nursing behaviour for terminally ill patients by Degner, Gow and Thompson (1991) or McClement (1993). Spiritual well being was achieved by actively listening to patients and families and was influenced by the

connecting relationship that had been established. Finding uninterrupted time to listen as patients verbalized their hopes and fears promoted spiritual well-being. This was supported in the literature review (Fuerst & Taylor, 1988; Pickrel, 1989; Scanlon, 1989; Taylor, Amenta & Highfield, 1995). Several authors, (Buckner, 1988; Collinge, 1990; Heslin, 1989; Hickey, 1986) maintained that meaningful communication included a life review. This particular behaviour was not identified in this study. Medical nurses provided spiritual care by reading religious material to patients, praying with and for patients, and coordinating interventions by the clergy. This finding was similar to the spiritual care provided by hospice nurses identified by Munley (1985) who described hospice nurses who respected diverse beliefs, were willing to discuss matters of spirituality and provide organized religion with comfort. Meeting spiritual needs meant that hospice workers accepted the norm that "whatever a patient asks in terms of spiritual support, (nurses should) do it yourself or get someone who can". This dimension of comfort care was not identified by Degner et al. (1991) or McClement (1993).

Patients and family members were appreciative of the spiritual support provided by nurses. Listening to patients took time away from other nursing activities. Therefore non-performance was rewarded when there was time to complete other nursing tasks or to go home on time rather than work overtime. The unit manager may be rewarding non performance when administrative activities prevent observation of this

invisible nursing work with the result that there was no consequence for this nursing behaviour.

Enhancing Quality of Life While Dying

The literature described behaviours categorized as patient rights and patient feelings (see Table 1). Degner, Gow and Thompson (1991) described behaviours that helped patients do things that were important to them as enhancing quality of living while dying. Behaviours analogous to Degner's were found in this study. Medical nurses actualized patient rights when the prime focus was the patient living within the confines of a ward setting rather than dying. The literature described the need for patients to talk about their fears about death and dying, medical nurses also joked with patients and continued to include them in ward activities reinforcing patient involvement in activities of living. Medical nurses designed creative compromises by manipulating the environment (moving beds and other patients) to create private space and bending policies and procedures in an effort to provide nursing that met the individual patient's needs and wishes. Similar behaviours were identified by Benner (1984) within the helping role domain and included maximizing the patient's participation and control. As in palliative and hospice units, visiting hours were flexible. When large families could not be managed during the active day shifts, medical nurses had them come in during the night when there was more space and time. Doing what was important was divided into specific behaviours that facilitated their accomplishment and included

creating a space for family and privacy, promoting choice and control and individualizing care.

Nursing behaviours that enhanced quality of living while dying were rewarded when patients and families remained comfortable with their chosen level of involvement in living. There were seldom overt consequences when the nursing behaviours were omitted from care. Omission did not involve safety, policy or procedural issues; in some instances implementation actually bent or broke organizational policies. Unit managers that rewarded independent thinking and the need to challenge established norms demonstrated support for these nursing behaviours.

Responding to Anger

A broad category called nurse feelings was identified in the literature (see table 1) and included feelings of anger, guilt and manipulation by family members. Degner, Gow and Thompson (1991) and McClement (1993) identified the category responding to anger and the need for nurses to respond with empathy, a finding supported in this study. Previous work identified anger directed at the nurse from patients and families (Degner et al., 1991; McClements, 1993). Medical nurses responded to anger from medical students, interns, residents and attending physicians as well as responding to anger from patients and families. In addition to feelings of anger directed at them, medical nurses also needed to respond to their own feelings of anger in an appropriate manner. Nurses felt angry when there was poor communication

regarding treatment goals and when decisions related to pain control and the resuscitation issue were made by doctors without consultation with other team members. Anticipating potential events and having discussions outside the event was rewarding in that there was a better chance that nurses would be heard. When multi-disciplinary team work was encouraged and facilitated by the unit culture, a mechanism was established to discuss issues in a rational manner which reduced conflict. Nurse anger was not rewarded by physicians who ignored it as they had the ultimate power to make patient care decisions. Doctors could report inappropriate nursing behaviours to the unit manager. Nurses found it hard to maintain a professional attitude instead of responding in an automatic retort. One way was to remove themselves from the situation. Benner (1984) identified a competency Building and maintaining a therapeutic team to provide optimum therapy. Behaviours within this competency were directed towards those activities that responded to team work.

