CRITICAL NURSE

BEHAVIORS IN CARE OF THE ADULT DYING

OF CANCER IN THE COMMUNITY

BY

PAT K. HELWER

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Abstract

Despite strides in research, prevention, detection and treatment of cancer in the last several decades, many patients diagnosed with cancer will require palliative care. The burden of providing palliative care is often undertaken by the family. Community nurses are in a key position to meet the needs of the dying patient and family, however little is known about what constitutes effective palliative nursing care in the community.

Guided by Benner's 'Novice to Expert' model and Pattison's 'Living-Dying' model, behaviors critical to care of the dying were identified from semi-structured interviews with ten nurses nominated by their peers, as 'experts' in care of dying adults.

Constant comparative content analysis was used to identify categories of behaviors essential in providing optimal care to adults dying of cancer at home and to their families. Two major categories emerged. The first category, labeled 'nursing behaviors' consisted of six themes: Developing rapport; Providing comfort; Responding to family; Coordinating care; Responding to colleagues, and Enhancing personal growth. The 'context' emerged as the second major category in this study and was identified as home care. The findings were compared with studies initiated by Degner, Gow and Thompson's (1991) research of critical nurse behaviors in care of the dying. The results of this study have implications for nursing practice, education and research.

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CRITICAL NURSE BEHAVIOURS

IN CARE OF THE ADULT PATIENT DYING OF CANCER IN THE COMMUNITY

CHAPTER 1

STATEMENT OF THE PROBLEM

"North American society has, over the last century, become

steeped in a bone-chilling fear of death" (Parsons & Parsons, 1992, p. 130).

Many people believe that the diagnosis of 'cancer' is synonymous with death

(Backer, Hannon & Russell, 1994). Once the patient is told the diagnosis, they

must cope with not only their personal fears but with those of their relatives,

friends, health care professionals, and society at large. Research to date reveals

a consistent pattern of nurses' and other caregivers' attitudes toward cancer as

largely negative and stereotyped, with cancer being seen as more devastating

than other life threatening diseases (Corner, 1988; Elkind, 1982). In Canada, it

was estimated that the number of cancer deaths in 1992 was 58,000. It was

further estimated that 115,000 new cases of cancer would be diagnosed, with

the number of new cases increasing by about 3,000 annually (Canadian Cancer

Statistics, 1992). Despite strides in research, prevention, detection, and

treatment of cancer in the last several decades, cancer continues to be a most

feared disease. "Of those who seek professional care, persons with cancer are

in the most vulnerable situation" (Gadow, 1986, p. 19). The increasing incidence

of cancer and the focus on cure versus comfort care, require that nurses and researchers examine ways of providing expert care for patients dying of cancer.

Since death has become a taboo topic, activities formerly performed by the family at the time of death have been assumed by special functionaries (Quint, 1967). Many dying patients would prefer to die at home but will most likely die in a hospital (Zuzman & Tschetter, 1984) where they may experience feelings of isolation and fear of abandonment (Tehan, 1982). The shortcomings of the modern hospital - a hierarchical structure with an emphasis on efficiency, technology and curing the patient at all cost - have led to the development of alternate care for the terminally ill (Schraff, 1984). The hospice movement emerged as a means of not only providing superior care but as a proposed means of providing lower-cost care than hospitals (Burns, Carney & Brobst, 1989). Rather than a place, hospice/palliative care is a health care philosophy aimed at improving the essence of life when a cure is no longer possible (Scott, 1992a). A fundamental principle of palliative care is that the patient together with the family comprise the unit of care (McCorkle & Germino, 1984; Reimer, Davies & Martins, 1991).

Methods of delivering palliative care vary. Home is preferred by many dying patients as it has the major advantage of familiar surroundings, family, friends, and a greater opportunity for self-determination (Tehan, 1982). Many patients could be managed at home for part of the palliative period if appropriate support from health care teams was available (Lubin, 1992).

Research reveals dying patients have physical, psychological and informational needs (Wingate & Lackey, 1989). Families need resources to support them in meeting the dying patient's needs (Martens & Davies, 1990). A systematic investigation of variables important to providing effective care of the dying has not been conducted (Brockopp, King & Hamilton, 1991) and a failure to link education to nursing practice and clinical outcomes is a major limitation in nursing knowledge (Degner, Gow & Thompson, 1991).

Benoliel viewed care of the dying as a nursing responsibility, stating "nurses themselves need to face the reality that care for the dying is essentially a nursing problem, not a medical problem...it is the nurses and their associates who deal with the day to day tasks of helping these people and their families" (1976, p.33). Nursing behaviors critical to caring for patients dying in their own homes and their families have not been examined. Little is known about palliative care in homes as compared to palliative care provided in institutions. Nurses caring for the dying require expert skills.

Expert skill is developed over extended, continued, and specific experience (Posner, 1988). Defining the nature of expertise has been a challenge in many professions. In nursing, Benner defined expertise as "a hybrid of practical and theoretical knowledge" (1984, p. 294). She suggested that the development of clinical knowledge is based upon the accumulation of paradigm cases. Depicted from clinical situations, paradigms generate knowledge, thus altering future nursing practice.

This examination of nurse behaviors, identified by their peers as expert in care of the dying at home, provides a beginning knowledge base for teaching nurses how to care for patients and how to support their families.

Purpose of the Study

The overall purpose of this study was to describe behaviors nurses identify as central to care of the adult patient dying of cancer at home. The following research questions were addressed:

1. What are behaviours that community nurses describe as critical to care of the adult dying at home that have a positive effect on the cancer patient and family?

2. What are behaviours that community nurses describe as critical to care of the adult dying at home that have a negative effect on the cancer patient and family?

3. How do the behaviours identified by community nurses in this study compare with the seven categories of nursing behaviours identified in Degner, Gow and Thompson's (1991) qualitative study of palliative care nurses and nurse educators and the six categories of nurse behaviors identified in McClement's (1993) study of ICU (intensive care unit) nurses?

Assumptions Underlying this Study

The following statements were assumptions of this study:

1. Nurses are instrumental in providing continuity of care for individuals dying of cancer at home and their family through communication.

2. Nurses reflecting on the care provided to the adult dying of cancer and the person's family will elicit descriptions of 'expert' behaviours.

3. Nurses providing 'expert' nursing care may become emotionally involved with the patient and the family.

Definition of Terms

Terms are described as they are used in this study:

cancer patient-individuals 18 years or older, female or male with a medical

diagnosis of terminal cancer.

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).

hospice/palliative care-a philosophy of caring for the physical, psychosocial and

informational needs of the terminally ill and their families, provided in a

variety of settings, and taking different forms according to the geographic

area and local customs (Townsend, 1989).

terminal care-care provided to a patient who is not expected to survive. Care is

directed to maximizing the patient's comfort by meeting their physical,

psychological, informational needs and other needs as identified by the

patient and family.

expert-the fifth stage of the Dreyfus model. The expert nurse has an intuitive

grasp of the situation, operating from a deep understanding of the total

situation. The nurse is able to zero in on the problem expeditiously,

because of her experience in paradigm cases (Benner, 1984).

paradigm case-a clinical experience that stands out and alters the way one

perceives and understands future clinical situations. Paradigm cases

create a new clinical understanding and open new clinical perspectives

and alternatives (Benner, 1984).

critical nurse behaviors-nursing behaviors central to care for the dying,

contributing to superior/positive patient outcomes or inferior/negative

patient outcomes.

home care-an integral part of a health delivery system that provides health care

services to individuals and families, over the life cycle, in their residences

(Rose, 1991).

home care nurse-a registered nurse, with 3 or more years experience in

    providing care for the sick and injured, in their place of residence.

intuition-an awareness or knowledge that seems to come unbidden and usually

    cannot be logically explained (Miller-Keane Encyclopedia & Dictionary of

    Medicine, Nursing & Allied Health, 1992).

advocate-the act of informing and supporting a person so that s/he can make the

    best decisions possible for her/himself (Kohnke, 1980).

Need for the Study

    The purpose of this exploratory, descriptive study, was to identify the

behaviors that nurses describe as central to providing home-based care to

adults dying of cancer in urban and rural Manitoba. Critical behaviors of nurses

working in acute care centers have previously been identified by patients, their

families and nurses themselves. Prior to this study, research identifying critical

behaviors of community nurses providing home care to the terminally ill cancer

patient had not been undertaken. This study was part of a program of research

that contributed to the development of a model of expert nursing practice in care

of the dying implemented by Dr. L. Degner and associates.

CHAPTER II

REVIEW OF RELATED LITERATURE

A review of the literature provided a context for how the dying are cared for in our society. The literature review was organized into the following subsections (i) attitudes toward death, dying, and cancer (ii) hospice/palliative care (iii) home care needs of adults dying of cancer and their family (iv) nursing care of adults dying of cancer at home and, (v) nurses' educational preparation in caring for adults dying of cancer.

Attitudes Toward Dying, Death and Cancer

This section of the literature included two categories (a) literature describing attitudes toward death, dying and cancer of the general society and (b) attitudes of nurses toward death, dying and cancer.

(a) Societal Attitudes

Historically, life was seen as a preparation for death, thus life and death were viewed as integral parts of the human experience (Martocchio, 1982). Until the twentieth century, a short life span, epidemics and famine contributed to high mortality rates. Death occurred at home with family, children and friends close by or in hospices located along the routes of crusaders, pilgrims and other medieval travellers. Fear and fascination with death began in the eighteenth century when death was no longer viewed as a part of life but as a break with life. Elaborate

funerals, monuments, and mourning prevailed (Backer, Hannon & Russell, 1982). In the early 1900s, significant technological changes, medical advances and industrialization precipitated rapid social change. Phillipe Aries (1974) described four stages in the evolution of attitudes toward death in western civilization. Historically, there was a resignation to death; then an acceptance of one's own death; later there was a fear of and fascination with death; and lastly, death was regarded as shameful and prohibitive. Since the 1950's we have been in a period of 'forbidden death'. Death became a technological phenomena, no longer occurring at home, but in the hospital with limited interaction between family and the dying person.

Mastering disease, illness, and death became the goal of medical care during the twentieth century. In 1969, Kübler-Ross summarized prevalent societal attitudes of the time when she wrote "Death is a fearful, frightening happening and the fear of death is a universal fear even if we think we have mastered it on many levels" (p.5). According to Saunders and McCorkle (1985), the medical model emphasized length of life rather than quality of life. In their devotion to curing, health care personnel began to de-emphasize their responsibility for caring (Campbell, 1986).

Knowing when and how to tell patients about death became a problem (Backer, Hannon & Russell, 1982; Benoliel, 1987-88; Clark & LaBeff, 1982; Jeffery, 1993; Kneisl, 1968; Knight & Field, 1981; Kübler-Ross, 1969, 1981; Wald, Foster & Wald, 1980; Weisman, 1979). Prior to the 1970s, doctors and

nurses claimed 'not telling' protected the patients from depression and anxiety

(Knight & Field, 1981). Today, dying patients are most likely to be told their

prognosis, but the 'death teller' dislikes the task because of the problematic and

uncertain nature of each situation (Clark & LaBeff, 1982).

The negative attitude society has toward death is similar to the negative

attitude society has toward the diagnosis of cancer. Cancer is associated with

protracted debilitation and dependency; intensive, unrelieved pain and

knowledge that one is dying (Backer et al, 1982). Canada faces a rapid rise in

the incidence of cancer over the next decade, and an equally dramatic increase

in mortality, with as many as 75,000 deaths per year expected by the year 2000

(Scott, 1992b). In summary, despite an increasing acceptance of death and

dying in our society, caring for the dying is seen as a growing problem in

Canada as the incidence of cancer continues to increase.

(b) Nurse's Attitudes to Death, Dying and Cancer

The attitudes of nursing personnel toward the terminally ill reflect attitudes

to death and cancer that are prevalent in the larger society. A 1969 study of

nursing home personnel revealed that 77% of the subjects encountered some

difficulty in caring for the dying or avoided discussing matters related to death

with a patient who was dying (Pearlman, Stotsky & Dominik, 1969). Similarly,

Kneisl (1968) reported that cultural taboos, hospital rituals, and defense

mechanisms operated to make withdrawal from dying patients a common

behaviour among hospital personnel. Corner (1988) critically reviewed research on attitudes toward cancer in a variety of settings, with a variety of personnel. She reported that despite different definitions of attitude and problematic research methods used in the studies, nurses and other health caregivers have negative and stereotyped attitudes toward cancer. Published lay autobiographies and interview transcriptions from earlier studies were analyzed to reveal that nurses and doctors were equally unhelpful in their communications with cancer patients (Thorne, 1988). Similarly Bond (1982), found the majority of close relatives had only superficial communications with hospital staff caring for cancer patients. Relatives are left very much to their own resources regarding the physical, psychological and social care of their family member .

Culture may also influence nurses attitudes to death and dying. In a cross-cultural study, Martin and Belcher (1986) compared Zulu nurses to South African and Mid-west American nurses. They concluded that Zulu nurses felt very uncomfortable around dying patients and avoided talking about the impending death of a cancer patient, when compared to the responses of the Midwest American nurses. However, is was not clear if the findings were due to cultural or educational differences. Further research is required on culture and attitudes to death.

A number of researchers have attempted to study variables that may be associated with death and anxiety/death avoiding behaviors of nurses. Popoff's mailed questionnaires on nurses' feelings about death and dying, returned by

15,430 nurses, revealed that 70% of nurses who "had come to terms with their own fear of death", felt confident to provide psychological care to the dying (1975, p. 49). Similarly, Reisetter and Thomas (1986) reported that personal experience with death was associated with nurses' greater awareness of therapeutic interventions. Personal experience was not defined. Brockopp, King and Hamilton (1991) used a non-probability sample of (n=32) palliative care nurses working in acute care centers to examine attitudes toward death and death anxiety. They found that palliative care nurses have a more positive attitude toward death, have less fear of their own death and death of others than nurses who do not work with the dying on a continuous basis. Analysis of the data collected from 372 registered nurses working in a variety of settings suggested that although nurses were likely to provide general nursing care and to communicate openly with the dying, they were not likely to provide continuing care for bereaved family members (Waltman & Zimmerman, 1991). In a recent study, 127 nurses completed a cancer attitude scale and 68 of the sample were interviewed in depth (Corner, 1993a). The interviews revealed that not only did nurses have a negative attitude towards death, but that they associate cancer with inevitable death. Samarel's (1989) ethnographic study revealed that the quality of nurses' interactions with patients depended on the patients' responsiveness rather than on their `acute' or `terminal' condition. Degner and Gow's (1988a) critical review of 13 evaluations of death education in nursing revealed that education may reduce students' death anxiety and/or attitudes to

care of the dying. However, the authors were not convinced of the findings because of numerous differences in study design, instrumentation, and data analysis used in the 13 studies that were examined. In a survey of 16 projects designed to study the effect of death education on nurses' death anxiety and attitude toward death, Brockopp et al. (1991) found no conclusive evidence to support the hypothesis that education was instrumental in modifying death anxiety and attitudes to death. Waltman (1990) found death anxiety in nurses was not predictive of behavioral intentions toward the dying.

In summary, it appears that nurses may hold negative attitudes toward the dying. The patients' responsiveness to the nurses' interventions, cultural factors and education of the nurse may affect nurses' attitudes and approach behaviours to the dying. Prior personal experiences with death and clinical experience in a palliative care setting may be other variables that create less negative attitudes toward the dying. Further empirical work to examine factors predictive of positive attitudes and their effect on care of the dying is needed.

Hospice/Palliative Care

This section of the literature review includes a) evolution of palliative care, b) philosophy and features of hospice care, c) the advantages of hospice care, and d) disadvantages of hospice care.

<u>a) Evolution of Palliative Care</u>

Historically, when death was accepted as a natural event, care of the dying was the work of the family with advice from a visiting physician. Nineteenth century medical specialization, technology, hospital bureaucracy, and escalating costs led to dehumanizing care for the terminally ill patient (Cassileth & Donovan, 1983; Koff, 1980; MacElveen-Hoehn & McIntosh, 1981; Zuzman & Tschetter, 1984). In 1967, Dr. Cicely Saunders, a medical doctor with previous education and experience in nursing and social work responded to the loneliness, isolation, lack of family involvement and unrelieved pain that seemed synonymous with individuals dying in acute care centers, by opening the first modern hospice in England (Campbell, 1986). The Canadian hospice care movement began in 1975 in Winnipeg and Montreal (Scott, 1992a). Between 1981 and 1986, there was a 200% increase in hospice programs, but a 1990 survey revealed that growth in Canada has been halted with a 4% decrease in total programs (Scott, 1992b). No reason was provided for this change.

Five types of hospices have been identified in the literature: (1) home care services, (2) hospice teams in hospitals, (3) palliative care units in hospitals, (4) hospices with hospital affiliations, and (5) completely autonomous hospices (Lundgren & Chen, 1991; MacElveen-Hoehn, 1981; Wald et al, 1980).

Increasing hospital costs and impersonal care have led to growth in home care services in Canada. Home health care is defined as "a continuum of comprehensive health care whereby health services are provided to individuals

and families in their places of residence for the purpose of promoting,

maintaining or restoring health, or of maximizing the level of independence,

while minimizing the effects of disability and illness, including terminal illness"

(McCorkle & Germino, 1984). Home care programs provide supportive services

to families enabling terminal patients to die at home (Lundgren & Chen, 1991;

McCorkle & Germino, 1984). Despite differences in location, hospice, palliative

and home care programs share a similar philosophy and offer similar services.

b) <u>Philosophy and Features of Hospice Care</u>

"Generally, the philosophy of hospice care is charact-

erized by the acceptance of death as a natural con-

clusion to life; hope can be offered so that patients

will not feel isolated and abandoned. Their humanness

and uniqueness are affirmed, and they have the right

to live and die in a manner determined by them, rather

than in a manner seen as ideal by the care providers"

(MacElveen-Hoehn & McIntosh, 1981, p. 32).

Based on this philosophy, hospice care is set apart from other terminal care by

several features:

. patient and family together are considered the unit of care

. comfort is actively pursued through the control of
physical, emotional, psychological and spiritual distress.

. an interdisciplinary team is involved in the planning and implementing of care. Patients and family are integral members of the team.

. support is available 24 hours a day, 7 days a week.

. trained volunteers are a component of the hospice program.

. bereavement care and follow-up are provided for the family.

. respite for care givers is provided (Downing, Brathwiate & Wilde, 1993;

Gotay, 1985; MacElveen-Hoehn & McIntosh, 1981; Tehan, 1982).

Although not all features are incorporated into all hospice care programs, the goals of providing a dignified, comfortable death for the terminally ill and caring for the patient and family together are increasingly recognized as important (Rhymes, 1990).

c) Advantages of Hospice Care

Some advantages of hospice care cited in the literature are related to existential issues, reduced health care costs and an alternative to euthanasia. Caregivers involved in hospice programs became leaders in pain control by explicitly making symptom control one of the goals of hospice care and by developing specific techniques of pain control (Gotay, 1985). McDonald (1990) contended that uncontrolled pain increases helplessness, hopelessness and despair; palliative care with its focus on easing pain may empower the terminally

ill patient. In a hospital versus hospice study (n=236), Kane (1985) found no significant difference in anxiety or depression between hospice patients and controls. However, hospice patients showed significantly greater satisfaction in interpersonal care and involvement in care decisions. The same study revealed that family members of hospice patients showed less anxiety and greater satisfaction with involvement in care. Although limited by sample size, Brown's (1990) study of 24 family members revealed that subjects preferred palliative care at home over care in any institution because they were able to: (1) be in the centre of meaningful activity, connected to family, friends and community, (2) live as normally as possible despite the illness and its ramifications, (3) maintain mutually supportive relationships with family and friends, (4) exercise freedom and control, and (5) experience reciprocity - having the patient at home created a 'shared awareness' with the caregiver.

In 1991, an Expert Panel on Palliative Care examined palliative care as a specialized program in the Canadian home care system. In a review of the report, Roe concluded that "people want to die in their own way in their own space" (1992, p.29). Data collected from interviews of a noninstitutionalized, nonstudent, representative sample of North Carolina individuals (n=500) led Zuzman and Tschetter (1984) to conclude that the majority of respondents (68%) preferred to die at home, if given the choice. Dawson (1991) conducted a mail-in survey of 100 bereaved family caregivers and reported that families experiencing a grief reaction are most likely to have their basic needs met at

home or when inpatient care is within a hospice rather than in a conventional hospital.

Despite the cited advantages of palliative home care, many patients do not die at home. In a retrospective study of 96 palliative care patients charts Lubin (1992) found that 94% of cancer patients die in acute care settings. Of the group studied, it was estimated that 35% of the patients 'could likely' or 'definitely could' have been discharged home at the time of their last admission (Lubin, 1992). Further studies are needed to explore patient and family preferences in choosing the location of their care during the process of dying and the advantages of various locations.

There has been controversy about the cost-effectiveness of home versus institutional care. Some researchers have found hospital patients were more costly to care for than hospice patients in the last year of life (Mor, Greer & Kastenbaum, 1988; Mor & Kidder, 1985). Conversely, in a randomized control trial of hospice care, Kane et al (1984) found that hospice was at least as expensive as conventional care. Gotay criticised Kane's findings, pointing out that the home hospice was not a separate program, as the patients on home care had no fewer inpatient days than controls. Of the hospice patients (n=137), 26% had undergone surgery, 38% were treated with radiation and 16% had received chemotherapy, indicating that hospice patients were receiving curative rather than palliative treatment (Gotay, 1985). Further research regarding the cost effectiveness of hospice care is required.

Another important argument for quality care of the dying has been advanced by Scott (1992b). Scott stated that the public needs to be informed that palliative care is an alternate to the quick death promised by euthanasia. By emphasizing the quality of remaining life and the ability of attending caregivers to provide comfort and care, hospice confronts the euthanasia movement head-on (Campbell, 1986). Further research is required given the multiple variables affecting care of the dying in the community. The assumption that home care for the dying is best needs to be tested under controlled conditions with attention to quality of life variables as well as to cost (Benoliel, 1986) with specific emphasis on caring behaviors helpful to patient and families.

d) Disadvantages of Hospice Care

The complexity of evaluating hospice care outcomes with such a burdened population makes research with this group particularity challenging. Inexperience and emotional involvement of family caregivers, inconsistent supervision of caregivers and poor pain control of patients are some of the disadvantages cited in the studies of hospice care. Parkes (1988) theorized that families of dying patients are ill-prepared to care for the terminally ill as they lack knowledge and skills and their emotional distress may create anxiety and tension, further aggravating patients' fears. Compared to bi-weekly home-hospice nurses' visits, hospital nurses are available 24 hours a day, monitoring the effects of medication, responding to changes in the patients' physical and

mental state and providing support to the patient and family. However, empirical support for Parkes' position was lacking.

The unavailability of care-givers and poor pain control are other disadvantages of palliative home care. Piloting a test to evaluate home hospice care, Pringle and Taylor (1984) found four of 44 patients were without caregivers, 40% of the patients' care-givers had no assistance in or out of the home, and 50% of patients had more than one care-giver. Home hospice has been identified with poor pain control (Kane, 1984; Pringle & Taylor, 1988). However, in Pringle and Taylor's study, when reasons for lack of pain control were examined, in seven of nine cases the patient/family chose not to follow the recommended medication regime. Research on the reasons for not following the recommended medication regime was not identified in this study. Further research is required to evaluate the advantages and disadvantages of palliative nursing care in homes.

Home Care Needs of Adults with Cancer

Patients with cancer have multiple and varied needs while dying at home. Wingate and Lackey (1989) provided useful definitions of physical, psychological and informational needs of cancer patients and their caregivers. Physical need is "a need for anything that continues, preserves, maintains or retains the individual's body functions" (Wingate & Lackey, 1989, p. 221). The need for adequate physical care of the cancer patient is frequently identified in

the literature (Gotay, 1984; Heinrich, Schag & Ganz, 1984; Hileman & Lackey, 1990; Hunt, 1992; Kristjanson, 1986; Longman, Atwood, Sherman, Benedict & Shang, 1992; Martins & Davies, 1990; Mayer, 1987; Petrosino, 1985; Wingate & Lackey, 1989). Problems with pain, anorexia, constipation, diarrhea, sleep, mobility and self-care were identified as physical needs.

"A need for anything that preserves, supports, and/or develops one's emotions, thoughts, and relationships with others" (Wingate & Lackey, 1989, p. 221) defines psychological needs. Anxiety, hostility, depression, isolation, reassurance, to be listened to, to be respected, and to be included in decision-making were included in psychological care. Psychological support was frequently identified as a need by dying patients (Blank, Clark, Longman, & Atwood, 1989; Gotay, 1984; Heinrich, Schag & Ganz, 1984; Hileman & Lackey, 1990; Kristjanson, 1986; Longman et al, 1992; Martins & Davies, 1990; Petrosino, 1985; Reimer, Davies & Martins, 1991; Wingate & Lackey, 1989).

Similarly, information, defined as "knowledge, information, or understanding that can be gained through education, experience, study, assistance, or by explanation" (Wingate & Lackey, 1989, p. 221) was identified by the terminally ill as a need (Gotay, 1984; Heinrich, Schag & Ganz, 1984; Higginson, Wade & McCarthy, 1990; Hileman & Lackey, 1990; Longman et al, 1992; Kristjanson, 1986; Martins & Davies, 1990; Reimer et al, 1991; Wingate & Lackey, 1989). Information needs included learning about the disease, expected changes, medications and personal care. Preservation of hope is important to

patients (Hileman & Lackey, 1990; Hunt, 1992; Martens & Davies, 1990) as well as the nurse 'being cheerful' (Longman et al, 1992; Martens & Davies, 1990). Coordination of services was also cited as a need (Higginson et al, 1990).

Most of the empirical studies on home care needs were exploratory and/or descriptive, with sample sizes ranging from 130 (n=65 patients and n=65 caregivers) in Higginsons' (1990) prospective study, to 16 (n=8 cancer patients and n=8 caregivers) in Blank et al's. (1989) descriptive study. The studies were cross-sectional, many lacked definitions, and there was inconsistent use of theoretical frameworks. Most of the research occurred within the past ten years. Further research is needed to identify palliative care needs of patients in their own homes.

Home Care Needs of Families Caring for Adults with Cancer

The presence of a caregiver enables terminally ill patients to remain in their own homes longer. The majority of family caregivers were identified as female, and over 50 years of age (Buckingham & Lupu, 1982; Decker & Young, 1991; Hileman & Lackey, 1990; Hull, 1990; Kane et al, 1984; Lindgren, 1990; Nugent, 1988; Petrosino, 1985; Stetz & Hanson, 1992; Wilkes, 1984).

The family, not just the patient reacts to the crisis and impact of cancer. The family is the first line of support (Edstrom, 1981; Lewis, 1986, 1983; McCorkle & Germino, 1984) and is also a client in need of nursing services (Tringali, 1986; Warner, 1992; Wright & Leahey, 1990). A review of empirical

research on family issues related to caring for the adult cancer patient at home yielded information on the areas relevant to nurses practising in the community. The family needs most frequently identified in the literature were information and psychological needs. Information about their dying relative was important to caregivers (Blank et al, 1989; Decker & Young, 1991; Edstrom & Miller, 1981; Higginson, et al, 1990; Hileman & Lackey, 1990; Longman, et al, 1992; Reimer, Davies & Martins, 1991; Rose, 1976; Ryan, 1992; Skorupka & Bohnet, 1982; Stetz, 1987; Stiles, 1990; Sullivan, Weinert & Fulton, 1993; Tringali, 1986; Welch, 1981; Wilson, 1992; Wingate & Lackey, 1989). Psychological needs were identified as: difficulty coping, emotional support, and fear of cancer (Blank et al, 1989; Davies, Reimer & Martins, 1990; Decker & Young, 1991; Gotay, 1984; Higginson et al, 1990; Hileman & Lackey, 1990; Hinds, 1985; Martens & Davies, 1990; Reimer & Martens, 1991; Rose, 1976; Ryan, 1992; Stetz, 1987; Stetz & Hanson, 1992; Sullivan, Weinert & Fulton, 1993; Welch, 1981; Wingate & Lackey, 1989).

Home caregivers frequently needed information on various aspects of providing physical care for the patient (Brown, 1990; Edstrom & Miller, 1981; Grobe, Ilstrup & Ahmann, 1981; Hinds, 1985; Rose, 1976; Stetz, 1987; Stetz & Hanson, 1992; Stiles, 1990; Welch, 1981). Family members needed (1) someone they could turn to, (2) support for decision-making, and (3) recognition for the work they did as caregivers (Blank et al, 1989; Brown, 1990; Decker & Young, 1991; Edstrom & Miller, 1981; Stiles, 1990; Wilson, 1992).

A need for respite care was reported as important to caregivers (Brown, 1990; Davies et al, 1990; Decker & Young, 1991; Hileman & Lackey, 1990; Hinds, 1985; Rose, 1976; Stetz & Hanson, 1992; Wilson, 1992). Caring for the dying patient and managing a household are new and additional roles for caregivers (Blank et al, 1989; Davies et al., 1990; Hileman & Lackey, 1990; Stetz, 1987; Wingate & Lackey, 1989). Pain control was cited as an area of concern for families (Brown, 1990; Edstrom & Miller, 1981; Kristjanson, 1986, 1989; Stetz, 1987; Stiles, 1990).

Family caregivers may also face financial difficulties (Blank et al, 1989; Decker & Young, 1991; Hileman & Lackey, 1990; Stetz & Hanson, 1992). The availability of nurses 24 hours a day, 7 days a week reassures family caregivers (Brown, 1990; Ryan, 1992; Skorupka & Bohnet, 1982; Stiles, 1990). It is important to caregivers to have questions answered honestly (Ryan, 1992; Skorupka & Bohnet, 1982; Stiles, 1990; Tringali, 1986) and to be given hope (Hileman & Lackey, 1990; Kristjanson, 1986, 1989; Martins & Davies, 1990; Tringali, 1986). Availability of emergency measures should they be required has been identified as a family concern (Longman et al, 1992; Ryan, 1992; Skorupka & Bohnet, 1982). Allowing the patient to be independent (Brown, 1990; Skorupka & Bohnet, 1982), adequate transportation (Blank et al, 1989; Rose, 1976) and legal counsel (Decker & Young, 1991) have been identified as needs by some family caregivers.

Q-sort methodology was used in a study of family satisfaction with

terminal care (n=210) in three different care settings (Kristjanson, 1989).
Families of terminally ill cancer patients in the palliative care unit and in home
care identified relieving pain quickly as most important to patient care. Families
of patients in the acute care units identified having the physician assess
symptoms thoroughly as most important to patient care.

With the exception of the Kristjanson (1989) study, the studies that were
surveyed tended to have small sample sizes, and were descriptive or
exploratory. Most studies were atheoretical and definitions of terms were often
lacking. Open-ended or semi-structured interviews were frequently used to
gather data. According to Lewis (1986), practitioners would do well to use open-
ended interviews to identify the families' dominant concerns. Research gathered
through interviews provides an increasing knowledge base in nursing. Although
there has been growth in research-based nursing knowledge, progress has been
slow due to the variety of methodologies used to gather data.

Nursing Care of the Adult Dying of Cancer at Home

Despite agreement that nurses should and do provide care to the
terminally ill, there is little description of what supportive care is or of how nurses
provide such care (Davies & Oberle, 1990). Empirically based studies of nurses
caring for patients dying of cancer at home and their families revealed that
behaviours that nurses identified as important to caring for the dying were
generally similar to those identified by terminally ill patients and their caregivers

(see Table 1). Competent physical care and psychological/psychosocial care were identified most often. Nurses identified important physiological needs as eating, elimination and personal hygiene (Heslin & Bramwell, 1989; Hunt, 1992; Lewandowski & Jones, 1988; Masters & Shontz, 1989; McGinnis, 1986; Mulhern, 1986; Peruselli, 1992; Petrosino, 1985; Stiles, 1991; Wingate & Lackey, 1989). Psychological/psychosocial needs were related to emotional needs of the patient and family (Heslin & Bramwell, 1989; Masters & Shontz, 1989; Mayer, 1987; McGinnis, 1986; Mulhern, 1986; Petrosino, 1985; Reimer et al, 1991; Ryan, 1992; Wingate & Lackey, 1989). Information needs were also identified by nurses (Lewandowski & Jones, 1988; McGinnis, 1986; Reimer et al, 1991; Stiles, 1990; Wingate & Lackey, 1989). Having care available 24 hours a day, 7 days a week was also described as availability of care (Ryan, 1992; Stiles, 1991). Nurses identified pain control (Petrosino, 1985; Stiles, 1991) and teaching (Ryan, 1992; Stiles, 1991), as important patient and caregiver needs . Answering questions about cancer honestly was important to nurses (Lewanowski & Jones, 1988; McGinnis, 1986; Ryan, 1992; Stiles, 1991). Spirituality (Heslin & Bramwell, 1989; Wingate & Lackey, 1989) and hope (Hunt, 1992; Lewanowski & Jones, 1988) were aspects of care mentioned by nurses. Mayer (1987) and McGinnis (1986) reported including the patient in decision-making was important during nursing care. Knowledge of community resources, locating equipment, homemaker help or volunteers to support the family were identified as nursing responsibilities (Reimer et al, 1991).

Nurses must develop a scientific body of knowledge in order to become credible clinicians (Ley, 1985). According to Latimer (1985), specific research should be directed toward describing what constitutes adequate, good, and exemplary care. Benner (1984) suggested the knowledge embedded in clinical practice is central to the advancement of nursing and that clinical expertise can be captured by interpretive descriptions of actual practice.

Despite an increase in research that identifies nurse behaviours essential to meeting the needs of the dying patient and the family, research studies on 'expert' nurse behaviours in caring for the dying at home are rare.

Educational Preparation of Nurses in Caring for the Dying

Providing superior nursing care to the terminally ill depends on many variables. Nurses' attitudes to death and dying and educational preparation are two of the variables. Nurses may protect their emotional integrity by distancing themselves from dying persons thus promoting patient isolation and abandonment (Fleming & Brown, 1983). "Overall, the evidence suggests that the majority of health care workers have not been adequately prepared for giving terminal care" (Benoliel,1987-88, p. 348). Corner (1993b) concurs, stating that education in palliative care is essential as care of the dying is increasingly becoming a nursing responsibility. Degner and Gow's (1988a) critical review of 13 studies evaluating death education revealed that nurse educators prefer an integrated or elective course approach to teaching students care of the dying,

despite recommendations in the nursing literature that all death education for nurses include a direct experience approach (Degner & Gow, 1988b). In a survey of baccalaureate programs (n=332) Dickinson (1986) determined that 80% had integrated educational units on death and dying into their other courses, 15% offered a full semester course or had one available in another department, and 5% have no formal death education course. Caty and Downe-Wamboldt (1984) used a questionnaire to survey nursing and medical schools in Canada n=33) revealing that integrating death and dying content throughout the curriculum was the most prevalent strategy. Although there is no empirical support for their position, Caty & Downe-Wamboldt (1984) state that integrating death education into the curriculum was "almost unanimously agreed upon as the best strategy" (pg. 37). In this study, validity and reliability of the findings are unknown, as the methods of data analysis were not revealed.

Corner and Wilson-Barnett (1992) triangulated data in an educational evaluation of newly registered nurses (n=127) to reveal that nurses associated cancer with inevitable death regardless of the stage of the disease or cancer site. Of the 34 nurses participating in Frommelt's (1991) study, 76.5% indicated they were unhappy with the education they had received on death and dying.

Degner and Gow (1988b) undertook a quasi-experimental, longitudinal study to examine nursing students behaviors in caring for the dying. They found that nursing students exposed to specific nursing education and clinical experience in caring for the dying had significantly better attitudes to care of the

dying than did the nursing control group who had received their education on death and dying using an integrated approach. Also, the experimental group reported more approach behaviours than the nursing control group one year post graduation. Using a paired t-test, Frommelt (1991) found support for the hypothesis that education has a significant effect on registered nurses' (n=34) attitudes to caring for the dying. Hare and Pratt (1989) studied nurses with varied exposure to patients with a poor prognosis of survival using a 2x3 factorial design. They found that the nurses with moderate and high exposure to patients with a poor prognosis were significantly more comfortable providing patient care than were nurses with low exposure.

To determine the most appropriate method of preparation for nurses in care of the dying, Degner and Gow (1988a) suggested three central nursing research issues need to be addressed: (1) how much death education is needed, (2) longitudinal experimental designs with sufficient sampling to detect significant effects, and (3) measurement of care results. This review of the nursing literature on death education in nursing revealed that death education has been incorporated into nursing curriculums, resulting in what appears to be improved nurses attitudes to care for the dying. As Degner and Gow pointed out, further research is needed.

Conclusion

A review of the literature revealed that nursing care of the terminally ill cancer patient has been influenced by societal and the nurses' own attitudes toward death and dying. Palliative/ hospice care has evolved since the first hospice unit, with its unique features and philosophy, was opened in 1967 by Dr. Saunders. Hospice care may result in cost savings in care of the terminally ill, enhanced personal care and it may be an alternative to euthanasia. The disadvantages of hospice/palliative care include poor caregiver preparation, lack of caregiver support in the home and poor pain control for the patient dying of cancer at home.

Research reveals that adults dying of cancer at home have physical, psychological and informational needs. Similarly, families caring for the dying at home most frequently identify that they require information and psychological support to care for their family member. Competent physical, psychological and informational needs were identified by nurses as most important to caring for the dying at home, reflecting the needs that were identified by dying patients and their family members. Some variables that influence nurses' attitudes to death and dying and the educational preparation of nurses to care for the dying were identified in this literature review but further research is required. This study has contributed to a beginning knowledge base in the identification of nurse behaviors critical to care of the cancer patient dying at home.

CHAPTER III

CONCEPTUAL FRAMEWORK

Two conceptual models were chosen for this study, (1) the Living-Dying .

model (Pattison, 1977), and (2) the Novice to Expert model by Patricia Benner

(1982, 1984) that was based on the Dreyfus Model of Skill Acquisition.

<u>Living-Dying Model</u>

The goal of the living-dying model was to maintain the quality of life by

assisting the patient and the patient support network toward maximizing their

potential in day-to-day living within the environment (Saunders & McCorkle,

1985). In this model the nurse was conceptualized as functioning in two

interrelated roles: (1) a problem-focused support system for patient and family,

and (2) a communication link between patient-family system and the larger

health care provider-community system (Benoliel, 1985; Saunders & McCorkle,

1985; Tornberg, McGrath & Benoliel, 1984). (see figure 1).

LIVING-DYING MODEL
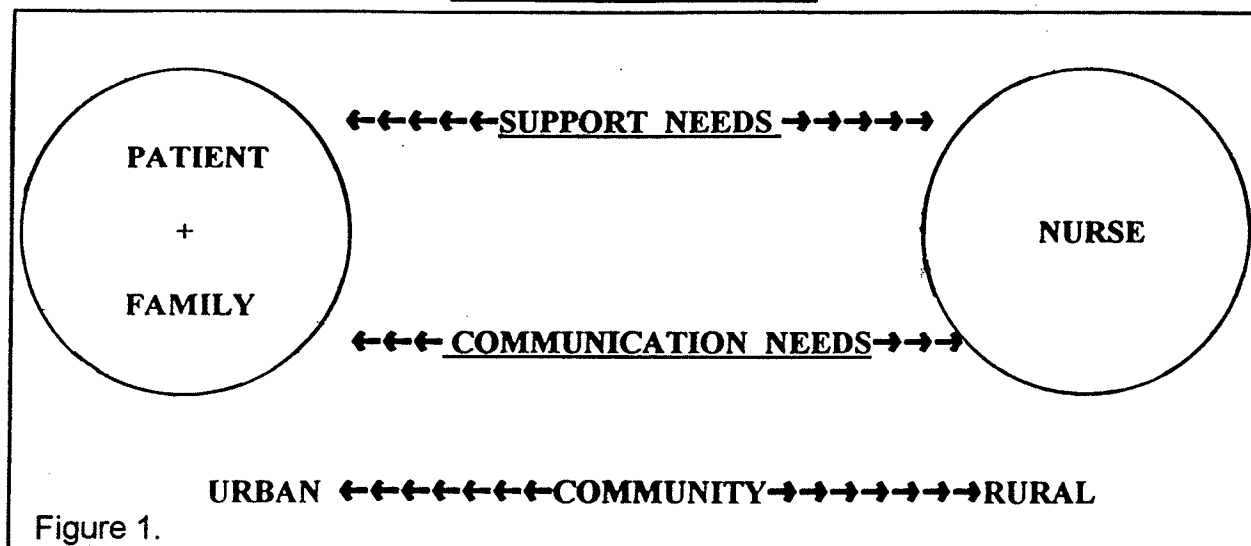
Figure 1.

The nurses' first role was directed toward helping the dying patient and members of the family cope with the stress and strain imposed by the demands of terminal illness. Support was conceptualized as the nursing interventions that promote patient self-care and involvement in decision-making as well as assisting the family to mobilize their coping resources (Tornberg et al, 1984). The second role was to provide continuity of care through communication. Nurses provide relevant information, collaborate in decision-making and coordinate services to ensure patient-centered care (Tornberg et al., 1984).

This model has been operationalized as 'transition services' in an extended care cancer program (Saunders & McCorkle, 1985) and applied in a case study (Tornberg et al., 1984). The model provided a useful framework within which to study 'expert' nurse behaviours in providing home care to the dying adult and the family. Nurses providing physiological and psychosocial care for terminally ill patients and their families corresponded with the first concept of the living-dying model, that of problem-focused support. Nurses providing information to the terminally ill patient and family is similar to the second concept of this model, that of communication facilitator. In this study nurses working in both rural and urban settings were found to provide support and information to the patients and family.

Novice to Expert Model

The second framework chosen for this study was Benner's (1984) Novice to Expert model. Benner's model of skill acquisition based on ascending levels of

proficiency, was originally outlined by Dreyfus and Dreyfus in an unpublished

report in 1980. They studied the common patterns employees displayed as they

acquired new skills and categorized them as novice, advanced beginner,

competent, proficient and expert (Dreyfus & Dreyfus, 1986). Belongia Le Breck,

(1989) provides succinct definitions for each level of proficiency described in

Benner's five stage model of nurse behaviors.

Novice-operates from rules, recognizes objective facts and features

relevant to the skill, but does not see them in reference to an

overall situation.

Advanced beginner-starts to identify aspects of clinical situations as

part of previous experiences and combines them with theory to

govern performance.

Competent-this nurse understands the situation and decides on

actions in a detached, analytical fashion. The organizational plan

takes on a hierarchy, so that the most important problems are dealt

with first.

Proficient-based on experience, the nurse displays an intuitive ability

to recognize and understand salient patterns in a task, and to

proceed with detached analysis on a course of action.

Expert-performance is governed by holistic similarity recognition,

no analysis is involved. The expert can group together situations

with similar patterns, features, actions, and goals. In a new

situation, the nurse unconsciously recognizes the category from past situations and takes immediate action.

Chi, Glasser and Farr (1988) provided a brief summary of the characteristics of experts. Experts excel mainly in their own domain (Johnson et al., 1981), and they identify large meaningful patterns in their area of expertise (Carter, Cushing, Sabers, Stein & Berliner, 1988; Chase & Simon, 1973; de Groot, 1966). Experts solve complex problems faster (Larkin, McDermott, Simon & Simon, 1980; Thompson, Ryan & Kizman, 1990) and have superior short and long term memory. Compared to novices who tend to represent a problem at a superficial level, experts see the deeper, more principled level of the problem (Berliner, 1987). Experts have strong self-monitoring skills and spend a great deal of time analyzing a problem qualitatively, trying to understand a problem from a mental representation (Chi et al., 1988).

There is a growing body of knowledge on nurse expert behaviours based on Benner's model. Jacavone and Dostal (1992) used a paradigm case to reveal that experts display a sense of saliency, intuitive judgement, and are totally involved when assessing and managing cardiac pain. To control for bias in this study, the authors used triangulation, prolonged engagement, negative case analysis, and an inquiry audit. Gatley (1992) used Benner's model in combination with clinical expertise to implement a district nurse course in Great Britain, stating clinical incidents involving 'experts' serve to increase knowledge and develop confidence (p. 86). In a study of novice and expert head nurses,

Dunn and Schilder (1993) found that expert head nurses were sensitive to long term planning, sought challenges at a different level, and were more skilled at viewing the situation as a whole than were novices. Less reliance on rules allowed experts to develop innovative strategies for problem-solving. Four methods of data collection enhanced the richness and validity of this study, but the study was limited by sample size (n=20) and the fact that the research was conducted in a single setting. In a rare study on expertise in community nursing, McMurray (1992) compared 10 novices with 27 experts that had been identified by peers and colleagues. Using a qualitative, interpretive approach McMurray collected data through participant observation, interviews with study participants and written retrospective accounts of clinical episodes. She found that combinations of educational factors, personal factors and experience influence the development of nursing expertise.

Recent studies implementing the novice to expert model support and enhance the nurse behaviours that were initially described by Benner. However, Benners' model has not been used to identify 'expert' nurse behaviors in caring for the dying in the community.

Critique of Novice to Expert Model

Benner (1984) described the expert nurse as having an 'intuitive grasp' of a situation. Benner and Tanner (1987) described intuition as an "understanding without rationale" (p.23) and that intuitive judgment is that which distinguishes

expert human judgment from computations exhibited by beginners and machines. Experts cannot always provide convincing rationale and explanations of their intuition (Benner, 1984; Dreyfus & Dreyfus, 1986). English (1993) argued that intuition as described by Dreyfus and Dreyfus is actually decision-making, whereas Benners' definition of intuition refers to a perceptual process that is explicated in models of memory from cognitive psychology. He criticized Benner's work for lacking objectivity, validity, generalizability and predictive power. English pointed out that if nursing is to become a research-based profession, nursing procedures need to be based on clinical research, and clinical assessment should be based on explicit criteria, not on intuition. Mitchell (1994) concurs, stating that there is no place for intuition in logic. Darbyshire (1994), defends the opposite view, although he praises English for explicitly identifying his positivist, cognitivist perspective. According to Darbyshire, it is this scientific position that has caused English to misinterpret and misunderstand the philosophical basis of Benner's work. Darbyshire states that English "fails to appreciate why it is simply not possible to explicate a complex human practice such as expert nursing" (p.757) and reduce it to a format that can identify or predict 'criteria' that constitutes expertise.

Factors such as experience, context and pattern recognition have been identified as important to the development of expertise (Benner, 1984; Dreyfus & Dreyfus, 1985, Larkin, et al, 1980). However, the model's "almost mystical descriptions and the insistence on uniqueness of each case, make research

supporting the theory difficult to design" (Belongia Le Breck, 1989, p. 45).

Despite the criticisms, Benner's framework was a useful tool with which to examine expert nurse behaviours. According to Darbyshire (1994), Benner's model is among the most "sustained, thoughtful, deliberative, challenging, empowering, influential...body of knowledge that has been produced in the last 20 years" (pg.760). Darbyshire further states that the model is truly empirically and research based as the 'paradigms' are derived from clinical data. Integrated with the Living-Dying model, the Novice to Expert model provided a meaningful context within which to study expert nurse behaviors in caring for the terminally ill patient at home (see Figure 2).

CRITICAL NURSE BEHAVIORS IN CARING FOR THE DYING IN THE COMMUNITY

←←←←←NURSE BEHAVIORS →→→→→

PATIENT

÷

FAMILY

NOVICE
ADVANCED BEGINNER
COMPETENT
PROFICIENT
EXPERT

NURSE

←←←←←←← CONTEXT→→→→→→→

URBAN ←←←←←←COMMUNITY→→→→→→→RURAL

Figure 2.
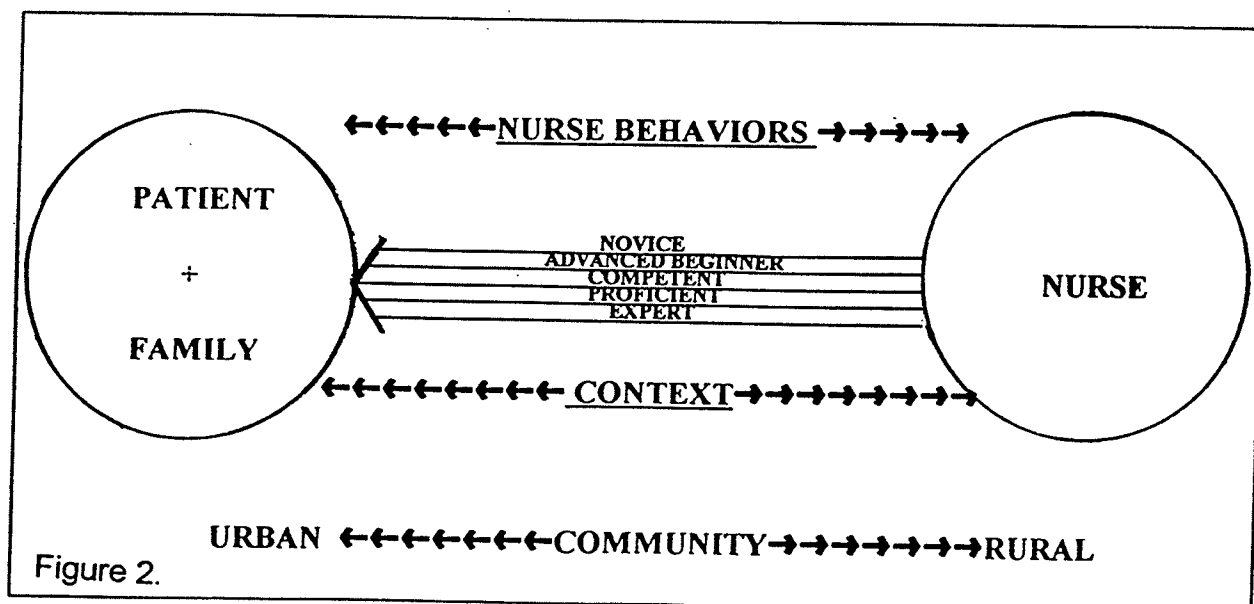
CHAPTER IV

METHODOLOGY

Research Design

The research question dictates the degree of structure a researcher requires in a study (Polit & Hungler, 1991). Exploratory-descriptive studies further the development of theory and explain phenomena from the perspective of the person being studied (Brink & Wood, 1989). Given the limited body of knowledge about what constitutes expert care of the adult dying at home, and the richness of the experience of health care in the community from the nurses' perspective, an exploratory-descriptive design was chosen to answer the research questions.

There were several assumptions implicit in the use of descriptive designs. Describing nurses' expert behaviors in home-based palliative care met two of the attributes of a descriptive design identified by Brink and Wood: (1) a single variable that is amenable to description exists in the population under study and, (2) there is little or no literature that describes the population at the present time (1989, p. 126).

METHODS

Sample

The purpose of this study was to describe 'expert' nurse behaviours in care of the dying. "Capturing the descriptions of expert performance is difficult" (Benner, 1984, p.32). Purposive sampling is a research strategy that maximizes

information while retaining the context (Lincoln & Guba, 1985) and is a useful tool to uncover practices, meaning and knowledge of expert nurse behaviours. To meet the needs of the study the informants chosen were considered to be the best able to detail the specifics of the situations they experience. The sampling method retained the unique flavour of the context and provided relevant data. Thus, the sampling technique ensured that both appropriateness and adequacy were met (Morse, 1991).

A purposive sample of ten nurses identified as expert in care of the dying cancer patient by three or more of their colleagues was taken from two groups of Manitoba community nurses. The sample was drawn from the Victorian Order of Nurses (VON) in Winnipeg and from Home Care nurses in the rural community of Selkirk. The nurses chosen were generalists whose work assignments frequently included caring for the dying cancer patient at home. Nurses with a particular interest in palliative care may have developed strong skills and carry a heavier caseload of palliative care clients. Nurses with advanced skills are referred to by their peers, are asked for consultations and advice, and may be asked to visit another nurses' client. The nomination process was used to identify the 'expert' nurse's from each group for this study. Choosing nurses from urban and rural settings was an attempt to maximize the differences between the nursing behaviors critical to care of the dying cancer patient in the two types of community settings. Previous research has shown that a sample size of ten subjects is sufficient when conducting qualitative studies (Munhall & Oiler,

1982). Data usually becomes redundant and no new categories of behaviours are identified by using additional subjects. A major criticism of purposive sampling is that the samples are biased by virtue of the sample selection. However, other sampling approaches would violate the qualitative principle of obtaining information from experts (Morse, 1991).

Instrument to Identify Participants

The instrument used to identify expert nurse behaviours was a modified form of the tool developed by McClement (1992). McClement's tool was based on: (1) Benner's (1984) descriptions of the attributes of nurse experts (2) research by Hiss, McDonald and Davis (1978) that identified physician educational influences in small community hospitals and, (3) descriptions of optimal nurse behaviours in the delivery of terminal care from the critical care literature. The critical care behaviors used by McClement were substituted with nurse behaviors that were identified as important from the literature by patients, families and nurses in caring for terminally ill adults while living at home (Appendix A).

Benner (1984) described nurse experts as having:

(1) an accurate, intuitive grasp of each situation with the ability to efficiently zero in on the problem.

(2) a perceptual acuity that provides a deep understanding of the whole situation.

(3) the ability to make decisions and manage complex situations in a truly remarkable way.

In the literature, the most frequently mentioned supportive nurse behaviours in caring for the patient dying at home and the family were identified as: (1) meeting physical needs - nursing care related to physical decline and providing comfort, (2) meeting the patients' and families' psychological needs - listening to the patient, answering questions honestly, (3) meeting informational needs - providing information, having knowledge of community resources (see Table 1). These needs were integrated with Benner's exemplars of nurse attributes to complete the instrument.

Interview Guide

A semi-structured interview based on Degner et al's. (1991) study was used to elicit from community nurses the behaviours they associated with positive and negative situations in care of the dying (Appendix B). Benner (1984) recommended the interview method as it 1) identifies the actual performance demands, resources and constraints, and 2) maintains a rich description of the holism of nursing practice. Initially, the nurse was asked to remember a situation involving nursing interventions that resulted in a positive outcome for the patient and family. Then, the nurse was asked to identify if the positive outcome was a result of what the nurse said or did, and the consequences of the nurses'

behaviour. The same approach was repeated, but the nurse was asked to remember a situation that resulted in a negative outcome for the dying patient and/or the family, and reasons for the outcome were sought.

Procedures

Following ethical approval from the Faculty of Nursing, and access approval from VON and Manitoba Health, the investigator met with the coordinator of the VON in Winnipeg, and Home Care coordinator in Selkirk to explain the proposed research project to them. After gaining approval from the coordinators, permission was solicited to attend the next regularly scheduled staff meeting. The VON coordinator preferred to disseminate information on the study to the community through the case coordinators based on a verbal and written explanation of the study by the researcher. The investigator provided home care nurses with a description of the study (see Appendix E) and the tool designed to nominate nurse experts (see Appendix A). The voluntary nature of the nurses' participation was stressed. A brief description of the study, extra copies of the recruitment tool and the investigator's phone numbers were left with the coordinators to give to nurses. A large envelope for the confidential nomination forms was placed in a location identified as convenient to the nurses. The envelope was collected by the investigator approximately four weeks later.

The forms were reviewed to identify nurses that had been nominated as 'expert' by three or more of their colleagues. The coordinators were asked to

supply the names and addresses of all nurses participating in the study. To maintain anonymity, the researcher requested privacy to copy the addresses and phone numbers of the nominated individuals.

Individuals nominated by their peers were contacted by telephone to determine their interest in participating in the study. Nurses agreeing to participate were provided with a description of the study (see Appendix E). They were informed that the interviews could take from 45-120 minutes and that they would be tape recorded. The interviewee selected the location of the interview, and mutually agreed upon times for the interview were arranged. The interview was initiated after a verbal and written description of the study was given to the nurse (see Appendix E) and a consent form was signed (see Appendix D).

Each subject was asked to complete a biographical data sheet designed to collect information related to educational background and work experience (see Appendix C). They were informed that: (1) participation in the study was voluntary, (2) the data would be kept confidential, and (3) the research findings would be reported in a manner that maintained the anonymity of the participants.

During the interviews the subjects were asked to reflect on their past experiences in caring for the dying. 'Layers of meaning' (Oiler, 1986) were peeled away to reveal the subject's interpretations of the experience. Questions such as 'What were your concerns at the time?' or 'What did you find most demanding about the incident?' were asked to reveal the context of the situation. According to Benner (1984), nurses accrue clinical knowledge over time and

lose track of what they have learned. Meanings of the situations were sought to identify and describe the behaviors that experts display during clinical practice.

Communication techniques used during the interviews were directed to establishing openess and trust. Eye contact and an open body posture were maintained. Paraphrasing was used to provide clarification and validation of the subject's statements. The subjects were informed prior to the interview that the investigator would take notes occasionally to track themes and key terms.

Subjects were told that the investigator might contact them later by telephone to clarify unclear statements made during the interview, however telephone contact was not required. After the data was transcribed, collated and categorized it was sent to the subjects for validation. The subjects were supplied with a stamped envelope, to return the data by mail to the researcher.

Data Analysis

The biographical data collected from the subjects was analyzed using descriptive analysis. The tape recorded interviews were transcribed verbatim. Data analysis was by the constant comparative method. A procedure described by Degner and Beaton (1987) was used to achieve reliability through consensus. The interviews were read by the investigator to identify patterns in the data. Phrases and sentences that represented themes or concepts related to the nurses' behaviors were separated into themes and later categorized using the Ethnograph computer program. All behaviors were compared and clustered until

themes that best represented the data emerged. The themes were then

compared and contrasted between and within groups until both the common and

unique characteristics of each group were identified and major categories

emerged. All transcriptions of the interviews were coded using this method. The

goal was to identify critical nurse behaviors as revealed by the interview data.

Later, operational definitions were written for each category. On completion of

the analysis the thesis advisor reviewed the categories of critical nurse

behaviors identified by the researcher.

As a credibility check, a draft of the collated data was distributed by mail

to the study participants for their critique. "A qualitative study is credible when it

presents such faithful descriptions or interpretations of a human experience that

the people having that experience would immediately recognize it from those

descriptions or interpretations as their own" (Sandelowski, 1986, p.30).

Evaluation of the Study

Methodological rigor is enhanced in a qualitative study if it meets the

criteria of credibility, fittingness, auditability and confirmability (Lincoln and

Guba, 1985, Sandelowski, 1986, Yonge & Stewin, 1988). Chalmers' (1992)

succinct definitions of Lincoln and Guba's four criteria guided the researcher in

the evaluation of this study.

Credibility refers to the ability of the researcher to describe and interpret the data being reported so faithfully that the persons having the experience, recognize it as their own (Glaser & Stauss, 1967; Sandelowski, 1986). Credibility of this study was enhanced by asking the subjects to critique the findings chapter to ensure the results of the research accurately reflected the nurses statements and meanings of statements. The participants validated that the findings and interpretations were congruent with their descriptions.

Fittingness refers to the 'fit' of the findings into contexts outside the study situation and when others in the profession view the findings as meaningful and applicable in terms of their own experience (Lincoln & Guba, 1967; Sandelowski, 1986). In this study, the fittingness of the data was addressed by providing examples directly from the interviews. This method enables the reader to validate the interpretations of the researcher. Previous research on critical nurse behaviors was used to compare and contrast the conceptualization of categories. Data revealed in this study was supported by descriptions of nurse behaviors found in the literature.

Auditability refers to the consistency of analysis of the qualitative findings. This criteria was met by maintaining a detailed 'decision-trail' throughout the study, enabling other researchers to follow the decision-making process. In addition, the same interview guide was used with all

participants in the study. Finally, the chairperson of the study, a researcher experienced in qualitative data analysis, examined the data and categories, establishing that consistency existed in the coding process and in the identification of categories.

Confirmability or neutrality refers to the freedom from bias in the research process and product. Confirmability is achieved when credibility, fittingness and auditability are established (Chalmers, 1992; Sandelowski, 1986). In this study, confirmability was achieved by meeting the criteria as described above.

Limitations of the Study

This study was limited by the following criteria:

(1) Data collected in face to face interviews and the researchers' previous experience in caring for terminally ill patients in the community may have influenced the results. Although the interviewer's intention was to remain objective , inherent biases and expectations about nursing behaviors may have been present.

(2) Lack of replicability is an inherent weakness of descriptive/exploratory studies. "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 their positions as a result of new experiences" (Brink & Wood, p. 147, 1989).

(3) The findings from this study will not be generalizable to community health nurses owing to the sample size and selection method used in this study. The size of the sample is small because the emphasis is on 'thick description' and on in-depth analysis of the data, rather than on generalization of the findings.

Summary

Ten nurses currently providing palliative care in the community, identified by their peers as 'expert' in care of the dying, were asked to describe situations in which their behaviors as a nurse resulted in very positive or very negative outcomes for the terminally ill patient and the family. Critical nursing behaviors in caring for the dying adult were identified by data analysis of the transcribed data.

ETHICAL CONSIDERATIONS

<u>Protection of Human Subjects</u>

In this study human rights were protected by the following procedures:

1. Approval to carry out the study was given by the University of Manitoba, Faculty of Nursing Ethics Committee prior to implementation. Access to community health nurses employed by the V.O.N and Home Care was provided by Continuing Care Programs Division, Manitoba Health.

2. All subjects agreeing to participate in the study were informed that their participation was voluntary and they were free to leave the study at any time. Prior to the interview subjects were given a verbal and written explanation of the

purpose of the study (see Appendix E). They were provided with the telephone numbers of the investigator and the advisor should they have any questions or concerns following the completion of the interviews.

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

4. To keep the identification of the subjects anonymous, participants were asked to complete a form to nominate nurse experts (appendix A), but not to sign it. Interviewed subjects were assigned a code number by the investigator. During transcription of the data, the identity of the participants was protected by omitting the names of nurses, patients and hospitals.

5. When recalling the events of a death scene or their experiences while caring for the terminally ill, some nurses became tearful. The investigator gave subjects emotional support and time to compose themselves before asking the subjects if they preferred to terminate the interview and continue at a later date, or if they wished to withdraw from the research study. All nurses continued the interview after having a few minutes to compose themselves.

CHAPTER V　　　　　**FINDINGS**

INTRODUCTION

　　　　Chapter five discusses the findings of the study conducted through

interviews of 10 community health nurses, on caring for the adult dying of cancer

in the community. Initially a description of the nurses' educational preparation

and experience will be discussed. The characteristics of the sample will be

followed by a description of the two major categories that emerged from the data.

The operational definitions of six critical nurse behaviors identified in the data

are supported by detailed excerpts from the interviews. A preliminary draft of

this chapter was distributed to the subjects to ensure that content validity of the

interviews was maintained during analysis. The data was changed to protect the

identities of the participants and names of hospitals. In the discussion of the

findings I=interviewee and R=researcher.

Characteristics of the Sample

　　　　A purposive sample of 10 community health nurses, identified by their

peers as 'expert' in care of the dying, participated in the study. Six respondents

were employed with the VON in an urban setting. Four nurses worked in a rural

area within a home care setting. All nurses were generalists, with no formal

preparation in caring for the terminally ill. Nine of the ten subjects were female.

The average years of nursing experience for the entire group was 17.5 years,

with a mean of 11 years in caring for the terminally ill. Rural nurses had provided

on average 13 years of palliative care in the community, while urban nurses

were slightly less experienced with an average of 9.8 years. Years of experience

ranged from 3 to 25 years for the urban nurses and 7 to 18 years for the rural

nurses. Five nurses had a diploma in registered nursing, two had a post diploma

degree in nursing and three had a baccalaureate degree in nursing. All

nominated nurses agreed to be interviewed by the researcher. They participated

in interviews ranging from one to two hours. Although all nurses working in the

community in Manitoba have palliative care patients on their caseload, this

sample may not be representative of all community health nurses. These nurses

were nominated by their peers as 'expert' in care of the dying and they may have

a larger number of terminally ill patients than their peers. Following the

interviews the researcher debriefed the subjects for a short period of time by

discussing mutual experiences in care of the dying and describing to the

subjects the process of data analysis that would occur after all the data had

been collected and processed.

Characteristics of the Data

The contents of ten interviews were analyzed revealing two major

categories 1) Nursing behaviors and 2) Context. Each category was then found

to have several interrelated themes (see Tables 2 & 3)).

Nursing behaviors emerged as the first major category in the data.

Themes related to nursing behaviors were A) Developing rapport B) Providing

comfort, C) Responding to the family, D) Coordinating care E) Responding to colleagues and, F) Enhancing personal growth. After repeated and prolonged contact with the data, the links that were evident in the nurse behaviors evolved into a pattern. A description of the pattern is provided.

All respondents indicated their ability to provide nursing care in the community was based on building an initial rapport with the dying patient and the family and/or significant other. The nurses maintained a trusting relationship by respecting patients' wishes and promoting their autonomy. Nurses subsequently initiated interventions to meet the patients' physical and emotional comfort needs. The data revealed that monitoring and maintaining effective pain control was a nursing priority. Patient teaching promoted autonomy and resulted in improved physiological and psychological comfort for the dying patient. Nurses were supportive of the patients' spiritual needs. They responded to the burden of the family caregivers by providing information and emotional support and by implementing nursing interventions that reduced the families' potential for future regret. Nurses' familiarity with community resources enabled them to coordinate care for their dying patients. Their knowledge and skill in communicating with doctors, pharmacists and social workers resulted in a role not sought by most nurses - that of a patient advocate. Nurses responded to colleagues by providing and receiving peer support. The support received from colleagues enabled nurses to feel more comfortable and confident in caring for the dying. The final theme to emerge was defined as personal growth. Nurses displayed

behaviors that demonstrate they have defined a personal role in care of the dying. The respondents revealed intuition guided their nursing behaviors. Each of the above categories and themes will be addressed separately and examples of the respondents verbatim comments will be presented to further describe, clarify and support the findings.

The second category, labelled context, pertained to the environment of dying patients. Nurses described hospital environments as promoting the authority of the caregiver. Conversely, the home environment supports the autonomy of the patient. Respondents pointed out the differences between institutional and community care often resulted in improved outcomes for the dying patient. Patients preferred to die at home, in a familiar environment, surrounded with family and friends. Despite efforts to accommodate the patients' wishes, under some circumstances nurses were instrumental in the hospitalization of patients. Lack of pain control and support systems were the most common reasons cited for hospitalization. Negative patient outcomes were most frequently related to limitations in the environment. Late referrals and decreased funding were two limitations cited in the data. Nurse behaviors, the largest category of behaviors to emerge from the data, will be discussed first.

FINDINGS- NURSE BEHAVIORS

Analysis of the interviews revealed that nurses implement interventions based on the individual patient needs. Knowledge of assessment and basic nursing skills guided the care that nurses provided in the home. Nurses consistently reported the uniqueness of each dying patient and their environment, however common elements were found in the data. The patterns of behaviors that emerged demonstrate that nurses have an expanded role in the community. In the final analysis of the interviews, Nursing Behaviors emerged as a major category with discrete properties. The properties of Developing rapport, Building relationships, Providing comfort, Responding to the family, Coordinating care and Personal growth were identified as six distinct themes in the behaviors of nurses. The operational definitions delineating each theme will be described.

Developing Rapport

The community nurses consistently reported that the single most significant behaviour they implemented was that of developing a rapport with the patient and family. The first step in developing a rapport was to build a relationship in the home. The nurse quietly and carefully listened to the patient and family for the first few visits. Their goal was to understand the patient needs, learn the 'home rules' and most importantly to build trust. The patients were

given a sense of security by the nurses' assertive, but not aggressive behavior. Nurses stated that 'as the years go on you gain a level of comfort in saying things'. Nurses are careful not to antagonize or intimidate people. Nurses intentionally sought emotional involvement in the home, seeking 'to become part of the family' and 'to establish a friendship level'.

The second step was to maintain a relationship or 'keep connected' in the home. This was achieved by respecting the patient and family. Nurses stated they were quick to learn respect for the patients' wishes 'even if it goes against what you believe in'. There was no 'rule of thumb' on how to approach care giving as each family had unique dynamics. By listening and 'feeling out' the interaction in the family, the nurse could support the patient and family. Some of the dimensions of respect the nurses reported were, respect for the patient's time, beliefs, wishes, way of coping, privacy, choices, right to treatment, and right to control. Nurses encouraged patients to express their wishes. This led to the third component in developing a rapport, that of promoting patient autonomy.

Listening to the patients' wishes gave nurses insight on how to approach patient care. Community nurses made suggestions to their patients, informed them of the available options, then they let the patient decide. They supported the patients' choice 'as long as it was safe'. Patients were provided with the teaching they needed to make informed decisions and then they were encouraged to take control. Out of respect for the many losses palliative care

patients experience, nurses expressed the philosophy that 'the patients' goals come first'. However, not all nurses implemented this approach. Patients, accustomed to supportive care of their regular nurse, resented aggressive treatment from replacement, nurses stating 'just don't ever send that nurse back'. Excerpts from the interviews provide support for the operationalization of building relationships.

Building Relationships

Building a relationship with the patient and family was the foundation for the nurses' future interventions in the home. Nurses adjusted to individual patient situations while attempting to create an atmosphere of openness and trust. Nurses were careful to not 'make any changes' in the home, preferring to 'fit in' with the already existing family dynamics. A breakdown in a trusting relationship could result in the patient's terminating the nurses' visits to the home.

> I'd pop by once every two or three weeks, just starting
> to get to know them a little bit. Talking about feelings,
> physical and emotional. Just developing a rapport.

> ...if you don't develop a rapport you won't get anywhere,
> because they need that trust. You need a rapport to be
> able to talk to them about getting a DNR (do not resuscitate)
> letter, and have they thought about choosing a funeral home?
> You need some kind of a rapport or you're like a bull in a
> china shop. I'm very comfortable with it, some just take a
> little longer than others.

As quickly as I can I build up some kind of a relationship
and go on a first name basis. I'll sit on the bed, or I'll
hug. Usually I'll give them a hug when I leave.

... we developed a good rapport. She said she didn't want
anybody else but me. I seem to understand her, to
listen to her. She hadn't been listened to previously.

You become such a big part of their family. I was in one
situation for so many years that I've seen the grandchildren
grow up. You know you are really a part of that family.

You get to know the family, not only the immediate family,
but you get to know who the extended family is and what the
dog likes to eat (chuckles). Palliative care in the home is
a very intimate experience for the nurse and for the family.

Overall, respondents were successful in establishing a solid relationship
with the dying patient and the family. Families expressed their gratitude to the
nurse and to the nurse's coordinators. Occasionally nurses received cards and
flowers from the family. Nurses reported they were remembered and
acknowledged by the family when they met unexpectedly in the community.

Respect for the Patient and Family

After establishing a beginning rapport in the home, nurses maintained a good relationship by respecting the patient and the family. Many types of respect were described in the data. One aspect of respect nurses described as frustrating to maintain was a family members' request that the patient not be told that their illness was terminal. Nurses were of the opinion that they were violating the patient's rights. Nurses described their position as precarious in these situations. While they strongly believed patients had the right to know about their illness and the determination of their future, nurses were also expected to meet the families' request to keep the prognosis from the patient. Circumstances not allowing for an honest and open relationship with the patient were described by nurses as most difficult. Nurses' respect for the patient and family served to maintain the initial rapport the nurses had established in the home and to promote quality to the patient's remaining life.

> I feel very strongly that the patient or client has the right to know. They should be informed. But when the family has specifically forbidden any discussion in front of the patient, when they don't want the diagnosis disclosed, I don't feel it is my position as the nurse to do so. If they are very strict about it, I feel I have to respect their wishes too. But I do feel, that as a family, they are doing a disservice in most cases. I can't think of a case where it isn't a disservice to the person that is dying, a very great one.

> One thing I did learn the hard way, very early, was to respect their wishes, even if it goes against what you believe in. I believe in

honesty, being up front and telling the patient. The patient has the right to know. The right to know his diagnosis and his prognosis. But that's my feeling.

We are there on their terms and they are most secure in their own home. There probably isn't another place in the world where a person feels more secure than in their own home.

I respected his time. In most cases we respect their time. If they don't like to get up in the morning, well, there are other people that do, so we see them first. I give my palliative care patients more leniency about time. That 's because I respect time and they don't have a lot of time.

We have to remember that this is what they prefer. If that's the choice they've made then we need to go with it.

Respecting whatever a person's beliefs are, and sharing your beliefs if you feel that it is appropriate.

You're going into a person's home and in every home the mix is totally different. The family dynamics and everything. I have to feel that out. I listen, respect, work with them and support them. I don't go in the home and say this is the way it's going to be done. That is most stressful for them.

An aspect of building relationships that is similar to, but different from respect, is the attention nurses give to promoting patient autonomy.

<u>Promoting Patient Autonomy</u>

Nurses used direct and indirect questions to assess the amount of autonomy individual patients preferred. Adults burdened with the knowledge that their illness is terminal react to the many losses they have endured with anger and denial. Nurses, aware of the adult need to be in control of one's life and situation, provide most patients with opportunities to make decisions and to be in control. Concerns for safety may be reason for the nurse to contract with patients. Patients experiencing falls or smoking in bed were two situations nurses reported that caused forceful negotiations between the nurse and patient.

Sometimes when you support the patient in refusing further treatment, the patient will say 'but my doctor says I should continue'. Some patients still see doctors as gods, up on pedestals. I tell them 'it's your choice, your life'. And I help them make the choice. They still make the choice. There is no room for being angry with the patient if they have a good chance at success and they decide no, I'm not having the surgery. That's their choice.

I sort of negotiate with the client how often they would like me to come. He would set the pace. Initially he said every other day or every third day was okay. Then it came down to every day and he agreed to it. He basically decided I should come every day and help him with his bath.

I think one thing you learn is to let them take the lead and give them as much freedom as they want to make decisions, so they still have autonomy. If on a particular day they don't want a bath, that's fine. Also sometimes they have good days and they want to talk and other days they don't want to talk so you don't push it. It's whatever they want to do as long as its safe and you know that they are comfortable.

I knew what was safe and what wasn't. I would contract with him and let him have some choices. You can usually do that in a certain way, you let them make the decisions. You make the suggestions and let him come up with the choices. He didn't want me to order a hospital bed. He wanted to order a fancy, remote controlled one. I said 'that's fine, that's fine'. He shopped around, he phoned and phoned. He had some control in accepting a hospital bed. He chose where it came from, how fancy it was, things like that. It was really important to let him have control.

He liked what he liked, when he liked it. This was just the type of character he was, so I respected that. We did have our confrontations, especially when it came to smoking. I really had to contract with him. We had to meet half way. Palliative patients report to me the most frustrating part of the illness is the loss of control of so many things. Loss of their feeling of wellness, the eventual loss of their life, loss of perhaps a job. So much loss of control.

Nurses developed an initial rapport by listening to the patient and family. They maintained their close, trusting relationship with the patient and family by respecting their wishes. Autonomy was promoted by encouraging the patient to make decisions and remain in control.

At times, nurses reported that developing a rapport took time. In some homes they 'did what they had to do' until a rapport was established and the patient was able to trust the nurse with their emotional burdens. In these situations, nurses relied on basic nursing interventions, giving the patient time to build a confident and secure bond.

Providing Comfort

The second major theme emerging in the category of nursing behaviors was providing comfort to the dying patient. Respondents reported patient comfort measures were related to physical symptoms, psychological/emotional support, spiritual concerns and information needs. Comfort care was implemented by the nurse, family, health care aides, friends, and at times neighbours. Single or collective caregivers were responsible for daily personal care, dressing changes, and medication administration. Although nurses were receptive to personally providing comfort care or to assisting other care givers, the patient situation dictated the approach to providing care. Flexibility in meeting the patients' comfort needs was the norm rather than the exception. Care was provided in homes or apartments, and at times community nurses visited their patients in hospital, revealing the strength of the rapport established during care giving. While they continued to maintain good interpersonal relationships in the home, they adroitly focused on clinical aspects of nursing care beginning with physical care.

Providing Physical Comfort

Patients were given a thorough physical assessment as soon as possible. Nursing interventions were then directed to meeting physical needs with the primary focus on alleviating pain. Once the nurse was confident pain was

controlled, oral intake, nausea, bowel and bladder function and sleep were

assessed. Although patients preferred to be at home, at times nurses would

arrange for admission to hospital for pain control. Nurses frequently assessed,

assisted or provided physical hygiene.

R: What is the other half?

I: Physical assessment. Basically, we assess how far the disease
has gone. Checking from head to toe, neurologically, physiologically,
pain control, hydration, food, calorie intake, urinary output. Whether
their bowels have worked and making sure that pain control is very
good. Having ways to counteract if the bowels are not moving
well. Because if the bowels don't move well, the person's not going
to eat either. If they're not eating, they're obviously going
to dehydrate and dehydrate and dwindle to nothing. At that point its
a vicious circle. It's important to control that vicious circle for
a little while because it buys a little bit of time and comfort. That's
what they want. It gives them time to adjust to the fact that yes,
this is the end, and to make peace with themselves and their family.

She didn't have to go to a central line and that allowed her to
stay at home and be with her family. They would wait for me to come
in because of the bone cancer. She had a transverse crack in her
sternum from being lifted up in the hoyer lift. I would help the
home health aide to position her and get her up. She would sit up
and look at her two kids come home at noon.

I'd go in daily. I tried to do mouth care, hygiene, helped
with getting the wash, and tidying up the place a little bit.
I'd sweep up by the side of the bed because there was food
littered all over. I'd give him his medication and I'd talk.

I will describe the last day she was alive. I was in there two
or three times that day. I kept getting paged to go in for

different things that had gone on. They were having a hard time keeping the oxygen bag in place, and keeping the pain and nausea controlled.

In most homes nurses integrated physical comfort measures with emotional support.

Providing Psychological/Emotional Comfort

The second theme in providing comfort behaviors was psychological/ emotional comfort measures. Listening to the patient was cited as an important nursing intervention. One nurse stated 'if you listen, you understand'. Nurses created 'an atmosphere of relaxation' ,tried to help the patient to 'feel safe' and told patients it was 'okay to cry'. Nurses comforted patients who were angry, bitter and in denial about their diagnosis. They reassured patients who were afraid of death and supported patients who were depressed. Nurses were vigilant for overt and covert communications between family members. In some homes emotional support was based on acting as an intermediary between patients and families. Some nurses gave the patient their home telephone number, a practice discouraged by their supervisors. Nurses explained their actions stating there were some people they intuitively knew would not abuse the privilege. Nurses stated 'being available' was reassuring to patients. In some homes, listening to the patient was the nurses' sole intervention. Patients appreciated the nurses' willingness to listen and provide emotional support stating 'what would I do without you?'

Trying to talk slowly, to take my time, to kind of create an
atmosphere of relaxation. Let's be calm here, let's think
things out. Just relax a little bit more and tell me about
your anxieties. What questions do you have? Anything we
haven't talked about yet that you might be curious about? Letting
them know that they can call anytime, and they do. A problem that
may seem small to me is major to them. I understand their anxiety
and help them work through it.

He really controlled what went on. It was interesting, a real
eye opener. He was a physician. When it came to any medication
he would tell me all the side effects. He knew everything and
I wasn't going to tell him anything. But when it came to dying,
the way your body changes, becoming more lethargic and anorexic,
he really counted on me to say how he was doing. It was
interesting because in common sense things he really needed
some assurance, support and guidance.

We talked about denial and we talked about anger. We
talked about childhood things with her. She had originally
been from Europe and as a child escaped during the war.
She had been through many atrocities during war time.

He knew his diagnosis...We talked about the fact that he was dying
and what emotions that brought out. I had him on my caseload for
two years. That was the best conversation we had. I talked to his
daughter and she said 'he doesn't tell us anything, if he has
enough money or how he is managing emotionally'. The family
thought he didn't sound quite right. He was quite open with me.

I can remember quite a few visits when we just sat cross legged
on her bed, and cried and talked. I remember one incident that
was really very hard for her. They were going somewhere in the
car and her little girl said to her 'I would like a new mommy,
I want a new mommy that's not sick all the time'. She cried
and cried, she broke down. She told me that it hurt so much.

Community nurses confidently encouraged patients to share their emotional burdens. They took the lead in exploring their patients' feelings, prompting them to verbalize their fears and to ask questions. An open non-judgmental approach allowed a trusting relationship to develop. Nurses listened to secret thoughts patients had not shared with family members. The closeness between patient and nurse allowed the nurse to gently approach the patients' preparation for their imminent death.

> Quite often I'm in with the patient, just the two of us.
> We're doing some kind of personal care and I get a chance
> to have a chat. That's when I'll say 'It's a long battle, isn't
> it?' or 'Do you ever get weary?' Maybe they will bring it up.
> Sometimes I'll ask 'Are you afraid of what is coming?'
> Sometimes there is fear. So you alleviate their fear. They
> just want to know.

Although nurses prepared patients for their deaths they were careful to 'never take away hope'. Nurses stated it was essential to maintain hope despite the patients' knowledge that their illness was terminal. Patients and families shared their angry feelings with community nurses if they had been told by inexperienced nurses that there was no hope. This was how one mother explained the need for hope to the community nurse.

> 'Why would they say that? We can't give up hope. I know my
> daughter is going to die, but if you give up hope, then you
> can't keep going. You still have to have hope'.

Providing Spiritual Support

Discussing emotional preparation for death with the community nurse gave some patients the opportunity to share their spiritual preparation. Nurses revealed they accepted the patients' beliefs unequivocally.

> We talked about spiritual matters. What comes after life and what do you think about it? Do you think about death? He hadn't thought a whole lot about death. He hadn't thought a whole lot about it, but he said he believed in an afterlife and heaven and that's about all he would allude to, that's as far as he would go. I tried to support him in that.

> You go there for months and months. You really get to know them quite well. Often they will talk about dying and what their fears are, what they believe they're going to, whether they have a belief in an afterlife or not. That was difficult for me because I didn't know much about the Native culture. I know some Natives are Christian and some are not. In this case, she didn't believe there was a heaven or that she would go to one. She believed more along the lines of reincarnation. That left me not quite knowing how to support her. Usually I'm prepared. I know how to listen and basically it comes right down to listening.

> On my first visit she said to me 'I've got cancer and I'm going to die at home. I want you to help me through this trip'. She was a very religious lady. I went to visit her on a weekly basis, for a very short time. I think it was somewhat easier for her because she was religious.

During the transition from living to dying, patients sought the nurses' clinical knowledge to enhance their self-care. Nurses identified teaching as an integral part of their role in community nursing.

Providing Information

Nurses were prepared to share their clinical and theoretical knowledge with their patients. They spent time teaching patients the effects and side effects of medication. Fear of addiction to narcotics was frequently verbalized by patients as the reason they tolerated pain. Nurses believed that tolerating pain was 'not acceptable' and attempted to teach patients theoretical reasons for maintaining good pain control. Nurses explained pain medications, blood pressures, changing colostomy bags and treatment protocols to the patient. They provided books, video tapes and pamphlets as alternate sources of information.

> That's another nice thing about working in the community...you're doing a lot of teaching. I find you get so much more cooperation. Patients are so much more compliant with their medication and their diet or whatever it may be, with some knowledge and understanding. They say 'I never had it explained that way'....
> It just takes a few seconds to explain that when they are on Tylenol #3, or something like it, there is a possibility it could be constipating and we try to nip it in the bud. When they are on analgesics, I include them in the teaching and then I let them be in control of their medication. They are usually really excellent at it. They need some knowledge of why they have to take it every four hours, otherwise they become fearful... I don't know if they think they're going to become a drug addict

or whatever. I dispel that myth right away. I use the barn door
and horse story. I tell them 'there is no sense closing the barn door
after the horse is already out'. They have done surveys and studies
that show you need a greater amount of pain medication to
bring pain back under control than to nip it in the bud.
Keep a certain amount of your pain medication circulating in
your blood stream all the time. Take it every four hours even
if you have to set your alarm'.

The first couple of weeks I was doing a lot of teaching. The
diagnosis was brand new. She had just received it and didn't
know what it was all about. She didn't really understand her
medications.

So rather than going in and saying 'you should be using
sterile gloves' it was more like 'wash your hands and try to
touch just the corners and that is fine'. If I were getting after
him and nit picking, I think he was the type of man who would
say 'lady, I'm dying, what do I care about medical asepsis or
what ever you call it'. So you give them their lead.

He wanted to know all his drugs, so I got him the drug book and
we went through them all .

Community nurses integrate physical care, psychological comfort,

spiritual support with patient teaching while maintaining a congenial, supportive

relationship with the dying patient. The family, as the primary caregivers in most

homes, also require nursing care.

Responding to the Family

Although some patients provide their own care in the home, most individuals are unable to accomplish independent self-care during the last stages of life. Family members, responsible for providing personal care in the home, often receive supplemental assistance from health care agencies. Assistance from home health care aides ranged from occasional respite care to 24 hour coverage. Nurses are sagacious in the home, responding to family and home attendants' needs, with the goal of promoting a calm and peaceful atmosphere.

Responding to the family emerged as the third theme in the category of nursing behaviors. Community nurses responded to the information needs of the family, provided emotional support and engaged in behaviors that reduced the families' potential for future regret. Initially family members sought information from the nurses on how to care for the dying person. One nurse stated 'the family had a real appetite for knowledge'. Teaching about giving and monitoring medications was a priority in many homes. Nurses taught the family that anorexia was common, that fluids were important and that physical changes would occur prior to death. Nurses taught the family how to give mouth care, skin care, how to turn and how to do deep breathing and coughing. Dressing changes, colostomy care and administering suppositories were also skills caregivers learned. Nurses provided information to the family with the goal of

'working as a team' to provide care. Families needed someone to answer their questions and to give them reassurance. Nurses reported that information gave the family a sense of confidence and control.

Family members were interested but afraid to ask how long the patient had left to live, or how the death would occur. Nurses described the signs of impending death, how the kidneys would fail and breath sounds would change. They told the family that their loved one was weary, ready for death. They 'paved the way' for the family by telling them the patient welcomed death and when the family was ready they could give the patient 'permission to die'.

Providing Information

> They were easy to teach. That was what they wanted from me; to teach them how to care for her. They were receptive to anything I suggested. To buy this, to do this kind of mouth care, to give this much fluid. Little suggestions. I thought it was going to turn out well and it was very positive.

> The first time I went to the home her husband was there. He was so worried that she wasn't eating. He asked what we could do to make her eat. I reassured him that it was okay. I told them about Boost, juices and milk shakes. These were suggestions if the person wanted to drink something. If they didn't want to drink, then quit nagging them.

> Knowledge is great. I gave them a lot of reinforcement, a lot of demonstrations and return demonstrations. Going back to the basics in teaching really does work.

I remember the first time I mentioned that he could be
incontinent they were totally blown over. The next day we talked
about it again. We went step by step about what they could expect.

The family started talking to me on the phone before I went in to
visit. He started to have wounds and skin breakdowns. His legs
broke wide open with ulcerations. I taught his wife how to do
dressings gradually. She wasn't eager to do it.

They did the bulk of the hands on care with guidance from us
for the things they were not familiar with. There was a catheter,
that kind of thing. With teaching they managed very, very well.
There was also a point when injections were needed. They called
on us for injections.

It is amazing how much each individual is capable of doing if
they have the right information. Having the information and being
given enough time to digest it all so that they are not overwhelmed.

I did a lot of listening and there was lot of teaching initially in
terms of laxatives, how morphine works and when you take it.

You teach them about medication because they are in control of it.
You teach them about pain control and skin care and whatever more.

I usually explain the breathing pattern. I say 'you'll know'. They
always do know, its so obvious.

Although family members were usually eager to learn care giving skills

they were often overwhelmed with the emotional burden of watching their loved

one die slowly, before their eyes. After their information needs were met, family

members shared their anxieties and fears during the nurses' visits. Nurses recognized the caregivers' unique situation and provided emotional support to ease their burden of care.

Providing Emotional Support

Nurses reported that most families needed reassurance and support. Nurses took time to listen to the concerns of the family and to explain the available options. Nurses were receptive to listening to the family vent their frustration or to encouraging and confirming the caregivers in decision-making. Nurses stated the family 'depend on you so much' because nurses 'take away some of the burden'. The burden of care is difficult to describe, but one husband said it this way:

> I've been through two wars and two plane crashes and none of
> that combined has been as hard as what this is to live through.

Although in some homes health care aides were present, patients continued to seek contact with a nurse sometimes 'just to talk'.

> Reassuring the family that they are doing fine. They sometimes feel
> they can't give the same care the patient would get in the hospital.
> I reassure them that they're doing everything and more. I go in daily
> and monitor the care. They are reassured when they know we're coming
> in daily and they are in contact with a medical person. They need the
> support. He started talking a little bit but he hadn't come to terms with
> her dying. He felt he couldn't care for her and she couldn't die.

They often need you in there reassuring them that they are doing just the most marvellous job.

I stay with them (the family) to guide and show them. They become much more confident and more willing to participate in the care, rather than pulling away. Then they feel they are doing something for the person as well. I give them confidence to administer medications. Their mental alertness is not at its peak at that point because they have so much stress. The person they love so much is dying. They're not able to think straight, consequently they need some guidance.

The daughter would give me a phone call. She felt frustrated. She knew what she had to do but she nursed all day and she didn't want to come to see her father and be a nurse all evening and night. So she thanked me for allowing her to be a daughter rather than being a nurse when she came home.

They seem to lose control and you have to pull the family together. There is sort of an anger inside when you are losing a loved one. The family will sometimes take that anger out on each other.

Sometimes we have to be a little, not cruel, but firm with some of the family. We point out that it's the patient's time now and that the most selfless thing to do is to let them (the patient) do what they want. Sometimes they (the family) are so wrapped up in the death, the pain and the grief that is coming they don't realize that it's so much harder on the patient if they are still alert. The patient doesn't want to die but there is nothing they can do about it. I tell the family 'all they want is your quality time, sometimes just to talk about it'.

Occasionally an unusual situation occurred that challenged the nurse to seek unique interventions. In the literature these cases are referred to as a 'paradigm case'.

> She was in and out of consciousness. When she awoke I got close to her and asked her if she thought it was her time. She nodded and said 'I think so'. She went on for several hours after that. By that evening I had spoken on the phone several times to the husband and the daughter that lived in the city. I felt that we were looking at the day that she was going to die. The husband and the daughter were so concerned. They wanted to know what they should do and how they were going to handle this. I said 'you want to keep her dry and comfortable; keep moving and turning her. Even though there is no response, keep talking to her and encourage her to let go'. I told the daughter and husband that she felt that day would be her last. Each time we spoke they said she isn't letting go for some reason. They said her breathing is so laboured and she is just not letting go. Then I remembered about the daughter out of province. I knew she had phoned during the evening, so I asked if the mother had a chance to talk to her at all. I knew she was extremely worried about the daughter's pregnancy and about the fights about whether the daughter should risk the trip to see her mom one last time. Both the husband and daughter said no, she had not spoken to the daughter; they didn't think that she would be able to hear. They said she was not talking to them, that she wasn't responding anymore. I said 'try one thing, try phoning back to the daughter out of province and tell her to talk to her mother even though her mother is not responding. Put the phone by her ear, so that she can hear. Tell her to tell her mom that she is going to be okay, that she's alright'. So they did that, they phoned her back long distance. There were many tears and it was very emotional. The daughter told her mom it was okay to go. About fifteen minutes after that she went.

Families require support to acknowledge and resolve problems in their relationship with the dying person. Nurses prudently encourage family members to settle their affairs with the patient to reduce the potential for future regret.

Reducing Potential for Future Regret

Nurses acted as liaisons between the family and the dying person. Their previous experience in care of the dying led them to encourage the family to make amends, to express their feelings and to clear their conscience prior to the death.

> I: The one thing I do tell them, that is most important, is if you have anything important to say, anything that is in your heart or mind, anything that you've always wanted to say, say it while she is able to hear.
> R: And do they?
> I: Most of them do. I tell them because 'there could be a time when you will want to say something and she will not able to answer back. But now she hears you. If you expect an answer back, say it now while the time is good because you will never have that opportunity again and you will live with that regret for the rest of your life'.

> I try to work through the family dynamics first. I see that as most important. If a person is dying, that has to be dealt with... They've got to enjoy this time and learn to appreciate each other a little bit more, because if he's going to stay at home, they will need each other. I pointed out to him that she is quite stressed, and she is. She does all the personal care.

> So that was a nice experience for the family because she just went to sleep. It was what she wanted. The husband really felt that he had done the best that he could do.

By encouraging behaviors that reduce the potential for future regret, nurses promote memories that help the caregivers through the grieving process.

Coordinating Care

The fourth theme to emerge in the category of nursing behaviors was coordinating care. Terminally ill patients require support systems to achieve a peaceful death at home. Debilitated by the disease and lethargic from analgesics, cancer patients frequently do not have the energy to seek their own resources. Family members and patients are often not cognizant of the resources available to them from various health care agencies in the community. Coordination of care for terminally ill patients was not a responsibility the community nurses actively sought. However, because of their knowledge of the health care system and of the resources available in the community, nurses found themselves in a natural position to advocate and to make decisions for their patients.

Resources

The supplies needed to give nursing care in the home ranged from hospital beds to incontinent pads. All physical aides that are found in hospitals were provided in the home. Nurses arranged for homemakers, respite care, 24 hour Licensed Practical Nurse services, volunteers, physiotherapists, occupational therapists, psychologists, and bereavement counselling.

We phoned the doctor. We used the university medication line. We did get hospice involved. We had volunteer visitors. People who would do the shopping. We know the resources that are available in the city and that are important in providing quality palliative care. We know where the supports are, where to get volunteer drivers to take people to treatments when they are living on pension or social security and can't afford $25.00 cab fares to get to the hospital for treatment. We know that the services are there.

We coordinated the radiation treatments, we ordered medication, we arranged transportation and equipment. He was coordinated with a palliative care unit but he did not want to go there. He wanted to stay at home and be at home. We ordered him monkey bars, rails, dressings, oxygen. Anything I wanted I could get.

We did get a hospital bed in there. They had to move the furniture around in order to find a place for the bed. We got all the supplies and equipment that we could possibly get in there, for her to stay home.

She did not want to go back to the hospital. She definitely wanted to die at home. We were able to do that, with the additional support workers in the home to provide assistance to the patient and her husband. We went in on a daily basis and then whenever it was necessary...

Through their knowledge and contacts with resources in the community, nurses frequently found themselves in the position of patient advocate. They recognized that positive patient outcomes depended on their willingness to speak for the patient. Nurses encouraged family members to take on the responsibility of contacting doctors, pharmacies or health care agencies. However, family members or significant others were not always available or able

to make the required contacts. Nurses frequently advocated with doctors to

adjust the dosage or type of analgesics. Similarity, they negotiated for services,

supplies, access to facilities. They requested increased nursing time for

palliative care patients from their supervisors.

Advocating

> If they need a narcotic, I need a written order, of course. So I anticipate
> it two or three days ahead and plan who will pick it up. As a nurse I feel
> I have to coordinate, be a nurse coordinator. We always have to
> coordinate the medications, making sure there are ample amounts.
> Thinking ahead.

> At first I'd ask the family to ask the doctor when he came to visit. The
> doctor always put the barriers up so I took that responsibility myself.
> I would phone the doctor. We had some really ticklish situations, but
> I was able to deal with them. That relieved the stress for the family.

> I act as a middleman, as an advocate for that patient and their family.
> It helps to take some of the burden from their shoulders. Then
> they have more energy to devote to the patient.

> This woman was remarkable, her GP(general practitioner) knew of
> this lump in her breast. She was a diminutive little lady, with a tiny
> chest on her, so the lump was so noticeable. The family were
> concerned. The daughters spoke to me and said that the doctor
> thought it was probably cancer but because of her age, there was
> not much he could do. She was in her 90's. I said 'because of her
> age! She's healthy as a horse, her heart is okay. Get another
> opinion.' So they got a second opinion and she had one of the
> best mastectomies I've ever seen. She did her post mastectomy

range of motion exercises better than many younger women.
She recovered totally and went on to live many years after that.

Often I have to tell the family, the patient wants permission to die...
you have to give them permission to die, tell them its' okay.

I can remember being very angry. It was a few years ago. A comment
was made that nurses working weekends couldn't allow for extended
time for palliative patients. I wasn't terribly tactful, I remember saying
'that's fine, we'll just tell people to die between Monday and Friday,
nine to five' (chuckles). It made me so angry, to think that people in
supervisory positions would make a comment like that.

Nurses seek opportunities to speak to patients regarding arrangements

for their death such as signing a DNR letter and preparing for the funeral.

Although speaking openly about making arrangements for one's death is difficult,

nurses' willingness to approach the topic helps to avoid ambulance and police

personnel arriving after the death has occurred, thus easing the death scene for

the family.

When you're involved with palliative care for a longer period of time
you have the opportunity to talk to people. You ask if they have a will
and if they have thought about insurance. You ask them if they have
reviewed the business types of things, funeral homes, cremation, the
burial. It's very tough to do. In this case I felt very rushed in some ways
because she signed her will the day before she died.

<u>Decision-Making</u>

Albeit nurses encourage patients to be in control and to make decisions, some palliative patients prefer to leave decision-making to the nurse. Similarly, families not capable of coping with the stress of caring for the dying are given guidance in decision-making.

> When you see them losing control, you have to make the judgments for them.

> They don't know if the problem is big enough that the doctor should be told about it, so they leave that up to us.

> While providing holistic care in the community, nurses find themselves in

the role of coordinators of care and patient advocates.

Responding to Colleagues

Constant giving is essential in palliative care. Community nurses reported 'you give much more of yourself in palliative care, it's very emotionally draining'. Nurses stated they were 'exhausted' when leaving a home after a few hours of supporting the dying person and family. During times of frustration and indecision, nurses shared their problems with their peers and were given support and ideas that were conducive to problem-solving. Nurses stated 'w e rely on

each other a lot' and 'it's good to talk to the coordinator, sharing the burden makes it easier'. One nurse reported sharing with colleagues 'takes a load off your shoulders because you don't feel like you're burdened with their secrets'. One group of nurses explored the topic of life after death stating they had 'great comfort with each other'. Responding to colleagues was operationally defined as nurse behaviors that provide emotional support and critical feedback to colleagues.

> I: We are supportive of each other as a group of nurses. I think there's a genuine humanism, or love of humanity in the nurses. Granted, we all get frustrated and spout off when things go wrong. But the bottom line is that when it comes to palliative care, we all have the desire to give a little bit more. It just so happens that this group of nurses have worked together for a long time. We have had deaths in our own families. All the nurses have experienced the death of parents, brothers or other family members. Other nurses have shown support during that time. You get to know each other's families. It's a very tight knit group...

> If I don't know how to handle something, there is always someone else that I can go to. I say 'this family is at their wits end, I'm at my wits end. What am I going to tell them? How are we going to get help? I need some help'. And there is help. If we don't know, we find out.

> I: You kind of bounce off each other. That's very important. We often use our coffee breaks or office time for that. One of the nurses I share my palliative patients with has become my personal friend outside of work. We tend to talk at night. We don't realize we're slipping into that.
> R: For the support?
> I: We need the support because there is no formal support through the office and we need it. If we're frustrated by something, we can

tell the second person. They can say either 'don't be stupid, you don't need to be frustrated by it' or 'yes, I understand. This is what I would do'.

R: Do you support one another?

I: We build that support ourselves. I tend to ask the same people because not everyone likes palliative care.

R: What does your group do that results in better care for patients?

I: We give continuity, emotional support and recognition that people need to verbalize and be comfortable with talking about dying. We are comfortable with our own lives and our own deaths. As a group of nurses we have worked together toward that comfort. We have spoken about spirituality and life after death. We have explored these topics as a group of nurses and then have felt comfortable exploring them with our patients. We have a great comfort with each other. A lot of people express their emotions. We understand when anger is anger at death and not at you because you're the nurse. The group that has worked together for a long period of time finds palliative care really rewarding. I would say our group works because of experience. We have seen a great many types of cancers, types of appliances and family's coping patterns.

One of the nurses that we had with us, she has since left, wrote a nursing care plan for the nurses. She went to the supervisors and said 'look, we need time for our nurses'. The care plan was about grieving and handling palliative care patients. We go through times of the year or stages when there are so many people on palliative care that there aren't enough hands to go around, to keep on top of the palliatives.

Nurses use a variety of methods to provide palliative care. Some nurses preferred to work in teams of two or three. Having several nurses in the home had the advantage of 1) sharing the burden of care with others and 2) increasing the continuity of care for the patient. An established relationship was beneficial to the patient and family as they were not explaining their problems repeatedly to new caregivers. Other nurses worked their caseload of palliative care patients

independently. These nurses consulted regularly with peers, citing one or two nurses they preferred to discuss their cases with.

It's important that they get to know different nurses and that we have a different pair of eyes to look at the situation; to come up with different ideas for any problems that might arise. A different nursing pool will have different problem solving skills and that's helpful, we rely on each other a lot.

There are probably three of us in the group I work with and palliative care has become our specialty. We share with each other, we spell each other off. We all sort of have the same ideas of continuity and that's important.

My co-workers say 'do you want to share some of your palliative patients?', because at any one time anywhere from 50% to 80% of my case load are dying.

A review of the data revealed that the personal growth of nurses was enhanced not only by the support of their peers but also from their personal reflections. Although each situation was unique, experienced nurses observed patterns in the care they provided to the terminally ill. Recognizing patterns enabled the nurse to anticipate and respond to patients' needs. Knowledge gained from years of experience enhanced the nurse's personal growth.

Enhancing Personal Growth

The sixth and final theme to emerge from the nurse behaviors category was enhancing personal growth. Community nurses displayed obvious confidence and comfort in care of the dying. The number of palliative care patients on a nurse's caseload varied from zero to eight. Some nurses stated that more than two or three palliative patients at one time was a heavy caseload while one nurse stated she had up to eight palliative patients at one time. Community nurses reported that although some of their peers avoided taking on palliative care patients, they did not. They believed they 'were developing' as palliative care nurses and they found that rewarding. