

**CRITICAL NURSING BEHAVIORS IN CARE OF THE DYING
ADULT IN THE INTENSIVE CARE UNIT**

BY

SUSAN McCLEMENT

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

MASTER OF NURSING

**Faculty of Nursing
University of Manitoba
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Abstract

Though the main function of the intensive care unit is to institute life saving measures, the fact remains that there is a great potential for patients to die there. Intensive care nurses are in a key position to meet the needs of dying patients and their relatives, yet these nurses often indicate that they feel ill prepared to manage this aspect of patient care.

A beginning list of six critical nursing behaviors in care of the dying adult in the ICU were identified in this descriptive qualitative study. The theoretical perspectives guiding the study were the Dreyfus Model of Skill Acquisition and Symbolic Interaction Theory. Ten intensive care nurses identified as "expert" in care of the dying by their peers were asked to describe situations in which a student or graduate nurse had displayed very positive or very negative attitudes to care of the dying. Behaviors identified after content analysis of transcribed interviews included: Responding after death has occurred; Responding to the family; Responding to anger; Responding to colleagues; Providing comfort; and Enhancing personal growth. Many of these categories of nursing behaviors were not clearly delineated in the literature.

Table of Contents

	<u>Page</u>
ACKNOWLEDGEMENTS	iii
ABSTRACT	iv
CHAPTER I STATEMENT OF THE PROBLEM	
a) Purpose of the Study	1
b) Research Questions	4
c) Assumptions underlying the study	5
5d) Definition of Terms	6
e) Need for the Study	8
CHAPTER II LITERATURE REVIEW	
a) Attitudes toward death in contemporary society	9
b) Educational preparation of nurses in care of the dying	15
c) The Environment and Philosophy of the Intensive Care Unit	19
d) The effect of dying patients on the ICU nurse	22
e) The family of the dying patient in the ICU	24
f) Nursing behaviors in care of the dying identified in literature	25
g) Summary	26
CHAPTER III CONCEPTUAL FRAMEWORK	
a) Quint's perspective	28
b) The Dreyfus Model of Skill Acquisition	30
c) Summary	35
CHAPTER IV METHODOLOGY	
a) Research design	37
b) Sample	37
c) Procedures	41
d) Ethical Considerations	44
e) Data Analysis	46
f) Issues of validity and reliability	47
g) Limitations of the Study	48
h) Summary	49

CHAPTER V FINDINGS

a)	Characteristics of the Sample	50
b)	Responding after death has occurred	51
c)	Responding to the family	57
d)	Responding to anger	71
e)	Responding to colleagues	74
f)	Providing comfort care	81
g)	Enhancing personal growth	85
h)	Summary	92

CHAPTER VI DISCUSSION OF THE FINDINGS

a)	Relationship of the findings to the Theoretical Perspectives.....	93
b)	Relationship of findings to the work of Degner, Gow and Thompson	96
c)	Implications of the study for education	105
	practice	105
	research	106
d)	Summary	107

TABLES

TABLE I -	Nursing Behaviors Identified in the Literature	109
TABLE 2 -	Categories of Critical Nursing Behaviors in Care of the Dying	111

APPENDICES

Appendix A	-	Tool for Identifying Nurse Experts	113
Appendix B	-	Semi- structured Interview Guide	116
Appendix C	-	Biographical Data Collection Form	118
References		119

CHAPTER I

STATEMENT OF THE PROBLEM

Introduction

Though the main function of the intensive care unit is to institute life saving measures, the fact remains that there is a great potential for patients to die there (Eastham, 1990; Farrell, 1989; Noble, 1982; Simon, 1980; Michaels, 1971). Intensive care nurses are in a key position to meet the needs of dying patients and their relatives, yet these nurses often indicate that they feel ill prepared to manage this aspect of patient care (Roch, 1987; Hickey & Lewandowski, 1988; Leske, 1986). As a result, the needs of the dying patient may not be met, relatives may suffer traumatic bereavement, and ICU nurses may suffer feelings of frustration, helplessness, and inadequacy (Collins, 1989; Farrell, 1989; Caughill, 1976).

That nurses everywhere experience difficulty in providing skilled and sensitive terminal care was identified by Quint (1967) nearly 25 years ago. Care of the dying remains a contemporary problem. In a comparative study conducted in 1977, Loch identified that the death of a patient in the intensive care unit was the single major source of stress for nurses, even if the nurse was not personally caring for the patient. Nurses in a recent Canadian survey ranked the potential research topic, "determine ways of helping nurses deal with questions of life and death and their own feelings of grief, loss, and frustration" as second in importance on a list of 144 topics (Western Consortium, 1984).

Intensive care nurses may encounter additional difficulty in caring for dying patients for the several reasons.

First, intensive care units are designed to maintain life, with a primary emphasis directed toward recovery or cure (Caswell & Omrey, 1990; Degner & Gow, 1988; Goldberg, 1985, Martocchio, 1980, Strauss, 1968). In the case of the dying patient however, the objective of treatment needs to shift from cure to care (Caswell & Omrey, 1990). This shift in focus may be problematic for nurses who equate the inability to cure with professional failure (Hare, 1989; Caughill, 1976; Noble, 1982; Simon, 1980). Mortality rates tend to be high in critical care areas (Eastham, 1990), and frequent deaths are believed to challenge the establishment and maintenance of a firm professional identity (Simon, 1980). Thus, an inherent tension exists:

It is the task of the ICU to provide the best chance for survival for those with acute, temporary, life-threatening problems. Those for whom a return to life with some quality is improbable do not fit this criteria. However, they may still be housed in ICU (Daly, 1980, p.443).

Secondly, care of the dying has typically received little attention in the overall curriculum in schools of nursing (Degner & Gow, 1988; Eakes, 1986; Quint & Strauss, 1964). The stress of dealing with people who are dying or bereaved may well be increased by lack of appropriate education and training (Eastham, 1990). Owing to the critical and unstable nature of the patient population in the ICU, nurses working there are necessarily involved in caring

for dying patients and their relatives (Eastham, 1990; Noble, 1980). However, the inevitability of death does not make it any easier for the nurse who is caring for the critically ill patient who is dying (Caswell & Omrey, 1990). Alspach and Williams (1985) contended that providing nursing care for dying patients can be one of the most rewarding experiences, if critical care nurses are knowledgeable about the dying process.

Although Field and Kitson (1986) suggested that the once carefully avoided subject of death is receiving more attention in nursing education, the most effective approach in providing this education has not been identified. Where death education does exist, the effect of programs has not been evaluated systematically (Degner & Gow, 1988). With little in the way of formal curriculum to prepare them, nurses are placed in the untenable position of having to care for the dying with very few guidelines (Lev, 1986). Consequently, many caregivers are left with the feeling that there is "nothing left to do" (Davidson, 1966).

Thirdly, much of the literature about what constitutes behavior believed to be helpful in care of the dying is anecdotal or opinion based (Eastham, 1990; Friehofer & Felton, 1976). Degner et al. (1991) asserted that in no field of nursing is the need to define the nature of expert practice more acute than in care of the dying. Friehofer and Felton (1976) identified nearly fifteen years ago, that if care for the dying was to improve, nursing behaviors that are considered helpful to patients and families needed to be clearly delineated. Benner (1984) believed that a wealth of

untapped knowledge is embedded in the practices and the know-how of expert nurse clinicians. Thus, systematic documentation of expert clinical performance in care of the dying is the first step in clinical knowledge development.

Purpose of the study

The overall purpose of this study was to describe nursing behaviors nurse experts identified as being critical in caring for the dying adult in the intensive care unit. The following research questions were addressed:

1. What were the behaviors that ICU nurses deemed "expert" in care of the dying by their colleagues, described as having a positive influence on the care of the dying adult in the intensive care setting?

2. What were the behaviors that ICU nurses deemed "expert" in care of the dying by their colleagues, described as having a negative influence on the care of the dying adult in the intensive care setting?

3. How do the behaviors identified by the ICU nurses in this study compare with the seven categories of nursing behaviors identified in Degner, Gow, and Thompson's (1991) qualitative study of palliative care nurses and nurse educators?

Assumptions underlying the Study

The following assumptions underlie this study:

1. There are patients for whom aggressive curative treatment becomes increasingly inappropriate.
2. Care of the dying is a process that involves the needs of the patient, family and caregivers.
3. Survivors are at risk emotionally and physically during bereavement.
4. Good terminal care presupposes emotional investment on the part of the nursing staff.
5. Emotional commitment to good terminal care will often produce emotional exhaustion.
6. Expert nurses are able to reflect on their experiences in care of the dying.

Definition of Terms

The following terms are defined as they were used in this study:

Bereavement - the state of having suffered a loss (Rondo, 1989, p.16).

Dying - a physiologic process that evokes many stresses and crises, and that ultimately terminates in death for the dying and in suffering for significant survivors (Alspach & Williams, 1985).

Expert - a person having special skill or knowledge (Concise Oxford Dictionary, 1982, p.339).

Expertise - the state of having expert opinion, skill or knowledge. It develops through a process of comparing whole and dissimilar clinical situations with one another, so an expert has a deep background understanding of clinical situations based upon many past paradigm cases. Expertise is a hybrid of practical and theoretical knowledge. Experience is a requisite for expertise (Benner, 1984, p.294).

Experience - occurs when an individual actively refines preconceived notions and expectations. Experience is gained when theoretical knowledge is refined, challenged, or disconfirmed by actual clinical evidence that enhances or runs counter to theoretical understanding (Benner, 1984, p.294).

Family - a group of people who share a past, experience some degree

of emotional bonding, and are usually living together. Members may or may not be related, and the ties that unite them may or may not be legal (Amenta & Bohnet, 1986).

Grief - the process of psychological, social, and somatic reactions to the perception of loss. This definition implies that grief is: 1) a continuing development involving many changes; 2) a natural, expectable reaction; 3) based on the unique perspective of loss of the griever (Rando, 1984, p.15).

Intensive Care /Critical care - refers to the care of the critically ill patient in a specific and specially equipped location of an acute care facility. It involves the nurse who is taking care of the individual patient whose life is threatened by the acute phase of a disease process, by the effects of surgical intervention, or as the result of trauma. Critical or intensive care often involves the utilization of life support systems, as well as aggressive and complex interventions (Fenton, 1987, p.9).

Intensive Care Nurse - refers to a nurse who is employed in a critical care unit.

Paradigm case - a clinical episode that alters one's way of understanding and perceiving future clinical situations.

These cases stand out in the clinician's mind; and are reference points in their current clinical practice (Benner, 1984, p.296).

Terminal Care - consists of the physical and psychological assistance provided during that period of time the patient is defined as in the final stages of living (Quint, 1967).

Need for the Study

This study will provide practising nurses with empirically based interventions to use in the clinical setting. An awareness of the fact there are specific things one can do for the dying patient and their relatives may help decrease caregiver feelings of helplessness and inadequacy, and promote greater approach behavior in care of the dying.

The generation of knowledge about what constitutes effective nursing care for the dying in the intensive care unit could serve as a beginning guide for structuring curricular content for critical care nursing education programs. This study will also contribute to the development of a model of expert practice in care of the dying as one in a series of comparative studies being conducted by Dr. L. Degner and her associates.

CHAPTER II

LITERATURE REVIEW

A review of the literature provides a context for understanding nursing behavior in care of the dying generally, and in the intensive care setting specifically. This chapter is organized into the following sections: I) Attitudes toward death in contemporary society; II) The educational preparation of nurses in care of the dying; III) The environment and philosophy of the intensive care unit; IV) The effect of dying patients on the ICU nurse; V) The family of the dying patient in the intensive care unit; VI) Nursing behaviors in care of the dying identified in the literature.

I). Attitudes Toward Death in Contemporary Society

An appreciation of the response to loss and death requires an understanding of the socio-cultural context in which they occur (Rando, 1984). The three general patterns of societal response to death identified in the literature are: a) death-accepting; b) death-defying; and c) death-denying (Long & Phipps, 1985; Rando, 1984).

Death-accepting societies view death as a natural, integral part of life (Long & Phipps, 1985; Rando, 1984). Death-defying societies believe that individual action can "vanquish" death (Long & Phipps, 1985). Death-denying societies (i.e. Western society) are typically characterized by a widespread refusal to confront

death (Long & Phipps, 1985; Rando, 1984; Feifel, 1974; Kubler-Ross, 1975; Howard & Scott, 1965). Why does the concept of death evoke such a reaction?

Some writers contend that death invites vigorous denial because to think of a time when we will cease to exist is completely incompatible with the notions of "achievement" and "the future" (Martocchio & Dufault, 1983; Feifel, 1974). Rando (1984) believed that death "...threatens us with the negation of ourselves and all that we value" (p.2). Koestenbaum (1971) noted that the while the idea of death in general provokes anxiety (and hence denial in many individuals), this anxiety is markedly heightened once a person makes the distinction between the "death of others" and the "death of self". Such conceptualizing arouses anxiety and uncertainty because the "death of self" is "...tantamount to the disappearance of the world." (Koestenbaum, 1971, p.28). This results in the attitude that death is horrible, catastrophic, and that it is not a natural part of human existence (Kerr, 1978; Kubler-Ross, 1975; Martocchio, 1980; Rando, 1984).

In addition to the fear of the annihilation of self, several other variables have been identified in the literature to explain why individuals have difficulty in dealing with death. They include the following:

1) Urbanization

Though not all researchers agree upon the negative effects of urbanization (Fischer, 1980), it is widely contended that the movement of increasing numbers of people from rural villages to

metropolitan areas has lead to increased feelings of alienation, and the destruction of a sense of community (Light & Keller, 1982). Urbanization is said to have removed individuals from nature and witnessing of the life/death cycle. It is also believed to have resulted in a decreased number of common rituals that help express feelings and guide behavior during death and bereavement (Kerr, 1978; Lifton, 1968; Rando, 1984).

2) Segregation of the aged and the dying

Dying today occurs mostly in hospitals (Feifel, 1977; Kubler-Ross, 1975; Manley, 1986; Mauksch, 1974; Rando, 1984; Sudnow, 1967). In 1890, only 20% of deaths took place in institutions whereas today nearly 80% do (Gonda & Ruark, 1984). The segregation of the aged and the dying into nursing homes and hospitals away from the rest of the population has transformed death into a foreign, solitary experience (Freeman, Brim & Williams, 1970; Lifton 1968). Aries (1974) observed that the ritual ceremonies of dying, once passed from the dying person to the family, are now passed directly to the hospital team. Glaser and Strauss (1965) noted that whether people chose to die in institutions, or whether families make those choices for them, outsiders wind up with the responsibility for care of the dying. Thus, there has been an "expulsion" of death from common experience, making it all the more difficult to confront when it occurs (Feifel, 1977).

3. The disintegration of the extended family

In the traditional extended family, different generations typically lived and worked together within the same household. The nuclear family by contrast is more isolated, and relatively free of other social bonds (Light & Keller, 1982). Fragmentation of family and kinship groups results in a decreased opportunity to experience the death of aged relatives as a natural part of the life cycle (Feifel, 1971; Lifton, 1968). Rando (1984) noted that increasing nuclearization of the family results in strong emotional attachment to fewer people. This diminishes the availability of emotional supports to cushion the impact of death when it occurs (Feifel, 1974; Howard & Scott, 1965). Such concentrated emotional investments render people victims of "high vulnerability" in bereavement (Pine, 1975).

4. Secularization from religion

Amenta (1986) noted that the purpose of all formal religions is to try to help people in their search for insight when they are forced to deal with existential questions provoked by suffering and death. Religion has been used to minimize the impact of physical death by focusing on immortality and the hereafter. As such, religion may be described as a coping mechanism (Amenta, 1986). A decline in religious belief characterizing death as the passage to a final reward reduces the meaning and purpose of death. Feifel (1971) asserted that in contemporary society, "fear of death reveals less concern with judgement, and more with total

annihilation and loss of identity" (p.4). Rando (1984) concluded that secularization from religion has resulted in the loss of an important coping mechanism for people when death and dying occur.

5. The deritualization of grief

Urbanization, the disintegration of the extended family, and secularization from religion have resulted in a decrease in the number of rituals practised to recognize death. And, while most of the literature suggests that well designed funerary rituals provide important psychological, social, and spiritual benefits for mourners (Cassem, 1976; Fulton, 1976; Keith, 1976; & Pine, 1976), funerary practices have been harshly criticized as being exploitive of the mourner's grief (Mitford, 1963).

How does the deritualization of grief affect one's ability to deal with death? Fulton (1976) believed that because traditional ceremonies help to express anger and anxiety, a decrease in such rituals will result in psychosomatic illness and aggression. Other researchers provide ethnographic evidence suggesting that as Americans move away from traditional funeral services, there is an increased risk of anger and aggression as these emotions tend to be more frequently expressed if funeral directors and clergy are absent (Rosenblatt, Jackson, & Walsh, 1972).

6. Advances in medical technology

Historically, hospitals were institutions for the poor and indigent, or those who were dying (Mauksch, 1975). Technological

advances have promoted a shift from the hospital as charitable institution to a place committed to restoration and cure (Feifel, 1974; Kubler-Ross, 1975; Mauksch, 1975). How does such a shift in orientation affect one's attitudes toward death?

Mauksch (1975) claimed that societies tend to "...endow the occupants of social roles and institutions with mandates which denote their purpose, their function, and their values" (p.8). The mandate for most hospitals is healing and recovery. Thus the patient whose disease cannot be cured is viewed as a failure of the mandate given to health care institutions, and the professionals who work there (Kubler-Ross, 1975; Mauksch, 1974). Kerr (1978) suggested that the occurrence of death becomes an "embarrassment" for those who presumably could have altered the course of events.

Degner and Beaton (1987) contended that because many effective treatment modalities are available, there is a deeply rooted belief in society that medical technology will eventually eradicate all disease. This results in aggressive treatment continuing until close to the time of death (Mumma & Benoliel, 1984). Casell (1974) and Rando (1984) argued that although advances in medical technology are able to extend life, the presence of such technology in modern society results in institutionalized, depersonalized care of dying persons. Technological advances have seriously compromised the ability to understand death as a natural part of human life (Rando, 1984).

II). Educational Preparation of Nurses in Care of the Dying

"Nurses have always had to deal with death because sick patients do not always recover" (Quint, 1967, p.10). However, a major shift in patterns of disease and treatment in the 20th century has influenced the nature of nurses' exposure to the dying process (Phipps, Buergin, Bauwens & Anderson, 1985). Chronic diseases such as heart disease and cancer are now the leading causes of death rather than acute infections (Gonda & Ruark, 1984). Because of the chronicity of disease, young people entering nursing have minimal exposure to or interaction with the dying (Degner & Gow, 1988a). Ironically however, nursing students are expected to deal with death as a "visible phenomenon" and to respond to it with effective, sensitive terminal care immediately upon beginning their education (Seidel, 1981).

People who work as health care providers are not born with an innate ability to provide skilled terminal care (Brim, Freeman, Levine, & Scotch, 1970). Thus, schools of nursing have had to provide some kind of training for this area of practice. That many staff nurses in hospitals feel ill prepared to cope with the problems of dying patients, and derive little personal satisfaction from these assignments, suggests that schools of nursing have not provided adequate training in this area (Fulton & Langton, 1964; Hoggatt & Spika, 1978; Quint, 1967). Preparing nurses to care for the dying is deemed to be an important part of nursing education, yet few nursing curricula adequately address this area of concern (Degner & Gow, 1988b; Eakes, 1986; Lev, 1986; Quint & Strauss,

1964; Wagner, 1964).

Research conducted by Quint in 1967 identified that nursing courses tended to give priority to the nurse's responsibilities for helping patients recover from illness or adjust to changes in daily living. Limited concern with dying was also revealed in schools of nursing by scheduling class discussions about care of the dying at the end of a course, assigning beginning instructors with the responsibility for leading such discussions, and failing to have an organized plan in place to ensure systematic assignment of students to care for dying patients (Quint, 1967).

Interviews conducted by Quint and Strauss (1964) with newly graduated staff nurses about their experiences as students suggested that preparation for care of the dying is far from standardized and, in most cases was lacking. After looking at schools of nursing to identify what customs, beliefs, and practices were taught about death, and how students are guided in this aspect of practice, Quint and Strauss (1964) discovered that: a) when instructors selected terminally ill patient assignments it was usually because the patient required the kind of care or treatment that the student needed experience with--the fact that the patient was dying was often secondary; b) some teachers equated terminal care only with the care given immediately preceding and following death; c) care of the dying was usually not judged to be important by the faculty.

The extent to which a nurse teacher is comfortable about teaching nursing care involving the dying patient is influenced by

his/her own personal experience with death. Because many teachers struggle with the unpleasant memories of distressing assignments they had as students, they are unable to teach about care of dying patients except in a stereotypical fashion (Wise, 1974; Quint, 1967). As a result, students may develop a stiff, impersonal manner when confronted with dying patients (Mervyn, 1971).

Field and Kitson (1986) were more optimistic about death education in schools of nursing. On the basis of survey information obtained from schools of nursing in the United Kingdom (n=192), these authors contended that the subject of death is now receiving serious attention in the curriculum. (Unfortunately, these researchers offered no information about the reliability or validity of their survey tool). Topics taught in the schools surveyed included attitudes toward death and dying, bereavement, communication with dying patients and their relatives, and physical therapy of the dying patient. While the schools in the survey were unable to precisely quantify the effect of death education on their students, most instructors believed that the students were less anxious, more aware of death related problems, and more confident with nursing the dying (Field & Kitson, 1986).

Current nursing research suggests that when course content dealing with care of the dying is offered in the curriculum, nurse educators prefer either an integrated or elective course approach without systematic assignment of students to care for dying patients (Degner & Gow, 1988b; Caty & Downe-Wamboldt, 1983; Yeaworth, Kapp, & Winget, 1974). The popularity of the integrated

approach to death education in nursing results in wide variability in the amount and type of education received within the same nursing program, and precludes determination of the amount and type of death education most effective in producing the desired outcome of improved nursing care for the dying (Degner & Gow, 1988b).

All prepared nursing students go on to become practising nurses who must care for people who are dying or bereaved. Caswell and Omrey (1990) asserted that "the lack of information on how best to achieve the quality of care desired for his or her dying patient may leave the nurse at a loss" (p.179). Eastham (1990) contended that nurses' stress in dealing with people who are dying or bereaved may be increased by lack of appropriate education and training. Popoff's (1975) survey report on death and dying involving 15,430 nurses who subscribed to Nursing 75 found that while some respondents experienced intensely gratifying rewards in care of the dying, almost 47% seldom or never experienced such gratification.

What is the outcome when students are offered courses in care of the dying? Degner and Gow (1988a) summarized the characteristics of 13 evaluations of death education following an extensive search of the literature. Evaluations conducted prior to that date suggested that death education may reduce anxiety and/or improve death attitudes in nurses, but the accumulated evidence is suspect owing to methodological problems (Degner & Gow, 1988a). These researchers conducted a longitudinal quasi-experimental study using one experimental group and two nonequivalent control groups

to evaluate the effectiveness of an integrated educational approach to death education. This approach included varying amounts of classroom and clinical exposure to death-related issues, and a required course that included planned clinical practice. A nonnursing control group was included to test for the effects of maturation on the two dependent variables, death anxiety and attitudes to care of the dying. Though response bias, reduced sample sizes at the time of the second posttest, and the nonequivalence of groups do pose threats to the validity of the study, results overall suggested that the students receiving an undergraduate palliative care course that included clinical practice had more approach behaviors in care for the dying one year postgraduation than did nursing controls. The precise "dose" of death education required in undergraduate programs has yet to be identified; however, it is clear that students need structured opportunities to learn about the delivery of terminal care.

III). The Environment and Philosophy of the Intensive Care Unit

Historical Evolution

Intensive care units first appeared in the U.S. in 1923 (Daly, 1980). Three major factors are believed to have contributed to the development of the intensive care unit concept. These include the advantage of continual surveillance of very ill patients, evolving surgical procedures that require extensive post-operative monitoring and observation, and a long standing interest

of hospital planners in developing hospitals with graded areas of patient care (Simon, 1980). Expanding medical technology in the 1950's and 1960's has also been identified as fostering the need for hospital settings designed specifically for the intensive treatment of critically ill patients (Quint, 1967).

Structure and Function of the ICU

The early intensive care units described in the literature housed patients in single rooms that were under direct visual surveillance of a nurse at a central nursing station (Simon, 1980). Strauss' (1966) study of the ICU environment found that structurally, ICU's were "literally carpentered" out of existing hospital space making them extremely crowded environments (p.8). Little has changed in the design of contemporary critical care units. They are still open wards that permit high visibility of patients. A vast array of equipment at the bedside continues to result in cramped quarters (Degner & Beaton, 1987; Martocchio, 1980; McGory, 1978; Michaels, 1971).

How does the structural design of the ICU affect the care of the dying patient? Martocchio (1980) argued that while open wards facilitate continual observation of patients (and hence early detection of deleterious changes), such high visibility results in a lack of privacy for dying patients and their families. Degner and Beaton (1987) specifically observed that patients "... in open units are sometimes exposed to the deaths of other patients although staff usually try to shield them from observing active treatment interventions such as resuscitation" (p.11). Crowded

conditions at the bedside tend to preclude the presence of visitors. Thus, "the dying person is more likely to be alone or surrounded by highly skilled well intentioned strangers, rather than families or friends" (Gorer, 1965; Martocchio, 1980).

Functionally, the intensive care unit has been described as an environment especially designed to provide lifesaving measures, life-sustaining supplies, equipment, and personnel resources (Lambertsen, 1968). Strauss (1966) defined the ICU as "the locale for patients who have a high potential for dying and in addition are worth saving or can be prevented from worsening" (p.8). Weisman (1980) described the ICU patient as occupying some kind of "sacred place". Caswell and Omrey (1990) argued that although dying patients require as much or more care than any other patient in the ICU, critical care medical guidelines dictate that such patients are low priority when allocating bed space. Clearly, ICU's are places oriented to saving lives rather than preparing people to die (Caswell & Omrey, 1990; Lambertsen, 1968; Quint, 1967; Wilson, 1990).

This curative, technological orientation affects the nature of nursing practice that occurs in the ICU, and ultimately, the nursing care that dying patients receive. Prior to world war two, the majority of nursing interventions carried out centred around direct physical contact with the patient (Quint, 1967). Quint (1967) contended that this contact was a source of great personal satisfaction for the nurse:

"... and even when the patient did not survive, the nurse had the opportunity to experience directly the feeling of having made a singular contribution to the patient's comfort and well being" (p.125).

Advances in medical technology have resulted in nursing practice that is more medically and procedurally oriented (Amenta, 1986; Strauss, 1966). It has been argued that such an orientation leads not only to the tendency to equate good nursing care with technical competence, but also to decreased attention to the psycho-social needs of dying patients and their families (Strauss, 1966). Martocchio (1980), Daly (1980), and Quint (1967) support Strauss' contention, but argued that technological advances have resulted in a depersonalized experience for the nurse as well.

IV). The effect of dying patients on ICU nurses

While the nurses' focus is to restore life, they must also reckon with those dying patients who are unable to be saved (McGory, 1978). Owing to the critical and unstable nature of the patients housed in intensive care, death tends to be a regular part of critical care nursing (Simon, 1980). The death trajectory of intensive care patients tends to be so rapid that there is no time for anything but the acute phase and death itself (Glaser & Strauss, 1965; Rando, 1984). Constant exposure to dying patients and their families subject nurses to repeated losses (McGory, 1978). Frequent deaths are believed to challenge the formation and maintenance of a professional identity (Daly, 1980). Manley (1986), Simon (1980),

and Sudnow (1967) suggested that death is frequently experienced by nurses as defeat and evidence of the failure of their skills. ICU nurses who are not able to shift from seeing the patient as "sick-curable" to "sick-dying" experience feelings of disappointment, anger and resentment, and may even experience the patient as resisting curative efforts (Simon, 1980).

It is not uncommon for nurses to employ communication strategies that prevent them from having to deal openly with a patient's impending death. The various levels of "context awareness" described by Glaser & Strauss (1965) allow nurses to effectively avoid the frustration and death anxiety that dying patients may generate. Unfortunately, such behavior blocks both the patient's grief and the occurrence of any meaningful nurse-patient communication.

Glaser and Strauss (1965) identified that many health care providers are left with the feeling that there is "nothing more to do" when it becomes evident that patients will not recover. Yet, this "nothing more to do phase" is believed by these researchers to be a crucial period because:

...at its inception the fundamental goal for the patient changes from recovery to comfort. As a consequence, the activities of the staff change radically. Before this phase begins, the staff focuses its efforts on saving the patient with all available means. Afterward saving efforts are superfluous to the goal of comfort. With a change in goals comes a change in rewards from patient care (p.178).

Sadly, the provision of comfort care for patients who are "dead in anticipation" is deemed by many health workers to be very unrewarding (Glaser & Strauss, 1965).

V). The Family of the Dying Patient

Families are often viewed as a system in which the sum is more than the total of its parts (Ferszt & Houck, 1986). "Anything that affects the system as a whole will affect the individual members, while anything that affects the individual members will necessarily affect the family as a whole" (Rando, 1984, p.327). Thus, the death and dying of one family member extends beyond that member to rest of the family.

The families of dying patients labor under incredible stress (Ferszt & Houck, 1986). They need to cope with the impending loss of their loved one until it becomes a reality, and then face the further crises of bereavement (Maddison & Raphael, 1972; Martocchio, 1980). Research investigating the needs of families of critically ill patients rate information needs and the need for reassurance as being most important to them (Daly, 1984; Hampe, 1975; Kristjanson, 1982; Leske, 1986; Molter, 1979). Intensive care nurses are in a key position to meet these needs, and to help families deal with their losses (Collins, 1989; Eastham, 1990; Krozek, 1991; Farrell, 1989; Waters, 1986; Webster, 1986; Wright, 1985; Caughill, 1976). While most nurses believe it is their duty to help support family members (Michaels, 1971), the literature suggests that nurses find such activity distressing (Bowland, 1977; Loch, 1977; Martocchio, 1980; McGory, 1978; Michaels, 1971; Quint, 1966; Strauss, 1968).

Richmond and Craig (1985) believed that sharing feelings of frustration and helplessness that result from constant exposure to

dying patients and their families may be seen as a violation of ICU staff culture. Consequently, nurses develop self-protective strategies that diminish their ability to provide humane care (Richmond & Craig, 1985; McGory, 1978). Several distancing tactics that critical care nurses use to minimize their interaction with the family members of dying patients have been identified in the literature. These include enforcing stringent visiting hours as a legitimate means for keeping families away from the bedside (Martocchio, 1980; Strauss, 1966); using impersonal professional jargon when talking to families (Kneisl, 1968); reassuring visitors that they are not needed because the patient's care is really dependent upon the use of complicated machinery (Martocchio, 1980); and retreating into technical detail when the family is at the bedside in order to give the appearance of being too busy to answer questions (Strauss, 1968).

VI). Nursing behaviors in care of the dying from the literature

A systematic search was conducted to identify behaviors described as central to care of the dying generally, and in ICU in particular. Both research and clinically based articles were included. Nursing behaviors mentioned by authors as being important in care of the dying in the ICU were written on cards and attached to each article. Similar behaviors were grouped and given a single title (See Table 1). Authors identified both positive and negative nursing behaviors in the literature, but because descriptions were often vague or broad, the extraction of specific

behaviors was somewhat difficult. Notable exceptions were the articles by Caswell and Omrey, 1990, and McGory, 1978.

The clusters of behaviors identified are 1) Comfort care; 2) Patient feelings; 3) Nurse feelings; 4) Support colleagues; 5) Patient rights; 6) Family care; and 7) Manipulation of the environment. These categories of behaviors are analogous to the categories identified from the literature review conducted by Degner, Gow, and Thompson (1991). One new category that emerged from the literature that was not identified by Degner and her colleagues was #7) Manipulation of the environment.

Summary

Several factors militate against adequate care of the dying in hospital. Whether in the role of patient, family member, or care giver, the majority of people in death-denying societies operate from the premise that death is an adversary to be conquered at all costs. This pervasive attitude coupled with burgeoning technological advances has legitimized protracted, aggressive medical intervention until close to the time of death. Hospitals generally, and intensive care units in particular, are environments committed to the recovery process. Dying patients and their families serve as potent reminders to hospital personnel of their inability to meet the organizational mandate of cure. Nurses and physicians often experience extreme guilt and a sense of failure when patients under their care do not recover. Distancing

tactics may be employed by nursing and medical staff to buffer the distress they experience when interacting with dying patients and their families.

Literature suggests that while nursing education prepares students to adequately perform routinized hospital activities, it has failed to teach them how to provide psycho-social care for the dying. Routine hospital orders and activities are not meaningful when implemented for the dying patient, and cease to be meaningful to the people doing them or to the patients who receive them (Mauksch, 1975). The identification of detailed, individualized nursing interventions are essential if nurses hope to be able to deliver skilled and sensitive terminal care to dying patients.

CHAPTER III

CONCEPTUAL FRAMEWORK

Two theoretical perspectives provided the framework for this study. They were: 1) Quint's research based perspective of how nurses learn to care for the dying, and 2) the Dreyfus Model of Skill Acquisition.

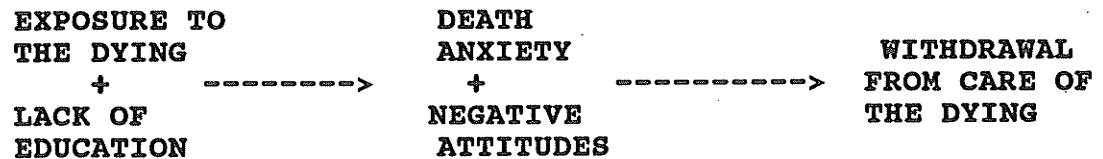
Quint's Perspective

Quint's (1967) perspective is rooted in the framework of symbolic interaction theory which assumes that human behavior and the appraisal of the self are shaped, controlled and altered through interactions with other persons (Chenitz & Swanson, 1986; Quint, 1967). Blumer (1966) noted that symbolic interactionism rests on three basic tenets:

- 1) Individuals act toward things on the basis of the meaning these things have for them;
- 2) Meanings of things in life are developed through social interactions with others;
- 3) Individuals handle or modify meanings through an interpretive process. The individual points out meaningful things to themselves and transform these meanings in relation to the experience.

Quint (1967) maintained that nurses would adopt the behavior of other health care professionals around them and limit their involvement in death related situations if they were exposed to care of the dying without accompanying educational support (See Figure 1). In contrast, if nurses were to receive systematic death education with planned assignments, Quint (1967) suggested they would be less likely to withdraw from care of the dying.

FIG. 1. Quint's Theoretical Model

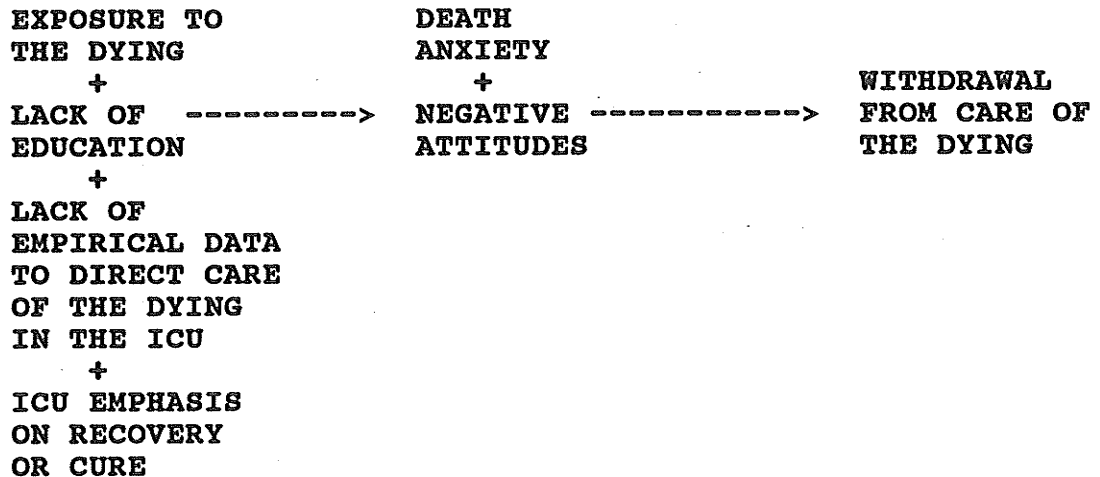


Quint's orientation has not been tested systematically (Degner and Gow, 1988), but her perspective has been supported by empirical studies conducted by Perlman, Stotsky, and Dominick (1974), and Shusterman and Sechrest (1973). Perlman et al. (1974) found that nursing personnel with less experience demonstrated a more open and direct approach in caring for the dying more than experienced colleagues did. The more experienced nurses in Shusterman and Sechrest's study (1973) tended to be more satisfied with traditional ways of managing the dying such as isolating them from

other patients and nor informing them of their true prognosis.

Based on a review of the literature dealing with the nature of intensive care nursing, Quint's model has been revised to reflect additional factors that make care of the dying in the intensive care setting problematic (See Figure 2).

FIG. 2 REVISED THEORETICAL MODEL



The Dreyfus Model of Skill Acquisition

Attempts to describe the cognitive processes involved in making judgments by comparing the methods and solutions of novices and experts in a given problem domain have been documented in the

psychological (Larkin, McDermot, Simon, & Simon, 1980), medical Swanson, 1981), educational (Carter, Cushing Pinnegar, & Berliner, 1988), and nursing literature (Westfall, Tanner, Putzier, & Padrick, 1986).

Berliner (1987) noted that while definitions of expertise commonly mention the term experience, the two are not synonymous. Rather, experience is necessary but not a sufficient condition for expertise. A comprehensive review of the literature about the nature of expertise by Chi et al. (1988) identified that experts across all fields possessed certain characteristics. They tended to excel mainly in their own domains (Johnson et al., 1981; Minsky & Papert, 1974), and saw large meaningful patterns there (Chase & Simon, 1973; deGroot, 1966). They solved problems and performed tasks quickly with little error as compared to novices, and appeared to have superior short-term memory and long-term recall (Chase & Ericsson, 1982). Experts tended to spend a great deal of time analyzing a problem qualitatively to try and "understand" it prior to attempting to solve it. Novices by contrast plunged right in (Chi, 1988). Finally, experts tended to have a greater awareness of when they made errors, why they failed to comprehend, and when they needed to check solutions than novices did (Chi, 1988).

Dreyfus and Dreyfus (1986) suggested that clinical judgment

could be thought of as a cognitive skill, and they developed a theory of skill acquisition which delineated five stages of performance based on increasing levels of clinical experience (Belognia Le Breck, 1989; Benner, 1984). Belognia Le Breck (1989) succinctly described the theory's five stages:

The first of the five stages of development is called novice. A novice recognizes objective facts and features relevant to the skill but does not see them in reference to an overall situation. The novice performs by following memorized rules. Advanced beginners in the second stage start to identify aspects of clinical situations as part of their previous experience and combine them with classroom knowledge to govern performance. The third stage is called competence. As the nurse identifies more elements of situations as important, the number of elements becomes overwhelming. Competence is characterized by the imposition of a hierarchical plan of organization on the situation so that the most important problems are dealt with first. Proficiency is the fourth stage of skill development in the Dreyfus theory. The proficient nurse does not select among alternatives but, being deeply involved in the task, reacts to a pattern of salient features in the environment developed on the basis of experience. The intuitive ability to use patterns without the need to decompose them into competent features is called "holistic similarity recognition by Dreyfus and Dreyfus (1986). The proficient nurse uses this process to intuitively recognize and understand a task, but uses detached analysis to decide on a course of action. In expertise, the final stage, holistic similarity recognition completely governs performance. The patterns of salient features of experts become associated with correct actions; i.e. experts just "do what works". Experts group together situations with similar patterns of features, actions, and goals. When a new situation is unconsciously recognized as similar to a category of past situations, an action comes immediately to mind (p.44).

Dreyfus and Dreyfus (1986) asserted that the path to excellence in performance was the result of the successive transformation of the four mental functions: 1) recollection; 2) recognition; 3) decision; and 4) awareness (See Table 2).

Table 2

Skill Level	NOVICE	COMPETENT	PROFICIENT	EXPERT	MASTER
Mental Function					
Recollection	Non-situational	<----- Situational----->			
Recognition	<---Decomposed--->		<-----Holistic----->		
Decision	<-----Analytical----->			<-Intuitive-->	
Awareness	<-----Monitoring----->				Absorbed

They explained that each row in Table 1 represented a form of mental function. In column one (i.e. NOVICE), all four forms are

in their primitive state, and in each subsequent column, one additional form has been transformed into its sophisticated state. The result is five columns, each one corresponding to the five stages of mental activity involved in skill acquisition.

Benner (1984) used Dreyfus' theory to describe data from interviews and participant observation of novice and expert nurses. and stressed the importance of context in studying nursing decisions (Belognia Le Breck, 1989). Both Benner and Dreyfus stressed the importance of context when studying expert performance: "...judgement must be studied in a particular context to be able to identify the pattern recognition process characteristic of expertise" (Belognia Le Breck, 1989, p.45).

Criticisms of the Dreyfus Model

The Dreyfus theory of Skill Acquisition focused on the practice of real clinicians and emphasized experience, context and pattern recognition. These are factors which have been recognized by other researchers as important in the development of expertise (Anderson, 1985; Larkin, McDermot, Simon & Simon , 1980). It has however been criticized for not providing a more comprehensive description of the cognitive processes and changes that occur with skill development (Belognia Le Breck, 1989).

Belognia Le Breck (1989) commented that the Dreyfus theory in "... its almost mystical descriptions and insistence on the uniqueness of each case make research in support of the theory difficult to design" (p.45). Benner (1984) countered this argument by equating the Dreyfus theory to Gestalt psychological accounts of problem solving by means of insight:

It is possible to describe expert practice, but it is not possible to recapture from the experts in explicit formal steps, the mental processes or all the elements that go into their expert recognitional capacity to make rapid patient assessments (p.42).

Despite its criticisms, the Dreyfus Model is still appropriate to use in attempting to study expert nursing behavior. Benner (1984) contended that the nursing profession could benefit from experts recording and describing critical incidents from their practice that illustrate expertise or a breakdown in their performance because "...when experts can describe clinical situations where their interventions made a difference, some of the knowledge embedded in their practice becomes visible" (p.36).

Summary

The theoretical orientation for this study was derived from Quint's (1967) study of how nurses learn to care for the dying, and the Dreyfus Model of Skill Acquisition. Quint's work though not

investigated systematically was research based. The Dreyfus model (1986) had the advantage of examining the performance of real clinicians, and has lead to relatively detailed theoretical descriptions when applied to nursing phenomenon (Benner, 1984).

CHAPTER IV

METHODOLOGY

Research Design

Of the many choices of research design that may be selected to investigate a problem, some are more appropriate or feasible than others (Polit & Hungler, 1987). Brink and Wood (1989) noted that the selection of a research design is based upon the level of knowledge about the topic being studied. Given the limited body of knowledge about what constitutes expert care of the dying in the ICU, an exploratory-descriptive design was used to answer the questions posed in this study.

Several assumptions have been identified as being implicit in the use of exploratory-descriptive designs (Brink & Wood, 1989). This study met those assumptions. First, care of the dying behaviors existed in the ICU nursing population, and were amenable to description. Secondly, there was little literature describing critical nursing behaviors in care of the dying from an ICU nurse perspective. Finally, the relevance of and rationale for the study were well supported by the literature.

METHODS

Sample

The purpose of this study was to describe "expert" nursing behaviors in care of the dying. Sample selection was carried out using a deliberate process that represented this perspective. Purposive sampling achieved the goal of selecting the "expert"

participants needed for the study. This sampling technique helped ensure that the sample selected was appropriate (i.e. facilitated understanding of the research problem) and adequate (i.e. the data obtained from the study was relevant and complete) (Morse, 1989).

A purposive sample of 10 intensive care nurses identified as expert in care of the dying by four or more of their colleagues was drawn from the intensive care units at one tertiary care facility (St. Boniface Hospital) and one community based hospital (the Victoria General Hospital). Previous research has shown that a sample size of 10 subjects is sufficient in conducting qualitative studies because data usually become redundant and no new categories of behavior are identified by using additional subjects (Munhall & Oiler, 1982). Because purposive sampling facilitated the inclusion of "certain types" of informants with "certain knowledge" sample selection in this study was admittedly biased. However, unbiased randomly chosen samples violate the qualitative principle of obtaining information from experts (Morse, 1989).

Tool for Recruiting Nurse Experts

The tool used to identify nurse experts in care of the dying adult in the intensive care setting was developed using Benner's (1984) descriptions of nurse expert attributes; Hiss, Macdonald and Davis' (1978) research identifying physician educational influentials in small community hospitals; and descriptions of optimal nursing behaviors in the delivery of terminal care from the critical care literature (Appendix A).

Attributes of nurse experts identified by Benner (1984)

included:

- the ability to make clinical judgements or manage complex situations in a truly remarkable way
- possessing a vision of what is possible in patient care situations
- having an intuitive grasp of each patient care situation and being able to zero in on the accurate region of the problem without wasteful considerations of unfruitful, alternative diagnoses and solutions

Hiss, Macdonald, and Davis (1978), dissatisfied with the traditional approaches to continuing medical education, developed a methodology to quickly and accurately identify educational influential physicians within community hospitals and to describe the personal characteristics that distinguish these individuals. These authors believed that the informal communication network which exists in the social structure of a hospital can serve as a possible method for delivering continuing medical education. Educational influential physicians serve to diffuse new knowledge and skills throughout the social structure, and serve as a "resource lender" or "process helper" when changes in the practice of medicine are being introduced.

Hiss et al. (1978) analyzed the responses of 394 practising physicians about their concept of a physician who is influential with his or her colleagues in matters of education and patient care. Factor analysis of the entire questionnaire resulted in the placement of the items into three factors. These factors

were labelled: communication, humanism, and knowledge. Cronbach's alpha computed to determine the reliability of each factor ranged from .76 for the humanism factor to .85 for the knowledge factor.

The nine top items reported by respondents were used to construct three carefully worded statements, one statement for each of the three basic factors which characterized an educational influential (E.I.). It is composed of three statements which describe the characteristics of an E.I., and the responding physicians are asked to name colleagues who match this description.

An annotated bibliography completed by this investigator focusing on care of the dying adult in the intensive care unit identified seven categories of general nursing behaviors. Those behaviors mentioned most frequently as being important in delivering optimal terminal care (i.e. facilitating the transition of dying patients from curative to palliative care; sensitivity to the needs of the family members of dying patients; and the ability to engage in frank, open communication with dying patients, their families, and other health care team members) were included with Benner's (1984) exemplars of nurse expert attributes to formulate the paragraphs used to identify nurse experts in care of the dying.

Interview Guide

A semi-structured interview guide was developed to elicit from intensive care nurses a description of the behaviors they associated with positive and negative attitudes to care of the

dying (Appendix B). Sellitz, Wrightsman, and Cook (1976) stated that the less structured interview is a useful approach when an investigator wants to determine how a respondent conceptualizes a topic. Guba and Lincoln (1981) suggested that the interview is more likely to elicit accurate responses on sensitive topics, thereby providing a more complete picture of the participant's world view than other forms of inquiry.

During the course of the interview, nurses were asked to describe the most recent incident they could remember in which a student or a colleague had a positive attitude: Was it something the student or colleague did or said? What were the consequences of the behaviors identified? The same approach was repeated a second time, but the subjects were asked to describe an incident in which a student or colleague had displayed a negative attitude to care for the dying.

Procedures

In the first procedure, the investigator met with the Unit Manager of the intensive care unit at the Victoria Hospital, and the Director of Critical Care Services at St. Boniface Hospital to explain the proposed research project to them, and determine their interest in it. The head nurses from both the medical and surgical intensive care units were present at the meeting the investigator held with the Director of Critical Care Services at St. Boniface. At the time of these meetings, the ICU at the Victoria Hospital did not have one person designated as "head nurse" of the unit, rather,

different staff members took turns rotating through this position.

Arrangements were made with both head nurses and the unit manager for the investigator to attend the next regularly scheduled staff meeting at their respective facility. During the meeting, the investigator provided the nurses with a brief description of the study, and handed out the tool designed to identify nurse experts. The voluntary nature of staff participation was stressed. Extra copies of the tool were left in the unit for nurses who did not get a chance to attend the staff meeting. A brief explanation of the study was also left in each unit along with the investigator's phone number. Completed forms were placed in an envelope located on the unit. The investigator returned to the units approximately two weeks following the staff meeting to collect the forms.

The forms were reviewed to determine which individuals were nominated by their peers four or more times as being "expert" in care of the dying. The investigator then returned to the units in order to obtain the addresses and phone numbers of the nominated sample. This was done in such a way as to protect their identity (i.e. at St. Boniface, the researcher was given the list of phone numbers of all staff, and was left alone to copy those required; at Victoria Hospital, the unit manager called up the addresses and phone numbers of all staff on her office computer. She then left the researcher to copy the required information and "log out" when finished).

Experts nominated by their peers were contacted by telephone to determine their interest in participating in the tape recorded

interview portion of the study. Mutually convenient times for the interviews were set up. Participants were informed at the time of the initial telephone contact that the interview would take from one to two hours to complete. All interviews were conducted in the respondent's homes. Two interviews were conducted at the kitchen table, seven in a living or family room setting, and one in an office in the basement within the home.

Prior to beginning the actual interview, each subject was asked to complete an information sheet designed to collect biographical information related to age, gender, educational background, and work experience (Appendix C). Participants were also given a form to read explaining the nature of the study (Appendix D). This form reiterated that participation in the interview was voluntary, that the data were confidential, and that reporting of the research findings would be done in such a way as to maintain the anonymity of the participants.

Asking subjects in the interview to reflect on past experience results in an uncovering of "remembered experience" as opposed to pure experience (Oiler, 1982). In order to control the bias that occurs in reflective activities, a process of bracketing (i.e. a pulling away of layers of facts and theories) was used by the interviewer. Questions such as "What do you mean by that?" or "What did you think when that happened?" helped bring the subject's experience into clearer focus during the interview.

Strategies used to facilitate trust and openness during the interview included maintenance of eye contact, an open body

posture, and the use of summative statements to clarify and understand the subject's point of view. Notes were not routinely taken during the interviews, however key words or phrases were occasionally jotted down by the investigator to help track themes. Subjects were informed that some writing by the interviewer might occur during the course of the interview. This activity did not appear to distract them.

In the second procedure, a comprehensive review of the literature was conducted to identify behaviors described in the nursing literature as central to care of the dying (Table 1). Both research based articles and clinically based articles were included. All nursing behaviors mentioned by authors as important in care of the dying were written on cards and attached to each article. Similar behaviors were grouped and given a single title. The vagueness with which some articles were described in the literature made them difficult to extract. Notable exceptions were the articles by Caswell and Omrey, 1990, and McGory (1980).

ETHICAL CONSIDERATIONS

Protection of Human Subjects

Human rights were protected in this study in the following manner:

- 1). Approval to carry out the study was obtained from the University of Manitoba School of Nursing Ethics Committee, St. Boniface General Hospital, and the Victoria General Hospital.

2). All subjects agreeing to participate in the study were instructed of the voluntary nature of their participation. Agreement to be interviewed constituted informed consent. Subjects who were interviewed were given both a written and verbal explanation of the purpose of the study (Appendix D). They were also provided with phone numbers with which they could contact the investigator or the advisor should they have any questions or concerns once the interviews were completed.

3). Confidentiality of the data was maintained as the only individuals having access to the gathered data were the investigator, the thesis advisor, and the individual hired to transcribe the tape recorded interviews. The interview audio-tapes and verbatim interview transcripts were stored in a locked drawer at the St. Boniface Hospital Research Centre.

4). The identification of participants who agreed to complete the form identifying nurse experts from among their colleagues was kept anonymous (i.e. they did not write their name on the form to identify it as their own). Code numbers were assigned to all subjects interviewed. Pseudonyms or general terms such as the patient and the nurse were substituted to illustrate the behaviors described by respondents in the interviews.

5). Because death in the ICU can be associated with strong feelings of anger, guilt, and frustration, the recollection of

vivid events surrounding terminal care had the potential to be disconcerting for the subjects. The investigator planned in advance to remain available to the subject should he/she become upset, and to offer to talk with him/her. Subjects always had the option to terminate the interview if they found the material being discussed too distressing.

Data Analysis

Wilson (1987) noted that "when a study involves open-ended, nonnumerical data collected through interviewing... the researcher is faced sooner or later with making sense of this mass of heterogeneous data in relationship to the study's central questions" (p.399).

The biographical information collected from subjects who were interviewed were analyzed using descriptive statistics. All tape recorded interview were transcribed verbatim. Constant comparative content analysis was used to analyze the data from the interviews. A procedure used by Degner and Beaton (1987) was used to achieve reliability through consensus. The first five interviews were read independently by the investigator and thesis advisor to identify essential behaviors. The behaviors were written on cards to achieve consensus in wording and meaning. Next, all behaviors were compared and clustered into categories that appeared to provide the best explanation of the data. Operational definitions were written for each category. Each of the interviews was coded into operationally defined categories. All of the coded data was then

extracted from the original interviews and organized under each of the final categories that emerged. Descriptions of the critical nursing behaviors identified from the interview data, and the inferences made from it were checked against the original data by the investigator's thesis advisor.

As a final check on validity, a preliminary draft of the results was distributed to study participants for their critique. This method, identified by Morse (1989) as confirming, helped to ensure that the data were complete and all parameters of the experience were described.

Issues of Validity and Reliability

Most exploratory designs pose problems for reliability (Brink & Wood, 1989; Leininger, 1985; Morse, 1989). Sellitz, Wrightsman, and Cook (1976) explained that in qualitative research "reliability is concerned with the consistency, stability, and repeatability of the informant's accounts as well as the investigator's ability to collect and record information accurately" (p. 169). In order to help ensure that the answers given by the informants were similar, the researcher asked the same question in a variety of ways during the interview (i.e. "What are the most important things that a nurse must do in caring for a dying patient in the ICU?" and "Tell me about the things you have done or have seen colleagues do for a dying patient that you felt were very important"). This helped to establish the equivalence of the data (Brink & Wood, 1989). Additionally, interviews were conducted in environments of the

subject's own choosing. Field and Morse (1985) stated that interviews conducted in such settings enhance the reliability of the data because it minimizes some of the environmental constraints and allows participants to feel comfortable and in control. Methods to achieve reliability during data analyses have been discussed elsewhere.

Concurrent pragmatic validity was built into the design as more than one method of data collection was used. The information obtained through an interview with one expert informant was verified by asking other experts about the same content (i.e. "one of the other nurses I have interviewed for this study sees basic hygiene and the basic things we learned in nursing school as being really important in caring for the dying. Do you see it that way too?") Interviews were tape recorded to provide an alternate form of data recording other than investigator memory (Morse, 1989). The transcription of the interviews verbatim also helped reduce subjective interpretation of the data.

Limitations of the Study

The following limitations were placed upon the study:

1. Owing to the nature of sample selection used in this study, the findings are not generalizable to all critical care nurses. Additionally, all subjects were Caucasian, and only one subject was male. Different perspectives in care of the dying may have been identified with more heterogeneous group of experts.

2. The choice of a face to face interview as a strategy to collect data meant that the interviewer's verbal and non-verbal reactions to the experiences subject's recounted had the potential to influence the tone of the interaction. Though the investigator tried to remain as objective as possible, past experience in intensive care nursing presupposed an inherent set of biases and expectations about nursing care that should or should not occur.

3. A weakness of this study owing to the exploratory design used is its lack of replicability. Brink and Wood (1989) noted that "no single researcher can return to the same subjects, ask the same questions, and receive the same answers. Persons change their minds, their beliefs, and positions as a result of new experiences. Therefore, the same researcher will not achieve perfect reproducibility from the same informants over time (p.147).

SUMMARY

10 intensive care nurses identified as experts in care of the dying adult by their peers were asked to describe situations in which a student nurse or nursing colleague had displayed very positive or very negative attitudes in care of the dying. Characteristics of the sample were analyzed using descriptive statistics. Transcribed interviews were examined using content analysis. The following two chapters present results and discussion of these findings.

CHAPTER V

FINDINGS

Chapter 5 includes a discussion of the findings from the study. The characteristics of the sample are described, and the six categories of critical nursing behaviors in care of the dying adult in ICU that emerged from the data are discussed.

Characteristics of the Sample

A purposive sample of 10 ICU nurses identified as "expert" by their peers in care of the dying participated in this study. Subjects ranged in age from 27-44 years. Nine of the ten subjects were female. Subjects had an average of 9.6 years of experience in intensive care nursing, with a range from 4-15 years. Seven subjects had a registered nursing diploma, two had a post-diploma degree in nursing, and one had a generic baccalaureate degree in nursing. Seven of the ten subjects had completed an Intensive Care Nursing Program.

The descriptions of the six categories of nursing behaviors identified in the study were written by the investigator using the coded interview data. These descriptions were checked against the original data by the advisor and appropriate revisions were made. As a final check on the validity of the inferences being drawn from the data, the preliminary draft of this chapter was distributed to the respondents in this study for their critique. Final descriptions of the six critical nursing behaviors are summarized in Table (2).

Responding after death has occurred

Three major themes emerged regarding nursing behavior after the patient had died. These included creating a peaceful, dignified bedside scene for survivors, supporting the realization that death had occurred, and demonstrating respect for the corpse during post-mortem care.

1) Behaviors designed to create a calm, dignified bedside scene for survivors.

The majority of nurses interviewed indicated that it was important to create a peaceful, dignified bedside scene for survivors who returned to the unit once their loved one had died. Such an atmosphere was achieved by a) modifying the appearance of the patient; and b) attempting to modulate the noise level in the unit when grieving families were present.

a) Modifying the appearance of the patient

It was important to nurses that the deceased looked comfortable, and "as much like themselves" as possible. Subdued lighting, and the removal of endotracheal tubes and invasive lines were cited as important in achieving this goal:

A dead patient always looks sort of ghastly anyhow, pale and waxy, the jowls kind of hang and stuff. I can't remember what patient I had recently...but I happened to peek behind the curtains before the family was coming in, and it was a really dim day and I thought I would put my light on. So I turned on the lights and I thought, oh God, that lady looks terrible with those lights on. Better that they come into sort of a dark, quiet place than have all those lights on and stuff.

I think just removing lines if possible. I mean families really don't want to see that. Just washing them off, finding their false teeth if they had them and putting them in. And make them look like they look comfortable. Often when families see them with all their tubes in and the majority of them could be taken out, like hide some of the tubes. Like make them look like they did before. I think they feel better about it.

Well you just try to make them look as comfortable as possible... I just try to tidy them up and they look as peaceful as they can for the family coming in and often its hard because some of the tubes can't come out. You'd like to just rip everything out and make them look nice but....

One respondent was ambivalent about doing interventions after death had occurred:

I know that there's a group of individuals that think that we shouldn't be doing all that, we should be leaving pipes and tubes exposed to help families realize that we did everything we could and so on. And I have mixed feelings about that and that might,... I'm not really in complete disagreement with that. You know, most of these people are around the patient when they are dying so they've seen this stuff. So now all of a sudden, they come into the room and you've dimmed the lights and chased everything away, I mean, what are you trying to hide... So I think its kind of futile.

b) Modulating the noise level

I: You try and respect the family but it's hard when there's another patient in another room and there's laughing in one corner. I mean that's the reality of it all and you can't stop what's going on because life continues.

R: Is there anything that you do or that you can do to make that cubicle where the dying patient is, you can kind of buffer the environment?

I: We usually pull all the curtains and some people put a sign out that says please be quiet. Mostly everybody, because they have report at the beginning of every shift, they know what's going on, which patients are passing away, and they try to be quiet.

The one thing that I find really difficult in the unit because of the physical proximity, back to another question, is the fact that your patient and your family may be dealing with one of the most major things that ever happened in their life, they're all standing at the bedside grieving and crying. And there's all sorts of laughing and kibitzing going on in the rest of the unit. That makes me very embarrassed and ashamed for that family and yet at the same time it's no one's fault, it's just... So within reason I try and sort of nicely sort of say to the rest of the staff that Mr. Smith's family is pretty upset and grieving at his bedside, could you maybe see if your visitors could go out to the waiting room.

The other part that I think must be very hard for the families, because life goes on, ah, the smiles on other people's faces, or the laughter in the unit, and this one's grieving....It's almost like, can you guys shut up here, this person is dying, what is the matter with you, have you no sensitivity, what are you laughing about?

2) Behaviors designed to support the realization that death has occurred.

Nurses also felt that it was important to support the realization that death had occurred. This was achieved in part by allowing the family adequate time to be alone with the body:

And then I'll just let them sit there for as long as they want. If they want to sit there for 6 hours they can sit there for 6 hours because I think it is important that they come to grasp what's happening so.....

Um, that's basically, and I always tell them to take as much time as they want, if they want to go out and then come back in, to let me know. If one family member wants to spend some

time alone, then that's easy to facilitate.

Some nurses felt annoyed and angered when staff members seemed judgemental of the amount of time families stayed at the bedside with the body:

They just have to realize that this is how it is, you know and uh, you can't push the family. That's not fair and it really annoys me when we do try to push them out because they need that time and most families don't stick around that long.

Everybody was frustrated with this son because he wouldn't leave. And we had an admission in emergency waiting to come into that bed you know... It's sometimes, at points it almost reminds you of a meat market, the bed is barely cold and already they have another body for it. And everyone was getting quite annoyed with me because I was letting this fellow stay so long... One girl suggested that I just get Security. And you know I found that, that made me really angry because I didn't think, I suppose I was being very indulgent but his father had just died, when shouldn't you be indulgent.

Some nurses felt that it was important to remove hysterical family members from the deceased's bedside because their emotional reactions had the potential to negatively effect the rest of the patients in the unit:

What she had a terrible time with, it was at the end of course. She didn't want to let go of his hand because she knew if she let go it was final and she couldn't. But she just.... the heart-wrenching sort of moment for her, and screaming at that time that she didn't want to let go and being in an open unit and not having privacy...ah, was very difficult because 2 fresh cardiac admissions were just coming in on the other side. I was trying the best to get a family member in, at that time, to get her out because it wasn't helping anybody at this time.

Such distraught family members were also encouraged to

verbalize feelings, once they were calmer:

Then...she had calmed down and I have a tendency to try and get them to reminisce of the good times, and she discussed a recent trip and what a good time they'd had.

Providing survivors with information about funerary arrangements and bereavement support services was also identified as being helpful in supporting the realization that death had occurred:

Particularly with people who aren't religiously oriented and they suddenly...it's like when you're getting married and they don't know what to do because you didn't go to this church and you've got to get yourself married somehow. Same thing when they die, they're not quite sure what the, what they're going to do... they don't have a minister and that you know, and just explain to them that there are people out there who just ah, they'll take care of everything for you and sort of trouble shoot for you...

We've had family members call and say, "I can't handle, I don't know what to do"... well, I'll get you in contact with some services to help you out... It doesn't have to be because you're out the door that we've forgotten completely about you.

3) Behaviors that demonstrate respect for the corpse during post-mortem care

In addition to creating a peaceful bedside scene, and supporting the realization that death had occurred, nurses felt that it was important to demonstrate respect for the corpse during the provision of post-mortem care. For some nurses, this meant talking to the body while preparing it to go to the morgue:

I just usually tell the patient what we're doing now. You've passed away and now we're going to wrap you up.

Oh, I just say things like I'm going to wash your face here, I'll just tuck this under here and let's get a clean gown on you, and I just do, I mean I have always done that.

So many people are so, I don't know, like the patient has died and they forget that they still are a person and I always talk to them like we're going to take these tubes out and I'm going to clean you up and cover you up, because if it was my Mom or Dad lying there I would want people to respect them right to the end sort of thing.

Other nurses never or rarely talked to the body:

R: Do you talk to the individual when you're doing post-mortem care?

I: No. Only maybe in a rare, the rarest of times when I got especially attached to somebody. I might have said a three word sentence or something, you know, just I can't recall, it may have been, just like a.....

R: Like a closure, like a good-bye to someone?

I: Yeah, real quick like that. Usually once they've gone, I have to admit I keep it pretty impersonal.

Nurses identified the importance of unhurried, gentle handling as a means of demonstrating respect for the corpse, and they were upset when brusque, rough handling occurred:

I don't like their heads dropped when they're being put on the guernsey, Ah, I guess part of it for me, is that I wouldn't want my Mom or my Dad or what ever treated like that. And ah, I guess it's not so much self, because I wouldn't know, and I've said to one of the porters, just think if that was your Mother, you know.

I: Even though you don't know them or you may not have not had a chance to know them um, what you do 2 minutes before they die as opposed to what you do for them after they've just passed away, that shouldn't change. Do you

know what I mean?

R: It's a continuation of the same process.

I: Exactly, oh, this person's gone. It's one less person on the unit sort of thing, you know. Because you can get into, if it's a very busy time on the unit and you're short staffed and that, you know you can be very inhumane to that person sometimes just about rushing them out and down to the morgue kind of thing. Okay, so I think you should be very sensitive to that person and treat them as you would anybody else..

It really distresses me and although, rationally and intellectually the body is just a package and I'm perfectly comfortable with that, I still think that they're ... it's a package that you treat with respect.

Responding to the family

Two major themes emerged regarding the response of the nurse to families of dying patients. These included a) behaviors responding to the need for information, and b) behaviors designed to reduce the potential for future regret.

a) Behaviors responding to the need for information

Nurses felt it was imperative to respond to the family when they demonstrated a need for information. Subjects in this study indicated that family information needs tended to include the need to know about the present course of treatment, and the patient's response to it.

Nurses noted that they spent a great deal of time giving explanations to families. They recognized the need for repetition of information given the variation in individual family members level of understanding and acceptance of the patient's condition:

They may not hear it on day one, or day two. But just to keep them.. they have the right to know and we don't have the right to keep it from them, you know.

And I spent an awful lot of time with the family, probably a total of hours, just sitting with them away from the patient and we just talked and we explained. So it really was an education process to try and make, to help them understand what our goal and function was.

There was a few of them, they were dealing with it and then a few more came in from out of town and stuff and all the questions started all over again.it was a lot of explaining the whole day.

Sometimes, nurses would target their information to one key person in the family group:

And I also sort of look at what the dynamics within the group are if I'm dealing with a group, a family group, maybe a spouse and her children and their spouses and look at who they look to for clarification or that sort of thing. And sometimes, for instance if there's a spouse of a patient involved and she tends to look at her daughter to see what the daughter thinks, then I'll often try and concentrate on the daughter if I feel that she's more of a, there's more chance that I'll be able to get my information across to her and she'll get it across to her mom in terms that she can understand.

Satisfactory communication with families presupposed a well informed nurse at the bedside:

You just can't breeze into a shift and not knowing what's going on, we tried dialysis and we tried this, we tried that. If you don't know what's going on....you need to know the whole picture, what's gone on with that patient basically. And if you don't then it's not fair to the patient.

...Because there's nothing worse than not knowing what's going on whether it be a dying patient, or you're caring for a patient that's not dying. You don't know what's going on, you

can't care for the whole realm of things, you just can't.

Many nurses stressed the importance of updating families about the patient's progress, particularly when the patient became unstable and they were asked to leave the bedside:

To just, especially during a crisis, make sure that they're not sitting in the waiting room for twenty minutes or longer wondering what's going on after you've shooed them out because the heart rate went down to 20, you know. Did anybody think to go back there and tell them that they can still come in or that it improved?

Some nurses felt it was important to have the family come to the bedside, if only briefly, during such episodes so they could see what was going on:

...if a patient suddenly becomes very unstable, although you certainly don't want the family in there in the muck and the mire of putting in lines and everything, they have to be a priority to get them in there at some point. And I think we're getting a little bit better at that, even from a nursing standpoint and even from a medical standpoint. But it used to be that when a patient was unstable the family didn't come in until the patient had died. Which is really, if I was a family member I would be really angry.

And that's another thing, let the family in, and oh man, do you want to let the family see him, his face is like a huge balloon and there's blood everywhere and it's just a disaster. But you have to let them in. Sometimes you have to let them in right then no matter what's going on.

A lot of people I find, you know, want to keep families away. I can see it if somebody is really critical and you need to be doing things...Because nobody, like laymen don't know what a 99 is and they don't know. I think sometimes having families walk in and see how much you're trying sometimes puts them at ease. It's the hardest thing is to sitting out in that waiting room and waiting, cause once you've been on

the other side of it you realize how long and how hard it is to sit there.

One nurse stressed the importance of encouraging family members to voice their questions and concerns, and indicated that family frustration was an understandable outcome when information needs had not been met:

And I think sometimes being on the other side, because my mom has been in the hospital a few times, and being on the other side of it you realize you just want to be included, like what's going on, and you're just sitting out there waiting and not knowing what's going on. That's a big part of a lot of families' fear and misunderstandings, the feeling that they're being pushed away and have no input.

- I: Especially if the family, if the patient has been there a while, they'll [the family] will ask you questions, and they'll ask other nurses questions and who really knows what's going on, because they haven't been informed. And they're frustrated and they want to know.
- R: So do you find if you can head that off and pass them along information....
- I: Yes, and if I sense that the family is being that way out of the corner of my eye, I'll just say to them, is there something wrong, do you need an answer to something? I'll answer anything I can and if I can't i'll get the doctor for you. And they just sort of, well, "it's okay". And I'm like, "No, it's alright if you're nervous about something that's alright, I might be too in the same situation.

I usually allow the family to stay through my initial assessments so that they can see me work and I consider things with them. I find very often family who want to be around a lot want to be around a lot because they feel they have to be, because there are some doubts that voo-doo can take place. Very often people perceive it that way.

Nurses were aware that not all family members wanted information about the patient's treatment and condition, thus they tempered the amount of information given according to family responses:

Some people don't want to know, you know. Some people find it very helpful to know exactly what will occur, other people will say, it doesn't matter, I don't care as long as she's not in any pain you don't need to tell me what's going on. So you have to be very attentive. Or sometimes they won't even say but you'll have got their attention and you'll begin speaking and then all of a sudden they'll cross their arms and their legs and they'll look away. So you know that sort of thing you have to be very attentive to.

Subjects identified that nurses failed to meet the family's need for information when they failed to take the time to offer explanations, imparted facts to the family in a cursory manner, deferred questions that the nurse could answer, and gave information in a way that "showed off" the nurses knowledge base:

And the family is just sort of given the basics, you know, this is what's happening and this is what we've done and ta da ta da and here's a chair.

...and for example, a negative thing would be, well, the doctor will have to talk to you about that. It is sort of saying nothing, again, you know, just leaving this family to flounder as to what....

They back away. Or answer questions very shortly. Don't approach the families, wait until the families come to them or always refer the families to, "I'll get the doctor to speak to you", even though it's a nursing concept or something that they could very well talk to the families

on.

"...if there's questions you just kind of act busy and maybe not give the full answer that you probably could give.

I: "... and in her attempts to educate somebody it always comes off as showing off and knowing everything and it makes me sick, I can't stand it.

R: Can you give me an example of that?

I: Oh, I would probably say something like, oh, just step up to the bed and go ahead and listen to him and talk to him because often it's the last sense to go before they become unconscious. And don't mind the catheter, it's going right into the atrium and the right ventricle of the heart, just in front of the pulmonary artery, but it's fine because it's all taped. Like, I hate it. And it's just rambling. And nobody cares what's going in, they don't care. It would be better to say, you know, get right up close to the patient, don't worry about those wires there, they look intimidating but they're all secured, you're not going to move or damage them. You know, that's all they need to hear....you don't have to show off, you know, show off and teach them.

And also, that nurse will not take the time to say to the family before they come in, now you realize that they look a little different. There are machines, what the machines do and warning them about alarms, the pressure cycling light, when you cough, it's terrifying for them, for those people who aren't comfortable in hospitals, they make a beeline out of there, you know and they look at you for that, it's ok it's only...remember I told you, when people cough this is what happens and it's okay, and you know. But not taking the time to explain it, like when they finally deal with the situation, going, would you be interested in knowing, you know, what all this is and why?

Nurses recognized that families frequently wanted information about the patient's condition and treatment directly from the physician. In such instances, nurses would "track down" the

physician to come and talk to the family, ask questions of the physician on the family's behalf and/or make the physician accessible to the family by providing them with the physician's phone number:

I think the number one priority is having the family well informed because they're kind of shuffled away and only the intern or the resident talks to them. To me, they're paying the neurosurgeon and they're paying the attending because you know, it's their family member that's in there and they have the right to go right to the top.

"...and it took them a lot to understand what damage had been done, there was nothing we could do to reverse it. Her brain is not getting any blood right now, you know. And a lot, a lot of the questions were around that. And why aren't the doctors here? Like really, like I can understand where they're coming from, you know.And like I was, that day it was, like I said they have to be talked to now, someone has to talk to them now. And it was always me having to go search down this doctor and get somebody over to them to talk to.

The one sister felt that she would like to know where things were at from a cancer point of view before they made the decision to withdraw anything. Well, I managed to track down that doctor at his son's hockey game and get his opinion.

"...and who is the spokes-physician for this family, who's number can I give, and who's willing to make a commitment to this family without saying, oh, well, I only deal with the lungs, you'll have to talk to the so and so, you know. And if you're not comfortable with being phoned up in the middle of the night, that's your problem. They should be informed and whether it's, if you fail to inform all along then you can expect to get calls because I'll gladly give out their numbers.

One nurse indicated that it was important to be present with

the family in order to clarify information they received from the physician:

I: ...and I always try to go if I'm the bedside nurse or if I'm in charge with the physician and speak to the family as well so I know exactly what was said and I can trouble shoot things that aren't said properly.

R: You made a comment about trouble shooting when things aren't said properly. Can you give me an example?

I: They're either so extremely insensitive and they just say she's going to die, or they skirt around the issue so much that I feel that they haven't got their point across to the family. Because usually you still have a family that's grasping at the positive, any little thing that's going to be construed as even the slightest line of hope will be grabbed onto by the family and often misconstrued. So often I'll have to step in at that point and say do you understand what Dr. so and so has said, that the cancer has advanced to the point where all the organs are affected, all the vital organs? They'll say multisystem failure. Well, what does that mean to a family?

b) Behaviors that reduce the potential for future regret.

Nurses did several things to help reduce family members' potential for future regret. Giving family members the opportunity to say what they wanted to say to the patient (whether the patient was still living or had died) was seen as critical in this regard:

I: I always encourage the family to say good-bye. And when I ask the family to come in after the patient has died, I always term it, "would you all like to come in and say good-bye to your Mom now"? Like term it in that way so and people seem to be able to identify with that.

R: You sort of cue them with how they might like to proceed.

I: Yeah. Because a lot of people are embarrassed by death. They're embarrassed to show either crying emotions or anger or they just sort of stand there and they just don't know what to do. And you know, maybe the next day they might say to themselves oh, geez, why didn't I tell Mom that I love her or say good-bye or something. They don't have to say good bye but I always term it in those words so they can, they have something to say if they want to or they can whatever they want. But it really does seem to work well, I've found.

I: We had this young fellow who was in his 30's and he was, had a tumor in his head and numerous times he came to us and um, finally he wasn't going to make it and his family stayed there and they had a chance to talk through everything. Um, as much as you can....It was very sad but it was handled very well.

R: Because things weren't left...

I: Things weren't left at all, no. They had a chance to talk everything out, say everything they wanted to say to each other and I think that's important.

"...and I always tell the family to yell into the ear and talk to them because you never know, that might be the one part of their brain that's still locking in. And you give them the benefit of that. And if there's something that you need to say to them that hasn't been said, this is the time to do it. And if for nothing else, who knows if they hear or not, but at least, you never know what kind of burdens people are carrying with them, but at least they get a chance to say it, you know.

And so we talked about whether he could still hear and I always maintain that yes he can, and please touch him and kiss and talk and say the things, you know, that you need to.

One nurse explained how she tried to facilitate such communication:

I: ...some people communicate very well together to begin with and they, it's usually not a problem but if they don't communicate well normally, it's going to be worse at a time like this.

R: So when you sense that, sort of when there's problem in communication with family and patient, how do you go about bridging that gap? Are there certain things that you do that work well?

I: Talking to them individually and seeing how they both feel and sometimes if you approach each of them about talking to the other one or and try to show them the advantages of what they've got to gain by communicating with each other that um, particularly for the person who's left how much better it can be for them if they've said their good-byes than...You know, voiced their concerns or that it can help them in the long run.

In order to have the opportunity to say what they wanted to say to their dying family member, it was essential that families have liberal access to the patient, and not be made to feel as if they were "in the way" when they were at the bedside. Thus, it was important that nurses be flexible with visiting hours and not make families feel like they were underfoot.
differences:

I don't like to throw family out at all, unless they're disturbing the patients. If they're making it more difficult for the patient and I think that's what the rules are meant for, is to give you something to fall back on if you need it. It shouldn't be there to be enforced all the time.

If they're not comfortable with certain things, feel free to excuse yourself. But I'll let you know when I want you to leave, otherwise, feel you're, feel free to stay and I think they need to know that. People are always trying to get out of your way all the time, they always feel they're in the way, they're not always in the way, you know. And I think they need to hear that.

If it's really busy on the unit and all these family are pouring in and out like, I'm sure they feel like boy, we're really in the road which is really poor because they want to be with them all the time you know.

Conversly, not all family members wanted to spend time with the dying patient at the bedside, thus it was important to respect individual family differences:

"... and if they don't feel comfortable don't make them come in. Don't force them. If you can't watch a member of your family die, then you don't make them have to".

Subjects suggested that family access was more stringently "controlled" when nurses were not comfortable with a grieving family:

But many people are not comfortable around a grieving family and they'll, not that a family doesn't need privacy, I don't think I have to spend every single second at the bedside with them either, but they will avoid the family. They ask the family to leave when they're doing their assessment. I never do that, even with a healthy patient, unless you know, I ask the patient first, you know, do you mind if your husband stays or do you mind if your wife stays or whatever. And I won't send them out unless it's going to interfere with me in some way, but 90 percent of the time it doesn't.

... it depends on who you're working with and what they think. Particularly the ones where they can't handle the situation, they're the ones who really stick to the rules.

Even when they had liberal access to the patient, nurses noted that environmental characteristics of the unit made private interaction between patient and family difficult. Given the environmental limitations of the unit, sometimes nurses felt that

it was better for the dying patient to be transferred to a private room on the ward:

There can be so much commotion going on around that there can't be..you try to give them privacy, we have one private room where we'll try to keep them, try to put somebody like that in a private room, but you can't always.

In our unit people are always hitting the curtains and hitting the patients when they've got the curtains drawn around them and um, I think it's terrible. It's really unfortunate that patients have to die in our unit because it's not a nice place for family to be. They have no privacy whatsoever. If you pull the curtains you can hear everybody crying or like you know, it's very difficult for them.

Often if it's a stage where we can't help them we'll try to send them upstairs to a room where they can have the privacy and have the family with them, you know, even, particularly if it's a younger patient, you can end up having children with them and everything else...If it's very busy and there's all kinds of commotion then we're really not doing them any favours if there's not going to be anybody to spend the time with them.

Lots of times, especially with your surgical patients you try to get the tube out and get them upstairs to a ward where they've got some privacy in a room, because it is important for the family.

Encouraging family participation in patient care was also identified as being important in helping to reduce the potential for future regret:

I'll often teach the family mouth care and things like that because like patients mouths are so cracked and dry. This is something that is very simple for them to do, they can't hurt the patient by doing it, like they won't dislodge the tube if

you show them how to do it, and it gives them a sense of you know, helping dad in his last hours. And also all the guilt feelings that the families have, you know, whether they need to feel guilty or not, it kind of helps to stave some of the guilt too.

I find that family members, when a patient is dying, they feel much better if they can do something, even if it's just rub that patient's back, rub their feet.

Broaching the subject of organ donation was identified by one nurse as beneficial in helping families reduce the potential for future regret:

I recently had, the guy that I was telling you about that was in his late seventies, early eighties, that was a failed open-heart surgery. ...And he had a really sad family history. He was estranged from all his family except for one son due to alcoholism and things. And he moved away to Ontario and left the wife and kids in between. And this one son had just two years, like before, had gone to Ontario, retrieved the dad, brought him back,, had him living in his home, and was just the nicest son. I guess he was maybe in his mid-thirties or so. To me this old guy had kind of a wasted life, I mean, you know, an alcoholic, hadn't really had a good career or anything to get satisfaction out of, and probably his son had bad memories of his dad leaving and stuff. This would be something maybe, like if the sone felt like it, that would help the son think that yeah, his dad had contributed to the world, to society. And boy, did he ever take up on that. ...And so I asked him over the phone and I said this is just something for you to think about, I was asking for the eyes, because of his history of alcoholism, and sepsis...And he says, you know, that is such a good idea,..I think it would really help me to feel better about dad dying, that he could have helped somebody else....I think it does make a difference you know.

c) Facillitating the transition from cure to palliation.

Many nurses felt it was important to be honest without dashing all hope when giving the family information about the patient's condition, even when the prognosis was very poor. And,

while nurses tried to include some positive information, they tended to reiterate the message that aggressive treatment was not having the desired response:

I never paint a totally hopeless picture to the family members. I always try to include at least one semi-encouraging thing. Like not unrealistically but something that like maybe gives them a little hope to hang onto. Like that he, that yes he is totally controlled on the ventilator but we haven't had to go up on the oxygen, like he's still able to breathe at 60%, which is better than having him on 100%. Like something that to a nurse or a doctor they would say who cares, he's on 80% already, who cares if he's on 100%? To a family a little thing like that it might give them hope to hold on to so that you don't destroy all their hope.

And I tend to be, I get criticized for this, a little bit too honest with them. But I don't think I'm too honest with families, I just shoot from the hip but in a nice way. I don't tell them he's doing okay if he's not doing well. But I do point out the little bit of positive.

I: I don't take their hope away completely, but I do dash it considerably. I would always say, there's always a glimmer of hope and I'll explain like a candle burning, the flame will go out, it's only a matter of time.

R: Is that sort of an analogy you use with people?

I: An analogy, yea. Because, you know, then you can sort of visualize, you need to visualize it, you know, it's right now things look good, but, the long outcome of it, it's not good. And I can't tell you that it will be ok. It isn't ok, but I'm here for you.

I don't believe go to someone to say, that the tests came back and he'll be dead in a week. You can't be brutal, but I'm not God either and I've seen patients for whom I thought that there was no hope, who have lived months or years and so I guess that, that I would feel that you'd have to say, this is what it looks like, and this is my opinion, but that's not for sure, you know, and I will say to people, you can always hope. I guess I feel I don't have the right to take that away from people.

And he asked me, you know, do you think she'll make it, you know. And he says well don't you believe in miracles? And I said, well, I've seen a lot of amazing things happen but I don't think it's going to but she may surprise me too. And you know, I think, realize that I think no, it's not going to come about but they still wanted that hope there...And one of the doctors that they had more or less told them that there was no hope, like he was very blunt. It was one way that I know that he was trying to be very helpful and very supportive of them but they didn't take it that way.

Responding to Anger

Subjects identified that it was important to show empathy and respect to patients and families, even when their anger was directed toward the nurse:

I don't take it personally or anything. I think that look at all the things we've done to them, they have to have some way of showing some reaction to all of the things that have gone on to them and that um, that we should verbalize to them that you know, things have been very difficult and that you understand it and, but that doesn't mean that you try and not give them care but you don't take it personally and you don't, you try not to get too frustrated with it because you start to resent that person that you're trying to take care of. And it's really not their fault.

... and we often say it's all right that you're mad at us, it's better that it comes out towards us than towards the patients. Fall apart in front of me if you feel you have to be strong when you go in there.

So you have to, I don't think it's helpful to be an angry nurse at the bedside, for the family and the dying patient, it doesn't help and we have to accept the fact that that's somebody else's business, I've done the best I can.

At times, it was difficult not to take patient/family anger personally. When this occurred, some nurses found it necessary to step back from the situation:

Well believe me, you just feel like you sometimes want to say wait a minute, you know, this has been just as hard on me as it has on you but you have to just think, well how would you feel? Like, try you just try your best to settle them and talk to them and you ...that's part of this whole process and uh, as difficult as it is, some days you think, oh man, this is really getting to me. You know, I'm trying my best and I'm still getting nothing but this, but I think it, I'll just try to ignore it and realize that it's just their way of dealing with the whole situation and after 12 hours you go home and have a glass of wine or something. But you have to be, you have to try your best in there and if you get to the point that you're frustrated, I just walk away from the bedside and do something you need to do for a while rather than showing your anger because it's not helping them or you.

"...walk away, try not to be caught up in the anger, and say things that I'm going to regret, and so add fuel to the fire, I'd rather walk away.

It's hard sometimes to keep your temper and your tongue, when often the anger and the impotence that they're feeling will be directed against you, you're just a faceless representation of this medical system that they have a million problems with....If I felt that my presence was helping them, even though they were directing all this at me I would still continue to be as involved. But if you feel that you're doing nothing but inciting them to be more and angry and more what ever, then I think it's to everyone's benefit to back off.

Nurses found the anger of families who were embroiled in long-term conflict particularly difficult to deal with:

Well, I think probably that girl I was telling you about was one of the worst patients that I ever had to deal with just because there were so many problems outside of her problems. You know, if you've got a nice caring family that every body gets along, it makes it so much easier because uh, you don't

have conflict to deal with on top of somebody being very sick....The family was fighting all the time...

There was a lot of anger. And I don't know how to deal with their anger. And I'm not a counsellor, I think that's the other thing is that, we're very comfortable when a minister can take over, ok.

On the surface, the family looks fine, underneath they're very dysfunctional and they're not able to show their anger towards each other so it's all directed at you. That's very difficult. For me that's the most difficult thing to deal with to the point that sometimes you are even personally attacked.

The family was a very tense, distant, violent family. It was very scary because the son was very volatile. And they all broke down too, crying at the bedside but it was more like a begging cry, like what were we doing wrong, what weren't we doing, how come we were trying to kill their father. It really scared me....And they were angry and they just wanted to blame somebody and unfortunately we were in the way, the surgeon and the nurses, it was our fault.

I: It was just, it was a family from hell. And, I guess the part that I found most difficult was that, you would spend ages talking to them, and it wasn't just the dying it was the whole. Like, I heard about the whole family right back to Abraham, and ah, trying to convince them that perhaps, outside counselling was a good idea, but this, although we would do what we could, we certainly didn't have the resources or the time to deal with all of their problems....It was, it was awful and ah, I find myself thinking this is your mother who is dying, can't you just ditch that stuff for a while and deal with it later. But obviously they couldn't.

One nurse noted that she tended to distance herself from angry, conflict laden families:

I find myself not being nearly as um, flexible. Like I'd say to them, well, I'm going to give her a wash now, I'd like you to go out and wait or I'm going to turn her. Whereas, with other families who are, were cooperative and who don't bring

their outside spite, they can stay while I give them a bath. It's not, I guess the other thing is, that it's made me subconsciously threatening, that, that I don't want them standing there saying, oh, you didn't turn right, or ah, you know....They were difficult enough to deal with, without having to worry about everything I was doing.

Responding to Colleagues

Nurses identified the importance of providing emotional support and critical feedback to colleagues:

And I knew that my friend, I'm sure that she was hurting about this because she was sitting very quietly and her face was kind of flushed afterwards and I just went over to her and I put my hand on her shoulder and I said are you okay, because I think we should talk to each other. Well she just started bawling and said I was okay until you said that. But she had been holding back. It was probably good for her, you know. And in fact as she was crying and we were crying at the same time, but it was just a lot of stress coming out.

We talk it out at, on breaks, or maybe time goes by, a few days go by, or weeks go by, and maybe a similar sort of incident occurs again, and you remember you had and reminisce. There's good times and bad times, and sometimes just the assurance that you didn't do it wrong, maybe it's just the way it is. Just seeking guidance from your peers as well, just to say, "how would you do it, what would you do?"...

Sometimes sitting in the back room and talking about what's going on helps a little bit. Sometimes you just need to verbalize what you're feeling, like I feel really shitty about so and so.

And I think because you have such anger built up in you about all the things that you've had to do over the last while that's probably made this person's life, you know, not very happy. We have a lot of problems with the anger that we have within ourselves and I think that comes out. And I think most of us like to sit around and talk about it, you know at the time or just after.

One nurse mentioned that she would support a colleague by

providing him/her with "time out" from a very angry family:

...when you've got a really angry family member, that's dealing with their anger and is displacing their anger and is displacing their anger upon you as the nurse, and you're feeling angry that the situation has happened too, rather than clash, you just step in and say something, "Is there anything I can do?," for your peer, and maybe just give them an opportunity to just step out while you take over, for a little while, because they're displacing such anger on this person that you can see that it's not going to take too much longer before they say something they'll regret.

Emotional support and feedback tended to be provided on an informal basis between nurses:

I: There's nothing terrible formal. I wish there was. I think it's something that we need to talk about more, our feelings and dealing with patients. Usually it's unspoken gestures. You know the girls that I work with a lot and I'm working with a dying family, they'll come by and I'll get a shoulder rub or they'll rub their hands up and down my back. Most of it is unspoken. Or they'll come up and say to me, ... it's usually very unspoken. As soon as the patient dies I'll turn around and one of them will have their belongings, the patient's belongings from the back for me. Sometimes they'll say, do you want me to take these out? I find that very difficult.

R: Getting the belongings gathered up?

I:it's something I just abhor doing and most of the staff know that so they'll often offer to do that for me...Or, you know, they'll say you go do your charting, I'll clean up here and they'll clean up the body for me. It's very unspoken but it's very there and it's appreciated. I find that we tend to, we don't talk about it a lot, you know, you do the unspoken things.

R: Do you formally or informally support each other?

I: Very informally. We, a lot of time we go for coffee or what ever. Yeah, like I was saying we have a very good network of nurses there and you know, say that my patient has died and come through post death care and stuff like that. And now I'm wandering around looking to help somebody else because I don't have anything to do because of my patient, you know, and somebody will come up and pat me on the shoulder and say, you did a good job, you know that family really seemed to accept the death or something. They are very supportive.

Respondents noted that planned "group support" was more apt to occur when frequent deaths were experienced on the unit:

And there has been times when there has been a lot of deaths and they've got people in to do an inservice or whatever, which is good.

Once maybe in the last year when they brought the Chaplain in and just where the girls were having a problem dealing with it, all the deaths that were happening, a number of young people, um, just to give them time to talk about it.

A few nurses felt that the hospital environment was not conducive to informal discussions of cases and venting of feelings:

I think that we tend to bury, a lot of us. You know, it isn't until you sit down and start to discuss it in this sort of a venue or in a more professional sort of setting, that you explore your feelings a bit more. Other than that the only time that we are really afforded together is at coffee break and who wants to spend their time discussing things like that, most people don't. So consequently it's not really, I mean even when you know how you feel it's not really discussed openly.

We often talk about it, especially now that we've got our nice little room. When you've got a nicer room to go back and talk you can sit there and not talk about it at coffee

because it's not the greatest thing to go downstairs and talking about it when there's families around because you never know, you know.

That's one bad thing about the hospital is there isn't an area where you can really, you know, you can go for lunch, where you'd like to sit and talk and that all the patients are down there, you have to be really careful...We do have a chat at the Chaplain's office that we go in sometimes.

It was important that feedback and support be offered in a timely fashion:

I: ...my colleague came over and said how are you doing and I said fine, ahhh!! That was my reaction that day because I had enough to deal with the family, like I needed not to say what I was feeling at that point and time. Like because I was going to start crying or breaking down and I thought, no, I can't do that because I still have to deal with the family.

R: So you needed that support but you...

I: Yeah, I knew it was nice to know that they were there and for them to say that but it was like, no I don't want you to come over and put your arm around me because I'm going to start crying. And you know, it was like after the shift was over and everything, you know, I phoned one of my friends later on that night and I just told them everything that happened that day which was great, but it's like I'm doing okay, I just need some time. I don't want to talk about it right now.

...the rest of the unit left me to do what I needed to do. If I wanted something they made sure I knew that I could call for help or, and they would just check in and say, you know, how are you doing and that kind of thing, um, and so basically they just let it happenand I guess it was the next day or something the nurse who had been in charge that day came up and gave me a hug and said "you did a wonderful job" and, and I thought, gee whiz, I have. As much as that's your job, sometimes it's nice to know that it's acknowledged.

Nurses felt supported when charge nurses gave them assignments that reflected an understanding of the stresses associated with caring for a dying patient:

...when you have a dying patient, the charge nurse tries the very best to split up the assignment so that's all you have. And that's fantastic, that's great.

...the charge nurses are often very good about saying, look, you know, you've had this person for three days or whatever, do you want to change?

And lots of times whoever's been involved in an emotional setting will be sent home early, you know if the death happened at one or something. By the time you get all your work done it's two or something and the boss will say why don't you go home, you were busy today.

The one thing that we often do is just to make sure that that person isn't having to relieve other patients, you know like.. and so that person is just having to focus on what's at the bedside..That's your focus you don't have to worry what else is going on in the unit kind of thing. And they're very empathetic towards you after you know, as far as uh, maybe you won't have a patient for the rest of the evening or something if it's possible on that unit...

I remember one nurse that could not stand to be around, it would just bother her you know, death really bothered her and she could not stand to be around this patient at all. She was just nervous and I said to the charge, I said why don't we give her patients from the OR because obviously she has a very difficult time, she's not having a good time and she's a nervous wreck. She's not ready for that. Because there are other people here that could do that.

In contrast, one nurse explained how it felt when collegial support was inadequate following a very stressful episode

involving multiple deaths:

I don't know what it is about nurses but in health care I don't think we help each other enough...Anyway, to put a long story short, after all that happened the only support we got was a job well done in the notation book. And I personally went up to my boss, the next day there was a shooting, and I had had it, I was ready to snap. I worked the whole Christmas season and somebody died. I went up to her and I said I need some vacation days next week, I'm going to take a week off. And she said, she said I'll see if I can arrange it for you. And I said there's nothing to see, I'm taking them off, I need seven days off, right away. And she gave them to me. But there was no what's the problem, you know? It was pretty closed.

Though the feedback nurses received from one another tended largely to be positive, there were times when more critical feedback occurred. One nurse indicated she would question a colleague's rationale for asking family members to leave the bedside when there was no apparent reason for doing so:

R: So what would you say if I was doing that?...

I: You may say that the family needs to have them there or maybe the family needs to be in there or I'd say to them, "If that was my husband you'd have a hard time throwing me out...Do they really need to leave? Why do they need to? They're not bothering anybody.

One respondent indicated that she would challenge a colleague at change of shift if the patient she was assigned to had not received adequate analgesia:

And probably anybody you ask will say that at one time of them working or something, especially in picking up patients, I don't care if the nurse is ten years senior to me if they haven't given the patient I'm picking up analgesic in the last eight hours I want to know why. Before that nurse leaves I flip to the analgesic page and see when the last analgesic...

One respondent felt angry and embarrassed when colleagues provided only very basic care to dying patients:

I: At first I feel very angry and being a profession, of course, there's good and bad apples in all, but it reflects upon the unit. We all think that we're doing the best that we can, we all want praise and it's important to use, and when there's somebody who's giving such negative vibes, first of all I'm angry, second of all, I'm embarrassed! And if it becomes a real issue, then we as charge nurses intervene and ask them to be pulled off the patient.

R: Is that something that you've done?

I: Yes. I've had family members approach me as charge nurses and ask me not to have certain members, for whatever reason. Sometimes they're not justified to me, but they're justified for them. But it could be the attitude, again, just the basics, no extras, and no time spent.

Though one respondent would not ignore a less than optimal patient/family care situation, she indicated that she was reluctant to directly critique a colleague's work because: a) not all nurses are comfortable caring for the dying; and b) it was too easy to draw erroneous conclusions about the handling of a particular case without knowing the "whole story":

It makes me feel badly um, but some people can't cope with stuff like that as well as others can and I don't know whether it's something you should go up and say you know, I don't think that you did that very well because that's just how you see it and um, I don't think that I would go up to somebody but I may go to the family and say how are you doing sort of thing. Um, but I don't think it's your ideal to just go over there and say look, I don't think that you've handled that very well because you don't know what went on over there at all. So I think you have to just sort of listen, it'll come out afterwards what happened. They'll say something or somebody will say something and you'll find out the whole story.

Providing Comfort Care

Experts identified the necessity of reducing both physical and psychological pain for dying patients. One behavior designed to meet this goal included communicating with patients.

Nurses indicated that it was important to listen and talk to patients about their perceptions and concerns in an honest, non-judgemental fashion. This demanded that the nurse be both physically and emotionally available to participate in the interaction:

I think the main thing is to listen to them and try to anticipate their needs and understand their needs or what they think their needs are.

Listening to them, letting them talk and seeing what they need and trying not to put your standards or...just because you think they need it doesn't always mean they do either. I might have a great fear of dying alone but that doesn't necessarily mean they do.

I spent a lot of time at the bedside with him and ah, and talked about um, how frightening it was not to know what was going on and ah, and these test are really not, not the most comfortable things to have and, and he had asked if ah, what would happen if nothing was able to be done surgically, and, and I always believe in being really honest, and, and so I think my answer at that point was that, well, that they would try to maintain you on medicine but that certainly your lifespan would be shortened. And we talked about things he'd done and all the good things he had to remember.

Most patients want to communicate right? And if it means pulling the tube out, then we'll do it, right? And where the constant explanations can be very frustrating but might in this case be worth dealing with it. If they can't write for whatever reason we use an alphabet and pointing and trying to do it, and yes it is time consuming. But if it's the patient who want to say something and maybe the last time they say something, it needs to be done whether it makes sense or not,

they should have that...

It was important that nurses communicate with patients whether they were responsive or not:

Like I always, always talk to my patients whether they're conscious or brain dead or anaesthetized or whatever. Just because if I was coming out of anaesthetic I would sure want somebody talking to me. And I always give an explanation to the patient before I do something, like okay Mr. So and So, now I'm going to suction you.

Nurses also felt that it was important psychologically to give patients a sense of control over their care when possible.

Such input served the dual purpose of fostering a sense of control, and promoting individualized care:

I: Giving them as much responsibility of their own care if they're alert. If they don't want to turn every two hours. There's certain things that we have to do but I think there's certain things that give them a little bit of leeway over it. As much as I can I try and let them do what they want and say that we have to do this but these are your options kind of thing, what do you want to do? If they want their grandchildren, whatever, make pictures and put them up.

Providing adequate analgesia was identified as fundamental in reducing the physical and psychological pain of dying patients:

Comfort measures, I'm a very big nurse for analgesia....in fact it's probably increased or of increasing importance in my mind of a patient who's treatment has been discontinued on. Because I mean that's the very last thing I want them to do is suffer. If there's no gain for it. Sometimes you have to weight analgesic against weaning and things like that and in that case there's a reason for not sedating the patient. But in a patient where treatment has been discontinued there's no reason whatsoever for the withholding of sedation or analgesics, in my mind.

In addition to communication, control over care, and adequate analgesia, subjects identified the implementation of thorough, basic nursing care as fundamental in reducing the physical and psychological pain of dying patients:

Well, you know, actually it's some of the little things that a nurse can do. If it's a long drawn out process of dying and you've got the time, why not wash the patient's hair if it's not going to hurt the patient...And you know, I mean I love having my hair washed by somebody else, maybe they will feel it. Like little things like that, the little extras.

In contrast, some nurses would engage in avoidance behaviors that resulted in neglect of patients, particularly psychological neglect. Subjects had difficulty recalling instances where they had witnessed poor physical care being given to dying patients:

So everybody in the unit that I work in gives basic nursing care as far as turning and mouth care routinely. I've never, ever seen a nurse like leave a patient who's treatment has been discontinued flat on their back with no suction or no mouth care or anything. It's kind of the last things that you can do for that patient as a person is care for their physical body even if their mind isn't there. And so I haven't ever seen, I think maybe the nurses that aren't comfortable with it ask somebody else to take that assignment for them or something, maybe that's why I don't see it.

More commonly, patients were well cared for physically, but the psychological aspects of care were neglected. Avoidance behaviors included limiting opportunities for nurse-patient interaction, focusing on the technical aspects of the job, and "just doing what needs to be done" when giving patients physical care:

Restrained quickly and sedated quickly. The joke is, if we have a sedated patient we have a happy nurse...

I: When they're afraid to get close to the patient and they're afraid to get close to the family and you can tell they're doing what needs to be done but that's all. They can hardly wait to get away from them.

R: Okay, so the "what needs to be done stuff would include things like...

I: Oh they're still giving the patient medication to keep them comfortable and turning them when they need turning but doing more the physical needs than the emotional needs and um, you know, they may just need to express their emotions and some people can't handle listening to that or listening to them crying or whatever, or showing any affection towards them, or they don't want to be involved in it at all.

I: ...unfortunately we have some, some nurses, and they're not by any means in the majority who are more concerned with machines than with people. Um, and that's really hard to watch without trying to butt in. And I guess that part of it is that, ah, for the most part, these nurses have never worked in any other place than in intensive care...

R: So they... were more into the technical part of the job, what sort of things would they not do...

I: I think that often, I'd notice, that they tend to be really brisk, you know, the patient medically is well care for, I mean, they certainly.. I have no qualms and I guess the other thing I have a problem with is that, they're medically cared for, but emotionally, that's, I see that as often more important..or maybe they're not talked to when they're turned, even if they're unconscious and not responsive, or maybe things are, are said, like "Oh God, look at this, you know, and it's ok to think that, or if you need to say it out of earshot, but you don't assume that because the patient is unconscious that they don't hear anything.

I: The basic physical care would get done with no extras. No luxuries.

R: So things like,.. what wouldn't? What luxuries?

I: No luxuries, like, oh, maybe the rubbing of the elbows, or rubbing of the feet or stroking of the forehead. It would be quick bath, turn, tie, cover-up, end of story. No communication.

R: So just the doing of things?

I: Right, don't talk to me, you can't talk anyway, you've got a tube in your mouth.

Enhancing personal growth

Many nurses had defined a role for themselves in helping the dying. Often, this meant helping patients and families articulate their preferences regarding medical treatment, especially "in the event of" sudden physical deterioration. Nurses expressed frustration when physicians insisted on a protracted, aggressive course of treatment that patients and families did not want:

Because it's the old torture theory that I have. You know, if it's not doing any good for the patient, then it probably is torturing them, if there's one tiny piece of their mind alive, having this breath forced into them or having this line stuck into them or whatever...

When nurses indicated to physicians that patients/families wanted such intervention stopped, they were often met with hostility:

I've really stood up and said well why are we doing this to this person and got some really interesting responses from doctors. Well they get very, one doctor got very upset and swore, let off a lot of steam at the rounds and said we've got to keep going, like he explained his reasoning and that was fine. I think I needed to know that he knew how the patient was feeling...

Well sometimes you just have to say to the doctor, look it we're getting no where. This patient is frantic, the family is exhausted and they don't want anything more done...

...we've had physicians call us a bunch of vultures, like sure it makes your life easier if you don't have this patient to look after. We have a few physicians who don't handle this whole area very well. And we sort of feel when you approach them with the DNR status that they perceive that you want them to give up on this patient. And often that's not the case. We'll approach them with the DNR status if a very elderly patient comes in who has the potential to become very ill, so that when the patient is still competent he can think about it and his wishes are known.

We used to have one doctor and he'd simply say, "Well, how do you know that the family isn't just trying to knock him off so they can get the money and whatever else? How do you know that?"

...some of the physicians of the older calibre, when you address them in regards to do not resuscitating patients, look upon you as if you don't want to do your job. You find that this person is becoming too much of a job for you to handle you just want them to just sort be gone...And what we try to do, is, people who have a very poor prognosis, that you've pulled through should be given the opportunity to discuss realistically with the family and the physician what they want to do in the event of another time, and some physicians feel the nurses are sloughing off and they're angry with that because I,...do not resuscitate on this patient doesn't mean I've quit caring.

Nurses were angered when the treatment wishes of seemingly alert patients were not sought because they were intubated or deemed

incapable of making such decisions:

I mean this man is 90 years old, he's had a heart attack, he was intubated, we brought him off the respirator and now he's having another heart attack and they finally start putting in lines. Why are they doing this? And the patient didn't want it. Do they not have any rights?...When it comes down to the end they'd say oh well, he's confused, he doesn't know what he's saying.

...Just because they're intubated their views are often overlooked, they're not asked. So I always say to them, well I think she's awake and competent enough to give you a little bit of info, why don't you ask her?

We had some cases where the patient want to die and the doctors aren't ready to give up yet. You feel really, like put in the middle again because the patient is writing and showing you all kinds of things. Often times they get really withdrawn and almost resistant to the nursing care because, you know, they've told you and they've written to you that I want to die, don't do that to me, that hurts...and it's not their wishes. And the doctors come up with well, they're not in a situation to make their own minds, they've been through a lot.

One subject was livid when a palliative course of care for her patient reverted to aggressive treatment merely because the attending physician had changed:

I: ...sometimes one week they'll decide that no more treatment should be done and you explain this to the patient and you explain it to the family and then Monday morning you have the same patient and there's a different attending, you know, and you're going and you're doing everything. Like I've spent the last eight hours talking to a family and saying like they're not planning on doing anything more. You learn after a while in ICU. Like tomorrow or the next day and then you decide to treat this which is, you look rather stupid when you tell families you know, we're not going to do anything and then the next day they come and they say I'm going to do this, that, and the other thing... Like why last week we weren't going to treat it and now all of a sudden we are, like what's changed, what's

dramatically changed that makes you think the outcome is better?

R: Nothing's changed but the attending.

I: Right

Nurses sometimes tried to appeal to reason in order to get physicians to abandon continued aggressive care of dying patients. Such an approach was not always successful:

I can remember saying to an MO, it backfired actually, because this woman was dying of breast cancer, I said, "If this were your Mother wouldn't you want us to stop?" And actually it turned out his Mother died of breast cancer when he was young and he'd never dealt with it. No, he didn't want us to stop. I thought, oh great...He also happens to be a doctor who did a twelve hour 99 on a frozen lady, so you have to understand he wasn't totally in touch with giving up. Defeat was a foreign word and he hadn't found the translation yet.

When appeals to reason failed, other approaches became necessary. One nurse described how she "worked" the medical system to get the orders she felt were in the best interest of her dying patient:

I:...there was no way this patient should be resuscitated, they weren't doing him any favors and they knew who the doctor was and that the doctor wouldn't agree but there was another doctor listed so we called the other one. The attending for ICU that was in charge of the patient would never say going in, "forget it". But the patient's family doctor who knew the patient and knew the family...So we just called him instead.

R: You sort of take the path of least resistance sometimes don't you?

I: But I mean we do that too, nurses do that too, right. If there's something we want from this person, we'll go to the other person.

In contrast, one subject described a scenario in which she felt that the physician had not treated the patient aggressively enough:

I: He had a ruptured aneurysm and it hadn't quite ruptured yet we didn't think and the doctor came to assess him and suddenly the patient sat upright in severe pain, and his pressure dropped and he was basically, he should have been a "99". And we went to give him adrenalin and the surgeon said, "No, I've decided that I'm not going to treat him...and he refused to accept this patient in the end so we just had to let this man go. And I said, well, "why didn't you try and save this man? He was a young man, in his early fifties...and to me it was the ultimate in cruelty, like don't accept a patient if you don't think you can treat them. I mean the patient wasn't even, his pressure was about 20 and he was still in a very low ventricular, and the surgeon barked at us to do an x-ray. And I said why? And he said I want to know for sure that he had a ruptured aneurysm. And he went purple and you know, looking at the man, looking at the man you know what he had, let's not torture him. And he was so insistent, he demanded we so an x-ray. And we were just beside ourselves and we had to x-ray this man. It was awful.

R: The final indignity.

I: It was, it was, just like why don't you stab him and get it over with, was how I felt. Afterward the surgeon came over and said, oh, I'm sorry, maybe I shouldn't have treated him that way...And I said "I can't believe that you wanted to do that, did you get your answer?" And he said, "Yeah. that's what I thought". And she said then why did you want us to do it when you know what it was? And he didn't answer, he just walked away, and the tears just came.

One nurse felt particularly good about documenting the patient's treatment wishes after discussing them with the patient at the bedside:

And he called me to his bedside and he said you know, I want to talk to you about you know, about if I would die or

something. And I said, oh sure, go ahead. And he said, well you know, if something happens I don't want a lot of heroics, he didn't call it heroics, he said I don't want you to do a lot of things to me if it doesn't look like I'm going to recover...And I said what would you like us to do or is there something specific? Are there places we should stop? So he clarified himself and I thought to myself okay that's good. And then I thought, well, I just can't leave it at this. He's imparted all these desires and wishes to me, he's basically told me his will....So I left progress notes and I wrote on it something to the effect that I was called to his bedside and he did not want to be the subject of resuscitation measures and he expressed that in the event that his prognosis would be poor and his recovery would be unlikely or a good recovery would be unlikely, that he wishes not to be resuscitated or to have unusual, to go beyond usual procedures to resuscitate him... I took it to the patient and said, look this is what I wrote, is this what you were thinking? And he said yes, that's correct. And I said well, okay, why don't you sign it and if something would ever happen then I can show it to who ever is concerned, your family or whatever, and it can help them to make a decision. Well wouldn't you know two days later he ends up on the ventilator. His heart gives out and he's doing really poorly and the chances of him recovering are very, very minimal..And somebody went through the notes to catch up on what had happened and saw that and they showed it to the family and the family went "Wow". So they pulled the plug.

R: You must have felt really good about that.

I: Yeah, I felt really good about that. I mean, that I, maybe if we had been busier or I would have had an extra load, I might have just have said oh, okay, that's interesting, don't worry about it. But I didn't and I decided to take the time. Yeah, I feel really positive about that.

Failure to define a personal role for themselves in the care of dying patients and their families made it difficult for nurses to become truly involved in such cases, or derive personal satisfaction from them:

It's kind of embarrassing in a way that you as a nurse or in the hospital profession, that we're supposed to save these people where there's nothing we can do if they've got cancer

or some dreaded disease that can't be cured. I mean it's just that they've had this massive MI and we can't fix them, you know...

I can recall several times when I began my career, my nursing career, having a dying person and just being too busy and being too uncomfortable to just jump in there and shake their hand and tell them who I am and say what can I do for you. And I hated that.

Enhancing personal growth required that nurses risk emotional involvement with patients and families:

Taking the risk of saying anything or just standing there sometimes is enough. I don't think you need to know a lot of big fancy communication skills to help families. You know, just being willing to get involved with the families and taking the risk of all the emotions you go through every time it happens.

One subject indicated that her initial program of nursing education had discouraged such involvement:

And ah, I think that you have to give of yourself. You can't, there is no way you can walk away at the end of your shift and not leave a part of yourself there, in order to do a good job. When I was a nursing student, it was drummed into us, don't get involved, don't get involved, and that was the biggest lie they ever told us. You can't be a good nurse if you don't get involved, and that's what I think you have to do.

Experts explained that "becoming involved" never came easily or automatically in practice:

You know, I think it just takes time and you realize after a while it's just something, like it, sometimes I was scared to say anything. Sometimes just standing there and trying to figure out what to say and realizing, well, they seem to be doing just fine with me being here that maybe I don't really need to say anything. And I think you just get a feeling

sometimes what they need and what they don't need.

Summary

This chapter has discussed the characteristics of the sample participating in the study, and the categories of nursing behaviors that emerged following content analysis of interview transcripts. Chapter 6 will present a discussion of the findings, and outline the implications of the study for nursing education, research, and practice.

CHAPTER VI

DISCUSSION OF THE FINDINGS

This chapter represents an analysis of the findings from Chapter 5 as they relate to: a) the theoretical underpinnings of the study; b) the proposed research questions; and c) the work done by Degner et al (1991) regarding critical nursing behaviors in care of the dying. The chapter concludes with a discussion of the implications of the study for nursing education, research, and practice.

a) Relationship of the Findings to Theoretical Perspectives

Quint's (1966) theoretical perspective proposed that exposure to the dying coupled with a lack of education fostered death anxiety, negative attitudes, and subsequent withdrawal from dying patients. The emphasis on cure or recovery in ICU, in combination with a lack of empirical data to guide nursing practice in care of the dying pose additional obstacles for nurses working in critical care environments.

The findings from Degner and Gow's (1988) longitudinal experiment identified that students receiving high doses of death education that included clinical practice demonstrated more self reported approach behaviors in care for the dying one year postgraduation that did nursing controls. As a result of their findings, these researchers proposed that direct involvement in care of the dying influenced nursing attitudes and subsequent

approach/avoidance behaviors in care for the dying (Degner & Gow, 1988). This perspective implies that respondent attributions about the presence of positive or negative attitudes in students or colleagues during vivid events could be used to develop a beginning description of critical nursing behaviors (Degner, Gow, & Thompson, 1991). The rich data generated by the ICU nurses in this study supports this contention.

Interestingly, many of the "experts" participating in this study indicated that they really didn't "know anything special" about care of the dying patient in the ICU. This rather self effacing perspective may be explained by the fact that nurses accrue clinical knowledge over time and forget what they have learned (Benner, 1984). Additionally, "...in expertise, holistic similarity recognition completely governs performance. The patterns of salient features of experts become associated with correct actions. Experts just "do what works" (Belognia Le Breck, 1989, p.44)

The nurses interviewed in this study had experienced a great deal of direct involvement in care of the dying adult in the ICU, and had many vivid memories to draw upon. They had developed a "cushion of experience". Benner (1984) described the cushion of experience as follows:

...They are relying on a global perception, the confidence acquired in reading whole situations. They are relying on their ability to recognize whole situations as similar and

dissimilar to past situations. They are not relying on precise procedures or rules for handling the situation, nor do they necessarily believe that they can control the outcomes. They do believe that their efforts can make a difference, and if not, they believe they can handle the outcomes (p.129).

Most significantly, nurses in this study were able to identify when their interventions made a difference in the care of the dying patient, and articulate what those interventions were. The systematic documentation of their expert clinical practice makes new areas of clinical knowledge available for further study and development (Benner, 1984).

b) Critical Nursing Behaviors in Care of the Dying

The purpose of this study was to describe nursing behaviors nurse experts identified as being critical in caring for the dying adult in the intensive care unit. Three specific questions were addressed:

Question # 1.

What were the behaviors that ICU nurses deemed "expert" in care of the dying by their colleagues, described as having a positive influence on the care of the dying adult in the intensive care setting?

Question #2.

What were the behaviors that ICU nurses deemed "expert" in

care of the dying by their colleagues, described as having a negative influence on the care of the dying adult in the intensive care setting?

Question #3.

How do the behaviors identified by the ICU nurses in this study compare with the seven categories of nursing behaviors identified in Degner, Gow, and Thomson's (1991) qualitative study of palliative care nurses and nurse educators?

Six categories of nursing behaviors were identified following content analysis of 10 semi-structured interview transcripts. All behaviors were compared and clustered into categories that appeared to provide the best explanation of the data. Operational definitions were then written for these categories. The categories that emerged included: 1) Responding after death has occurred; 2) Providing comfort; 3) Responding to anger; 4) Enhancing personal growth; 5) Responding to colleagues; and 6) Responding to family. Both positive and negative behaviors were identified by respondents.

Nurses' descriptions in this study provided clear examples of critical nursing behaviors and the resulting consequences when behaviors were not present. In contrast, descriptions in the literature reviewed were much more general and, in many cases could not serve as directives for action. While not exhaustive, it was apparent that the literature alone was not an adequate starting point for the development of a model of expert nursing practice in

care of the dying in the ICU environment.

Relationship of the findings to the work of Degner et al (1991)

Several similarities existed between the sets of nursing behaviors in care for the dying described by Degner and her colleagues (1991) and this study. Six of the general categories of behaviors that emerged from interviews with ICU nurses in this study were analogous to the categories generated by palliative care nurses and nurse educators in the work of Degner et al (1991). However, several important differences were noted.

First, a seventh category, "Enhancing the quality of life while dying" identified by Degner, Gow and Thompson (1991) did not emerge as a distinct theme in this study. Enhancing the quality of life while dying involved nurses helping patients do things that were important to them (Degner, Gow, and Thompson, 1991). Successful implementation of this strategy requires an interval of time during which nurses can develop nurse-patient rapport, and patients who are capable of identifying about what is important to them. These conditions do not always exist in critical care settings because acutely ill dying patients in the ICU customarily have a rapid dying trajectory (McGory, 1978).

However, nurses in this study identified that when patients were more "long term" dying, they implemented a variety of interventions designed to help improve physical and psychological

comfort. This is congruent with the work of Fleming, Scanlon, and D'Agostino (1987) who identified that the concept of comfort had a multifaceted meaning and encompassed a wide range of nursing activities. Specific activities included personalizing the bedside environment, including friends and family in patient care, and individualizing care plans to reflect specific patient needs and preferences. Nurses saw these measures as being important in promoting the comfort of long stay patients, notably their psychological comfort.

Second, nurses in the study by Degner and her associates (1991) identified the importance of maintaining a sense of calm and family involvement during the death scene. In contrast, the ICU nurses in this study indicated the importance of responding after death had occurred. Subjects stated that they encouraged family involvement with dying patients while they were still alive in the ICU, however they explained that patients were often admitted into the unit and died so quickly that the conceptualization of the patient as "dying" or a "death scene" rarely had time to occur. Additionally, the "death scene" in ICU is often one of frantic intervention aimed at prolonging life. This restorative focus also makes it difficult for the nurse to think of the patient as "dying".

Respondents explained that when patients in the ICU became unstable (and hence potentially closer to death) family members were usually ushered from the bedside. The relegation of family members to special waiting rooms away from the patient's bedside

has been noted previously in the literature (Martocchio, 1980; Michaels, 1971; Strauss, 1968). Nurses identified that this was done to protect families from having to witness aggressive interventions and invasive procedures designed to "save" their loved one's life. One respondent likened these interventions to "pulling wings off flies". It may be argued that such a scenario is conducive neither to a sense of calm or family involvement.

Third, palliative care nurses and nurse educators in Degner, Gow and Thompson's (1991) study did not stress the importance of nurses creating a dignified, peaceful bedside scene for survivors to return to once the patient had died. This may be due to the fact that families were more apt to be present during the death scene in palliative care situations than in acute care settings, and there would be no interventions carried out at the time of death in the palliative care setting that would leave either the patient or the bedside environment in a state of disarray. As one respondent noted, "we really do inflict a lot of atrocities on people at the end".

Fourth, nurses in this study repeatedly indicated the importance of respectful handling of the corpse when preparing the body for the morgue. Both sets of respondents identified the importance of treating dying patients with respect while they were still alive, but nurses in Degner, Gow and Thompson's (1991) study did not specifically discuss treatment of the body after death. The behaviors identified by ICU nurses in this study are similar to those of ICU nurses giving post mortem care to patients who have

donated organs (Wolf, 1991). Nurses in Wolf's study were saddened by the death of the donor, and viewed post-mortem care as the opportunity to achieve closure with the patient. They respected the body, and saw the provision of post-mortem care as providing comfort even after death.

Fifth, the nursing behaviors that were operationalized as negative instances of "Providing comfort" for dying patients in the work of Degner et al (1991) were "avoidance behavior that results in neglect" and "poor symptom management due to poor knowledge base". ICU nurses interviewed for this study reported that while avoidance behaviors that resulted in neglect did occur, the neglect tended to be psychological rather than physical. This finding is supported by Mervyn (1971) and Webster (1986) who indicated that while the management of the dying patient's physical symptoms is often carried out systematically and efficiently in health care settings, little attention is directed toward the provision of psychological support. Strauss (1966) noted that because of the tendency to equate good nursing care in the ICU with technical competence, the "psychology" of the patient often went neglected. Poor symptom management secondary to the nurse having a poor knowledge base was not a problem ICU nurses identified in their peers.

Sixth, nurses in both studies identified the importance of showing empathy and respect for patients and family members who were expressing anger. The source of the anger was understood and was not taken personally. Degner, Gow and Thompsen (1991) noted

that some of the ways nurses who had not developed a philosophical approach to managing anger reacted were avoiding the patient's room, speaking harshly, or showing their frustration to the patient or family member. ICU nurses in this study indicated that while chronic avoidance of angry patients and families or reacting with harsh responses were negative behaviors in care of the dying, avoidance in the short term was an understandable, acceptable reaction. Respondents indicated that taking "time-out" from anger laden situations was a safety valve that prevented them from saying or doing things that they might regret later. Thus, as long as it was short lived, a reaction of this nature was not seen to denote nurse insensitivity to patient needs. This perspective is significant, and may serve an important, protective function. Vachon, Lyall, and Freeman, (1978) noted that nurses working on a palliative care unit who had been socialized to know that the "good nurse" never had bad feelings worked in relative isolation from each other, and felt that they were the only "bad" nurse who at times felt angry, depressed, frustrated, helpless and hopeless. Prolonged feelings of this nature can lead to caregiver burn-out (Kalish, 1981; Shubin, 1978; Vachon, 1978; Worden, 1982). In order to avoid this, is important for nurses working with the dying to understand and respond to the feelings they experience (Rando, 1984).

Seventh, while both sets of nursing behaviors identified the importance of responding to colleagues, neither the literature reviewed nor the subjects in Degner, Gow, and Thompson's study

(1991) explicitly mentioned the concept of timeliness when providing emotional support and critical feedback to colleagues. In contrast, the timeliness of support and feedback was seen as being very important to ICU nurses.

Finally, the category "Responding to the family" in both studies identified the importance of behaviors that respond to the family's need for information, and reduce the potential for future regret. However, ICU nurses also indicated that in the course of responding to family members need for information they attempted to facilitate the transition from curative to palliative care. Much of this occurred in the course of giving information to the families about the patients response to treatment. This is supported by Degner (1991) who noted that "shifts in focus become apparent in patient, family, and staff communications" (p.406).

Such a shift marked an important transition for those involved in the patient's treatment. It was important to nurses during this transition time that they neither completely dashed all hopes of cure for patients and families, nor made them feel abandoned once active treatment was discontinued. Subjects were particularly critical of physicians who failed to communicate any hope to dying patients and families. The literature suggests that health professionals may hesitate to communicate hope for a variety of reasons. Some professionals feel that fostering hope in seriously ill patients encourages denial, and fosters false reassurance (Northouse and Northouse, 1991). And, despite the fact that some research indicates that denial serves to protect patients from

hopelessness (Brewin, 1977; Cassileth et al., 1980; Wool & Goldberg, 1986), many professionals continue to view it as maladaptive.

Northouse and Northouse (1991) contend that some professionals find it difficult to offer hope to patients with extensive disease or receiving palliative care because they continue to equate hope with cure. "Clearly, to communicate hope, professionals need to recognize that hope means the ability to maintain morale and courage, not just the ability to eradicate disease" (Northouse & Northouse, 1991, p.917). Nurses in this study helped maintain hope by assisting patients to focus on the moment, review their assets, and maintain important relationships. These strategies are similar to those identified in Miller and Knapp's (1986) research about helpful communication strategies with cancer patients.

Instances of negative nursing behaviors in care of the dying in this study had their genesis in avoidance and withdrawal. Intensive care nurses find the care of dying patients, and dealing with upset or bereaved relatives very stressful events (Lochoff, 1977; Noble, 1980). Hampe (1975) noted almost two decades ago that family members of dying patients saw doctors and nurses as being "too busy" to be concerned with their difficulties. Acceptance of this professional demeanour provides a legitimate means by which health care providers avoid concerning themselves with family bereavement. More critically, caregiver failure to drop the mask of professionalism has been characterized as tantamount to inhumane treatment of the dying (Ufema, 1975).

ICU nurses in this study strongly believed that caregivers needed to risk involvement with dying patients and their families, even if they weren't sure just exactly what to say or do. As one respondent noted, "Sometimes you just have to jump in there and do it". They remembered feeling uncertain about how to help, but over time had worked through their anxiety about how to proceed. Not all caregivers are able to achieve this. In contrast, nurses who remain preoccupied with saying the "right thing" and being "professional and objective" when caring for dying patients shift the focus of concern away from the dying patient to themselves (Lamerton, 1985; Mazzawy, 1985; and Trent, 1985).

The consequences of minimizing contact with dying patients and their families are well identified in the literature (Baker, 1963; Bunch & Zahre, 1976; Dugan, 1987; Kneisl, 1968; Morris, 1988; Quint, 1966). How nurses help relatives accept the death of a loved one and deal with the initial stages of grief may influence their subsequent experience of the grief process. Clearly, despite the usually short-term contacts with patients and their family members, critical care nurses' responses to bereavement are important, and may have long term implications (Eastham, 1990).

Implications of the Study

Recommendations for a) education, b) research, and c) practice can be made as a result of the findings from this study. They include the following:

a) Recommendations for Education

1. That educators structure courses in care of the dying to emphasize the intervention phase of the nursing process.
2. That educators debunk the myth that emotional involvement in care of the dying is antithetical to the notion of professionalism.
3. That educators encourage and support students in their interactions with dying patients and their families.
4. That educators expose students to the behaviors of nurse experts in care of the dying in the clinical setting.
5. That educators provide students with requisite knowledge about dying, grieving, family dynamics, and therapeutic use of self in nurse-patient relationships.

b) Implications for Practice

1. That administration recognize the need for staff feedback and timely support when caring for dying patients.
2. That nurses identify the importance of supporting one another (informally or otherwise) in the face of repeated loss.
3. That patients and families be given information about the illness experience clearly, directly, and thoroughly.
4. That nurses assess family dynamic patterns and identify the presence of actual or potential stresses in these interactions
5. That health care providers provide beginning bereavement

counselling for families who have experienced the death of one of their members.

c) Implications for Research

1. Only one group of respondents were included in this study, and as a result, the list of critical behaviors in care of the dying may not be complete. This study could be repeated with nurses from (i.e. medical-surgical units; the community) to see if they identify different categories of behaviors in care of the dying.
2. The patient population in this study was limited to adults. Critical nursing behaviors in care of the dying neonate and pediatric patient need to be explored with nurse experts working in these areas.
3. Maintenance of a sense of hope in relation to communicating with families about the response of the dying patient to treatment was a recurrent theme in this study. A descriptive study to identify the role hope plays in the experience of the families of dying patients is required to further explore this theme.

Summary

Inadequate instruction about how to care for the dying coupled with a practice grounded in recovery or cure has reinforced the perception of many health individuals that there is "nothing left to do" for dying patients and their families. The six categories of nursing behaviors identified in this study could serve as a guide for structuring critical care nursing education programs about care of the dying. The identification and description of specific nursing interventions in care of the dying is imperative in order to demonstrate to students and practising clinicians that a clearly defined role exists for them in the delivery of terminal care.

TABLES

TABLE 1 NURSING BEHAVIORS IDENTIFIED IN THE LITERATURE

TABLE 2 CRITICAL NURSING BEHAVIORS IN CARE OF THE DYING

TABLE 1
NURSING BEHAVIORS DESCRIBED IN THE LITERATURE

GENERAL BEHAVIOR	SPECIFIC BEHAVIORS	SOURCES FOR SPECIFIC BEHAVIORS
<u>Physical Care</u>	Gentle handling Pain control	Stanik (1989)
	Attention to monitors, I.V.'s and infusion pumps	Sheppard (1989)
<u>Communication with the Patient</u>	Reassure that "expert" help is near by Provide opportunities to discuss death	Farrell (1989)
	Create simple systems of communication for patients unable to speak	Simon (1980)
	Explain all procedures and care to unresponsive patients	Bledsoe (1987)
	Identify and attend to spiritual needs	Farrell (1989)
	Respond to call bells and monitor alarms quickly to communicate "availability"	Stanik (1989)
	Avoid non-verbal behavior showing despair	Simon (1980) Farrell (1989)
<u>Communication with the Family</u>	Provide privacy for patient-family talks	Stanik (1989)
	Provide family with brief, regular updates on patient condition, and inform immediately re deterioration	Farrell (1988) Hampe (1975)
	Allow family to "ventilate"	You'll (1989) Hampe (1975)
	Encourage family participation in care, if they desire	Bledsoe (1987)

TABLE 1 - continued

GENERAL BEHAVIOR	SPECIFIC BEHAVIORS	SOURCES FOR SPECIFIC BEHAVIORS
	Attend to "paper work" and "detail" to convey to family that nurse is too busy to talk	Sheppard (1989) Quint (1966)
	Justify the physician's decision re care goals when they conflict with family wishes	Wilson & Jacobsen (1990)
<u>Communication with Colleagues</u>	Arrange family meeting with physician so the former can ask questions and voice concerns	Wilson & Jacobsen (1990)
	Hold regular, informal inter-disciplinary meetings to allow all team members to vent feelings and resolve difficulties encountered in caring for dying patients and their families	Farrell (1989)
	Seek support from "experienced" staff to plan care for the dying patient	Richmond & Craig (1985)
<u>Manipulation of the Environment</u>	Place chairs at the bedside for visitors When possible, put bed siderails down	Simon (1980)
	Arrange equipment so it come between the visitor and the patient	Bledsoe (1987)

TABLE 2

CRITICAL NURSING BEHAVIORS IN CARE OF THE DYING ADULT IN THE ICU

BEHAVIORS	OPERATIONAL DEFINITIONS	
	POSITIVE	NEGATIVE
Responding after death has occurred	Behaviors that create a peaceful, dignified bedside scene for the family	Behaviors that show lack of respect for the family
	Behaviors that supports the realization that death has occurred	Judgemental behavior that limits the time family can spend with the body
	Behaviors that demonstrate respect for the corpse during post-mortem care	Rough, impersonal handling of the corpse
Responding to the family	Behaviors that respond to the family's need for information	Cursory explanations deferring to M.D., showing off knowledge base
	Behaviors that reduce the potential for future regret	Controlling behavior that limits family/patient contact time
	Behaviors that facilitate the transition from cure to palliation	
Responding to anger	Behavior that shows empathy and respect even when anger is directed at the nurse	Avoidance behavior or angry response
Responding to colleagues	Behaviors that provide emotional support and critical feedback to nurses	Behaviors that show difficulty in providing timely, adequate feedback to nurses
Providing Comfort	Behaviors that reduce physical and psychological pain	Avoidance behavior that results in neglect of patients, particularly psychological neglect
Enhancing Personal Growth	Behaviors that show that the nurse has defined a personal role in care of the dying	Behaviors that show lack of confidence and anxiety in care of the dying

Appendix A
Tool for Identifying
Nurse Experts

Disclaimer

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 consent to participate in this aspect of the study. You will not write your name on this form to identify it as your own. 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, and you may withdraw from this part of 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 ICU nurse(s) you work that best fit each description. The nurse must have had from between three to five years of experience in adult intensive care nursing, and presently be involved in patient care. You may write the names of up to three nurses for each paragraph. The same nurse may be named for more than one paragraph. You may name yourself if you feel it is appropriate.

Paragraph A

They are nurses who can facilitate the transition for dying patients from curative to palliative care. They realize that there is little they or others can do to prolong the life of the patient, but they maintain a vision of what is possible when it comes to providing comfort for dying patients and their families. They help the dying patient maintain a sense of self-esteem and dignity.

Name -----

Name -----

Name -----

Paragraph B

These nurses are especially sensitive to the needs of the families of dying patients. They promote an environment in which the participation of the relatives in care of their family member is possible, should the family so desire. They recognize that many relatives feel a need to be helpful to the dying person. Because they appear to have an intuitive grasp of the needs of dying patients and their families, they are able to provide terminal care in a truly remarkable way.

Name -----

Name -----

Name -----

Paragraph C

These nurses are excellent communicators. They promote clear, rational communication between dying patients, their families, and other health care team members. They are sensitive to the needs of both the patient and family to talk about their impending loss and what it means to them. They can respond effectively to the fear and anger that dying patients and their families may express. They seem to be able to zero in on the accurate region of the problem.

Name -----

Name -----

Name -----

Appendix B
Semi-structured
Interview Guide

Semi-Structured Interview Guide

What constitutes a critical incident?

* An incident in which a student or colleague had a positive attitude toward care of the dying patient or their family (i.e., was it something they said or did?).

* An incident in which a student or colleague had a negative attitude toward care of the dying or their family.

* An incident in which you feel your intervention with a dying patient and/or his family really made a difference in patient outcome either directly or indirectly.

* An incident that went unusually well.

* An incident in which there was a breakdown (i.e., things did not go as planned).

* An incident that was particularly demanding.

* An incident that you think captures what care of the dying adult in the ICU is all about.

Information that needs to be elicited from respondents:

* The context of the incident (e.g. shift, time of day, staff resources).

* A detailed description of what happened

* What were the nurses concerns at the time?

* What was the nurse thinking about as they care for that dying patient and/or their family?

* What did the nurse feel during and after the incident?

* What, if anything, did the nurse find most demanding about the incident?

*** Adapted from: Benner, P. (1984). From novice to expert: excellence and power in clinical nursing. Menlo Park: Addison-Wesley. pp. 300-301.

Degner, L.F., Gow, C., & Thompson, L. (in press), Critical nursing behaviors in care of the dying.

Appendix C
Biographical Data
Collection Form

Structured Data Collection

I.D.# _____

Date _____

1. Age

Age (years) _____

2. Gender

Gender _____

3. Years of experience in Intensive Care Nursing

Years _____

4. Most recent level of nursing education completed (CHECK ONE)

a) Registered Nursing Diploma _____

b) Post-diploma degree in nursing _____

c) Baccalaureate degree in nursing _____

d) Master degree in nursing _____

5. Have you completed an Intensive Care Nursing Program?

Yes _____

No _____

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