Enhancing Personal Growth

In the literature "nurse feelings" was a broad category that identified behaviours that dealt with death anxiety and fear of dying (see Table 1). This study found that as with the studies of Degner et al. (1991) and McClement (1993), nurses had defined a personal role in caring for dying patients. This was similar to the supportive dimension identified by Davis and Oberle (1991) as preserving own integrity. Participants spoke of feeling privileged to be involved in this

important event and attempted to make all patient/family interactions meaningful, no matter how small or short. "You may be the last person to offer that patient a glass of water so you go the extra mile and put ice into it". Learning that death and dying was not always a negative event and indeed was a normal outcome of living was described as a major step in their professional development. This is supported by Benner (1984) who identified maintaining a flexible stance towards the patient, technology and the bureaucracy as a nursing competency. Medical nurses believed the person lived until they died. Nurses sometimes had to overcome their own personal limitations. Nurses reflected on their work with dying patients during coffee talk, speaking with a professional friend or family member. Identifying a personal role enabled nurses to be comfortable and indeed enjoy caring for terminal patients. Benner, (1984) also identified the importance of coming to terms in some personal way with what the patient was confronting before becoming good at working with patients. Medical nurses were intrinsically rewarded by being involved in privileged and meaningful work.

Nurses on medical wards spoke of the diversity of patients. The contrast between those patients who were acutely ill and expected to experience restored health and those who were terminally ill was challenging, motivating and what kept them in medical nursing. Nurses in this study had no difficulty caring for each patient no matter what the expected outcome of that care. In a descriptive study, Samarel (1989) focussed on the role transition required for a group of hospice nurses to meet the needs of both terminally and acutely ill patients. It

was hypothesized that role conflict would result when nurses attempted to meet the needs of a varying and seemingly disparate population. She concluded that acute and terminally ill patients generated different types of nursing tasks but their basic need for caring remained the same. Medical nurses in this study thrived on the variety of patients; meeting their diverse needs motivated them.

Responding to Colleagues

Degner, Gow and Thompson (1991) identified the importance of a collegial network that provided emotional support and critical constructive feedback to one another. Nurses relied on their colleagues for support although some nurses wanted their managers to notice their hard work, similar to the findings of Lindsay and Attridge (1989). Medical nurses spoke of their need for support and also the importance of offering support to their colleagues, behaviours identified as necessary in a supportive environment (Eakes, 1990; Mills & Pennoni, 1986; Smith and Variglu (1985). Supportive behaviours included listening without passing judgement, encouraging and providing relief for each other. The majority of nurses felt comfortable offering support. In some situations nurses needed to delegate the care of their other patients in order to be with a patient who was dying.

Not all nurses thought all care delivered was as good as it could be and some viewed special care of the dying as spoiling. Expert nurses coached other nursing staff and if that did not improve the care for dying patients, then they took over the care themselves. Nurses felt

good when they were able to offer support to a colleague; an intrinsic reward that was similar to rewards of teamwork in other situations.

Managerial Support

There is a body of literature that describes acute care hospital wards that focus only on cure; it is suggested that caring behaviours central to a palliative orientation will be absent because of the stress of these apparently conflicting goals (Amenta, 1986; Thompson, 1985). The results of this study dispute these findings by identifying critical nursing behaviours for terminal patients similar to those identified in a palliative care setting. Benoliel (1988) and Thompson (1985) suggested the importance of setting; the head nurse/unit manager has a pivotal role in creating and maintaining the cultural norms of the setting. The unit manager controls the professional culture of the unit by setting the standards that determine the nursing care that occurs on the unit (Aiken, 1990; Lewis, 1990) and has a direct and significant bearing on nurses' affective responses and attitudes towards care for the dying (Thompson, 1985). If the expectation is that nurses care for others (patients, families and colleagues), then nurses must also experience caring behaviours in their workplace (Holman, 1990; Norris, 1989). Dingwall et al. cited in May (1991) suggested that consequences of individualizing patient care may result in confusion of personal and institutional objectives. A highly idealized attempt to attain a personal nurse-patient relationship may lead to strains between the demand of the nurse, the needs of the patient and the organization of

the work on the ward. By encouraging and rewarding some behaviours while discouraging and/or not recognizing others, the unit manager exerts considerable influence over nursing practice. Nurse managers on two medical units encouraged and facilitated nursing care that focused on patient needs thus blending the ideologies of palliative and curative care. Expert nurses working on these units learned to do the same. Behaviours that were important were rewarded.

Recommendations for Future Nursing Research, Education and Practice.

This research was one of a series of research projects to determine the critical behaviours for nursing the terminally ill. Previous work included nurses educators, and nurses working in palliative care, ICU, pediatrics, and in the community. All research identified similar clusters of basic nursing behaviours. That subjects reported behaviours without researcher observation can be viewed as a limitation of this study.

Recommendations for Nursing Research

1. That further research is required to determine by observation, if reported critical nursing behaviours are practiced.
2. That further research is required to determine the outcomes of these critical behaviours? For the patient, the family, and the nurse?
3. That the impact of a non-nurse unit manager be studied in relation to supporting performance of critical nursing behaviours. Does this effect nursing care for the terminally ill? If so in what way?

Recommendations for Nursing Education

1. That behaviours identified as critical for dying patients are recognized as behaviours already within the nursing domain.
2. That nursing educators stress the importance of maintaining the person as the focus of nursing care.
3. That communication skill building for student nurses include practising those skills necessary to effectively communicate with physicians in various stressful situations.
4. That students and new staff would benefit from working with nurses who can model expert nursing care for dying patients and who would offer timely feedback.

Recommendations for Nursing Practice

1. That unit standards of care for terminal patients be developed.
2. That nursing care for dying patients be included in orientation of new staff and become a practiced skill that is evaluated as a component of performance appraisal.
3. That unit managers create a supportive work environment in which staff feel supported 1) by recognizing and rewarding all components of nursing work including "caring" behaviours 2) by facilitating performance of nursing care for dying patients with an appropriate staffing ratio, and continuity of patient assignment 3) by recognizing organizational barriers to care for dying patients and striving to reduce them.

Conclusions

Behaviours critical to care for the dying on two adult medical units were identified. Five behaviours were analogous to behaviours identified by nurse educators and palliative care nurses. The common view that 'care' is absent in a 'cure' environment was not supported. Rewards for most nursing behaviours were intrinsic and seen to be part of exciting, motivating, meaningful work. Patients, families, colleagues and managers rewarded behaviours critical to care for the dying. Medical nurses continued to practise behaviours that were overtly and/or covertly discouraged.

Palliative philosophy developed out of recognition that needs of patients dying in hospital settings were largely unmet. Specialized units and hospitals were established to meet those needs. Many nurses already have skills that are critical to care for dying patients. At issue is the opportunity to practice those skills in an environment that recognizes and encourages the performance of them facilitating the delivery of personalized care.

TABLE 1.
Nursing Behaviours Described in the Literature

General Behaviour	Specific Behaviours	Sources for Specific Behaviours
Comfort Care Provide optimal comfort through maintenance of physical comfort	■ proficient and efficient physical care	Martocchio (1986)
	■ Demonstrate competency in technical skills	Mayer (1987)(1986) Styles (1990) Wolf (1991)
	■ Ensure thorough pain control	Hesslin (1989) Kristjanson (1986) Magno (1990) Martocchio (1986)
	by monitoring	Fuller et al. (1989) Larson (1987)(1984) Moseley (1985)
	by giving medications on time	Freihofer & Felton (1976) Gonda & Ruark (1984) Kristjanson (1990) Matuk (1991) Mosley (1985)
	by reducing pain producing activities	Heslin (1989)
	■ Position for comfort	Rosdahl (1991) Zerwekh (1988)
	■ Ensure adequate symptom control with minimal complications	Daeffler (1985) Kristjanson (1990) McGarr (1987) Sherman et al. (1988)
	of nausea and vomiting	Heslin (1990) Moseley (1985)
	of constipation	Moseley (1985)

TABLE 1. Nursing Behaviours Described in the Literature (continued)

General Behaviour	Specific Behaviours	Sources for Specific Behaviours
<u>Comfort Care</u> Provide optimal comfort through maintenance of physical comfort (continued)	of odour of breathing difficulty of fatigue ■ Offer alternate techniques for symptom control ■ Anticipating care needs ■ Use of appropriate touching ■ Maintain good hygiene	Fuller et al. (1989) Martocchio (1986) Moseley (1985) Rosdahl (1991) Moseley (1985) Petrosino (1985) Moseley (1985) Sherman et al. (1988) Moseley (1985) Jones (1990) Mayer (1987) Samarel (1989) Heslin (1989) Kirsching (1986) Kristjanson (1990) Rosdahl (1991)
<u>Patient Feelings</u> Engage in meaningful communication with the patient	■ Provide time to undertake a life review ■ Enable realistic hope and goals	Buckman (1988) Collinge (1990) Heslin (1989) Hickey (1986) Wright (1985) Fuerst & Taylor (1988) Hickey (1986) Lewis (1986) Martocchio (1986) Mazzawy (1985) Pickrel (1989) Scanlon (1989) Ufema (1987) Wright (1985) Benoliel (1988)

TABLE 1. Nursing Behaviours Described in the Literature (continued)

General Behaviour	Specific Behaviours	Sources for Specific Behaviours
<u>Patient Feelings</u>	■ Actively listen and respond to patient identification and expression of fears	Buckman (1988) Dugan (1987) Ferszt & Taylor (1988) Hamilton (1988) Heslin (1989) Hickey (1986) Librach (1985) Jones (1990) Larson (1986) MacDonald (1990) Magno (1990) Mayer (1987) Moseley (1985) Pflaum & Kelly (1986) Scanlon (1989) Webster (1986) Wright (1985)
Engage in meaningful communication with the patient	■ Provide spiritual support	Conrad (1985) Reed (1991) Wolf (1991)
(continued)	■ Reassure that help is available	Kristjanson (1990) Larson (1987, 1984) Mayer (1987)
	■ Respond to calls quickly	Sherman et al. (1988) Wright (1985)
	■ Convey empathy by appropriate eye contact, hand movements,	Buckman (1988) Dugan (1987) Jones (1990) MacDonald (1990) Rieman (1986) Samarel (1989) Scherr (1989) Stott (1990) Tyner (1985)
	■ Accept patient's particular response to dying	Scanlon (1989)

TABLE 1. Nursing Behaviours Described in the Literature (continued)

General Behaviour	Specific Behaviours	Sources for Specific Behaviours
<u>Patient Feelings</u>	■ Persuade patient to do what others think is best	Kennedy (1985)
Engage in meaningful communication with the patient	■ Offer advice	Buckman (1988) Thorne (1988)
(continued)		
<u>Nurse Feelings</u>	■ Acknowledge own feelings of loss and mourning	Eakes (1990) Kerr (1978) Mandel (1981) Samarel (1989) Ufema (1987) Webster (1986)
Come to terms with own fear of dying	■ Provide time to reflect upon care given	Eakes (1990) Mandel (1981) Munley (1985) Samarel (1989)
	■ Develop realistic comfort goals	Benoliel (1985) Eakes (1990) Scanlon (1989) Trygstad (1986) Tyner (1985)
	■ Develop willingness to become involved	Conrad (1985) Eakes (1990) Mandel (1981)
	■ Develop strategies to deal with anger, guilt manipulation by patients and families	Mandel (1981) Munley (1985)

TABLE 1. Nursing Behaviours Described in the Literature (continued)

General Behaviour	Specific Behaviours	Sources for Specific Behaviours
<p><u>Nurse Feelings</u> Come to terms with own fear of dying (continued)</p>	<ul style="list-style-type: none"> <li data-bbox="613 575 935 737">■ Accept feelings of ambiguity, vulnerability, inadequacies, and powerlessness <li data-bbox="613 768 935 863">■ Recognize personal needs and coping strategies <li data-bbox="613 894 935 989">■ Develop strong positive attitude towards the elderly <li data-bbox="613 1020 935 1094">■ Limit conversations to non-death topics <li data-bbox="613 1178 935 1272">■ Maintain composure and control of feelings 	<p>Archer (1988) Holman (1990) Kerr (19780) Waters (1987) Wright (1985)</p> <p>Scanlon (1989)</p> <p>Eakes (1990) Gonda & Ruark (1984)</p> <p>Benoliel (1983) Nimrock et al. (1987) Shedletsky & Fischer (1986)</p> <p>Eakes (1990) Lamerton (1985)</p>
<p><u>Support Colleagues</u> by providing affirmation, assistance and time</p>	<ul style="list-style-type: none"> <li data-bbox="605 1373 959 1499">■ Respect own pain and pain of co-workers by listening to each other <li data-bbox="605 1562 959 1625">■ Offer physical assistance <li data-bbox="605 1667 959 1751">■ Create time for closure (go to funeral) <li data-bbox="605 1793 959 1877">■ Reduce new staff stress by education and role modelling 	<p>Hutchings (1991) Munley (1985) Scanlon (1989) Smith & Variglu (1985) Tyner (1985)</p> <p>Smith & Variglu (1985)</p> <p>Beaudoin (1990) Hutchings (1991)</p> <p>Munley (1985)</p>

TABLE 1. Nursing Behaviours Described in the Literature (continued)

General Behaviour	Specific Behaviours	Sources for Specific Behaviours
<p><u>Support Colleagues</u> by providing affirmation, assistance and time</p>	<ul style="list-style-type: none"> ■ Provide administrative support by acknowledging importance of psychosocial care 	<p>Benoliel (1988) Munley (1985)</p>
(continued)		
<p><u>Patient Rights</u> <u>Respect patient individuality</u></p>	<ul style="list-style-type: none"> ■ Encourage and maintain optimal independent functioning ■ Help patient to maintain sense of control by offering choices /participation in decision making ■ Pursue patient goals based on patient values and desires 	<p>Condera & Schoessler (1985) Daeffler (1985) Gonda & Ruark (1984) Kerr (1978) Rosdahl (1991) Webster (1986) Williams (1982) Wright (1985)</p> <p>Aroskar (1985) Hamilton (1988) Jones (1990) Kennedy (1985) MacDonald (1990) Magno (1990) McGarr (1986) Spaar (1987) Ufema (1987) Wright (1985)</p> <p>Larson (1986) Martocchio (1986) Mayer (1987) Mazzawy (1985) McGarr (1986) Mitchell (1987) Spaar (1987) Styles (1990) Webster (1986) Wright (1986)</p>

TABLE 1. Nursing Behaviours Described in the Literature (continued)

General Behaviour	Specific Behaviours	Sources for Specific Behaviours
<u>Patient Rights</u> Respect patient individuality (continued)	<ul style="list-style-type: none"> ■ Help patients learn about treatments and alternatives ■ Ensure patient privacy ■ Provide continuity of care ■ Assure dignity after death ■ Ensure patient knows the truth ■ Advocate 	Aroskar (1985) Deaffler (1987) Uffema (1987) Wright (1985) Daeffler (1985) Spaar (1987) Webster (1985) Wright (1986) Webster (1986) Wright (1985) Wolf (1991) Trent (1986) Styles (1990)
<u>Family Care</u> Support family by including them in care	<ul style="list-style-type: none"> ■ Keep family informed about present condition ■ Prepare family for imminent death ■ Continuous assessment of family needs 	Chekryn (1985) Hull (1989) Rosdahl (1991) Webster (1989) Wright & Dyck (1984) Wright (1985) Lemay (1985) Munley (1985) Moseley (1985) Rosdahl (1991) Wolf (1991) Chekryn (1985) Heslin (1989) Kirschling (1986) Petrosino (1985) Scanlon (1989) Sherman et al. (1988)

TABLE 1. Nursing Behaviours Described in the Literature (continued)

General Behaviour	Specific Behaviours	Sources for Specific Behaviours
<u>Family Care</u> Support family by including them in care (continued)	<ul style="list-style-type: none"> ■ Teach family effective communication skills ■ Symptom control ■ Provide positive comments about patient ■ Be available ■ Provide for respite care, follow-up care, and bereavement ■ Encourage ventilation of feelings 	Chekryn (1985) Heslin (1989) Scanlon (1989) Kirschling (1986) Kristjanson (1990) Eakes (1990) Gonda & Ruark (1984) Scanlon (1989) Wright & Dyck (1984) Wright & Dyck (1984) Scherr (1989) Scanlon (1989) Kristjanson (1990) Rosdahl (1991) Thorne (1988)
<u>Environment</u> Modify environment to meet patient family needs	<ul style="list-style-type: none"> ■ Create a home like environment ■ Allow family to be near patient ■ Create a sense of "unhurriedness" ■ Provide for quiet peaceful environment with frequent rest periods 	Kristjanson (1986) Nimrocks et al. (1987) Parry (1986) Wolf (1991) Hull (1989) Kirschling (1986) Wright (1985) Buckner (1988) Jones (1990) Naysmith & O'Neill (1989) Moseley (1985)

TABLE 1. Nursing Behaviours Described in the Literature (continued)

General Behaviour	Specific Behaviours	Sources for Specific Behaviours
<u>Environment</u> Modify environment to meet patient family needs (continued)	<ul style="list-style-type: none"> ■ Demonstrate "person" not disease is focus of care ■ Ensure freedom from odours 	Dugan (1987) Wright (1985) Fuller et al. (1989) Martocchio (1986) Zerwekh (1988)
<u>Facilitator Role</u> Facilitate interactions among all involved in care	<ul style="list-style-type: none"> ■ Teach communication skills to family members ■ Share knowledge of patient care with family members/other staff ■ Coordinate other staff to reduce time, pain, redundancy ■ Foster interdisciplinary teamwork ■ Determine DNR status 	Heslin (1989) Jones (1990) Matuk (1991) Sherman (1988) Stott (1990) Daeffler (1985) Heslin (1989) Kirschling (1986) Kristajanson (1986) Fuller (1989) Benoliel (1988) Conrad (1985) Degner & Beaton (1988) Flemming et al. (1987) Riesetter & Thomas (1986) Rosdahl (1991) Scanlon (1989) Simmons & Given (1972) Styles (1990) Tyner (1985) Rosdahl (1991)

General Behaviour	Specific Behaviours	Sources for Specific Behaviours
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TABLE 2.

CRITICAL NURSING BEHAVIOURS IN CARE FOR THE DYING: ON ADULT MEDICAL UNITS

Behaviour	Positive	Negative
Connecting	<ul style="list-style-type: none"> ■ Behaviours that promote the development of a relationship with the patient 	<p>Behaviours that are reserved and distancing</p> <p>Behaviours that focus on tasks</p>
Supporting the Family	<ul style="list-style-type: none"> ■ Behaviours that connect and support the family and its members ■ Behaviours that respond to the family's need for information ■ Behaviours that include family in care or relieve them of this responsibility, according to their wishes. ■ Behaviours that reduce the potential for future regret ■ Behaviours that prepare the family for the death event 	<p>Judgemental behaviours</p> <p>Behaviours that disregard the family's questions</p> <p>Behaviours that demonstrate lack of family assessment</p> <p>Behaviours that demonstrate disregard for patient/family's wishes</p> <p>Avoidance behaviours</p>
Providing Comfort	<ul style="list-style-type: none"> ■ Behaviours that reduce or eliminate physical pain ■ Behaviours that prevent unnecessary procedures including recuscitation. ■ Behaviours that maintain presence and spiritual well-being 	<p>Withholding analgesics</p> <p>Failure to anticipate needs.</p> <p>Avoidance</p> <p>Behaviours that are flippant</p>

TABLE 1. Nursing Behaviours Described in the Literature (continued)

General Behaviour	Specific Behaviours	Sources for Specific Behaviours
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Table 2. (continued)

Behaviour	Positive	Negative
Enhancing Quality of Life while Dying	<ul style="list-style-type: none"> ■ Behaviours that create an an environment conducive to patient/family interactions. 	Behaviours that maintain a "hospital" environment
	<ul style="list-style-type: none"> ■ Behaviours that promote choice and control 	Distancing or avoidance behaviours
	<ul style="list-style-type: none"> ■ Behaviours that promote personhood 	Strict adherence to hospital policies and procedures Seeing a disease not a person
Responding after death has occurred	<ul style="list-style-type: none"> ■ Behaviours that demonstrate respect and support for the family's realization of death 	Behaviours that show lack of respect for the family and their grief
	<ul style="list-style-type: none"> ■ Behaviours that create a peaceful and dignified bedside scene 	Behaviours that demonstrate lack of appreciation of the potential impact of the death scene
	<ul style="list-style-type: none"> ■ Behaviours that demonstrate respect for the body during post-mortem care 	Rough impersonal handling of the body
	<ul style="list-style-type: none"> ■ Behaviours that demonstrate reponding to other patients 	Ignoring other patient's need to acknowledge the death event

TABLE 1. Nursing Behaviours Described in the Literature (continued)

General Behaviour	Specific Behaviours	Sources for Specific Behaviours
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Table 2. (continued)

Behaviour	Positive	Negative
Responding to Feelings	■ Behaviours that demonstrate professionalism, respect and empathy wherever anger is directed	Responding in anger
Responding to Nursing Colleagues	■ Behaviours that provide emotional and concrete support and critical feedback to nursing colleagues	Behaviours that demonstrate insensitivity to colleague's needs
Enhancing Personal Growth	■ Behaviours demonstrating the development of a personal role in care for the dying and their family	Behaviours that focus on tasks rather than caring
Managerial Support	Behaviours that recognize and support nursing work	Rewarding only visible tasks

Appendix A

Medical Nurse Expert Identification Tool

Medical nurses expert in care of the dying will be identified by modifying a technique developed to analyze group structure called a sociogram. To create a sociogram, all members of a group are asked independently to name those people with whom they would most like to interact on a given occasion for a specific purpose. The responses of each person are plotted. The result depicts in visual form the nature of the relationships. "Stars" within the group are determined by the frequency with which they are mentioned by members of the group.

A modification of this technique was successfully used by Hiss, MacDonald and David (1978). Physicians were asked to describe colleagues they felt were influential in matters of education and patient care. Responses from 394 physicians were analyzed. The results clustered around the factors of communication, humanism and knowledge. The reliability of each factor was computed using Cronbach's alpha; the range was from .76 -.85. Three carefully worded paragraphs were constructed from the top nine influential items reported by respondents. Those participating in identification of educational influencers were asked to identify those colleagues who best fit the descriptions listed.

In this study, attributes of expert nurses described by Benner (1984) and behaviours identified in the literature as critical to care of the dying will be the basis of three descriptive paragraphs depicting nurses expert in care of the dying.

Attributes of nurse experts identified by Benner (1984) include:

- the ability to anticipate problems, to future think.
- having an intuitive grasp of the importance of situations and the ability to assess what can be safely added to or omitted from medical orders.
- using and maintaining a team approach; gaining support from other nurses and health care workers.

The death and dying literature reviewed by this investigator identified eight categories of nursing behaviours. Those mentioned most frequently related to provision of patient physical comfort by alleviating symptoms, the recognition of the importance of meaningful communication, the enabling of hope and participation in decision-making, and facilitating / coordinating behaviours when interacting with patients, families and team members.

Appendix BSemi-Structured Interview Guide

The purpose of the interview will be to elicit from medical nurses those nursing behaviours they know made a difference, either positively or negatively, to the care of a dying patient. Nurse experts will be asked to describe the most recent incident they can remember. Benner (1984) suggests that these incidents come to mind readily. A critical incident, according to Benner (1984) is:

- * an incident in which a nurse said or did something directly or indirectly, that made a positive difference in patient outcome
- * an incident in which a nurse said or did something that had a negative effect on a dying patient
- * an incident that went unusually well
- * an incident in which there was a breakdown, that is, it did not go as planned
- * an incident that is very ordinary or typical
- * an incident that the nurse thinks describes what nursing care of the dying on a medical ward is all about
- * an incident that was particularly demanding

The following information will be included in the descriptions of critical incidents:

- * the context of the incident (shift, time of day, staff resources, other happenings on the unit at the time)
- * a detailed description of what happened
- * why the incident is critical to the nurse
- * what the nurse was thinking about during and after the incident
- * what the nurse was feeling during the incident
- * what was demanding about the incident?
- * how was the incident recognized by others? Rewarded? Punished?
- * what would have made a difference?

* what were the consequences of the incident to the nurse?

***Adapted from

Benner, P. (1984). From Novice to Expert: Excellence and Power in Clinical Nursing. Menlo Park: Addison-Wesley pp. 300-301.

Degner, L., Gow, C., & Thompson, L. (1991). Critical nursing behaviours in care of the dying. Cancer Nursing, 14(5), 246-253.

Appendix CDisclaimer

You are being asked to voluntarily give your opinion about the statements on this form. By identifying the name(s) of your nursing colleagues that best fit the description outlined in each of the following paragraphs, you will be giving your consent to participate in this aspect of the study. Do not write your name on this form. You may choose not to respond to one or all of the paragraphs, if you so desire. Whatever you decide, your employment in this institution will not be affected in any way. Any questions you have will be answered; you may withdraw from the study at any time. There are no known risks to you should you decide to complete this form.

INSTRUCTIONS

Please read each paragraph carefully and indicate the name(s) of the medical nurse(s) with whom you work that best fits each description. The nurse must have at least three years medical nursing experience and currently be involved in patient care. You may write the name of up to three nurses for each paragraph. The same nurse may be named in more than one paragraph. You may name yourself if you feel it appropriate.

Paragraph A

They enhance the quality of remaining life for dying patients by providing comfort. They know how to alleviate distressing symptoms for dying patients and choose the strategy with the least complications. A high degree of clinical competency is present in all aspects of their nursing care. They find time to be with dying patients even when there is no physical task to perform. They are able to anticipate problems and develop strategies that minimize anxiety.

Name _____

Name _____

Name _____

Paragraph B

The importance of psychosocial care is demonstrated by these nurses who focus is the patient not the disease. They engage in meaningful communication with dying patients and families. They are able to zero in on the accurate region of problems and provide empathic responses. They enable realistic hope and encourage patient participation in decision making. A sense of "unhurriedness" is conveyed in all patient interactions.

Name _____

Name _____

Name _____

Paragraph C

They are nurses who coordinate and meet multiple patient needs by establishing nursing priorities which are altered as patient conditions change. They are able to respond to other team member's emotional pain. They provide collegial support by offering assistance and respecting the feelings of others. They build and maintain a team effort by facilitating clear communication among patients, families and other members of the health care team. They seem to intuitively know when to call the family or physician.

Name _____

Name _____

Name _____

Appendix D

Consent Form

Study Title: Critical Nursing Behaviours for Care of the Dying: on an Adult Medical Unit.

Investigator: Joan Harbeck, R.N. B.A.

Joan Harbeck is an R.N. studying nursing behaviours critical to care for dying patients on adult medical units. She believes that identification of nursing behaviours will lead to improved nursing care for dying patients and their families and contribute to a developing model of expert care of the dying.

I know that I am one of ten nurses to be approached to participate. I was selected because my nursing peers thought I fit the description on the form given to us by Joan Harbeck, at a staff meeting. I know my participation in this study is strictly voluntary and that I can refuse to answer any question, and withdraw at any time without penalty.

I know there are no direct benefits for me if I participate in this study. Indirectly, my contribution may help to improve nursing care for dying patients. I realize that there are no known risks to me or any other. If strong feelings are evoked during the interview, I understand that I can stop, re-schedule the interview, or withdraw from the study without penalty to myself or my position in this hospital. If I need emotional support it will be offered by Joan Harbeck or another support person of my choosing.

I realize that approximately one and one-half hours of my time is required. An audio tape recorded interview will take approximately one hour. At a later date, a review of the identified behaviours will require an additional one half hour.

I have been assured that my identification will not be revealed. Information I give will be identified by code number only, and be kept in a locked drawer at the St. Boniface General Hospital Research Centre. Joan Harbeck, Dr. Lesley Degner, Dr. Elizabeth Hanson, and the person hired to type the interview will be the only people to see the typed interview. General terms such as patient and nurse will be used when the study is written. When the study is completed the audio tape recording will be erased and the written interviews will be shredded.

If I have any questions about the study or my participation in it, I know I can call Joan Harbeck at 787-3395 or 787-8037 (office) or 488-1173 (home).

I agree to participate in this study and have received a copy of this consent form.

Date

Participant's Signature

Investigator's Signature

APPENDIX E

Structured Data Collection

I.D. # _____

Date _____

1. Age (years) _____
2. Gender _____
3. (a) Years of experience in nursing _____
(b) Years of experience in medical nursing _____
4. Level of nursing education (CHECK ONE) _____
 - (a) Licensed Practical Nurse _____
 - (b) Registered Nursing Diploma _____
 - (c) Post-Diploma degree in nursing _____
 - (d) Baccalaureate degree in nursing _____
 - (e) Masters degree in nursing _____
5. Have you other educational preparation for care of the dying patient?

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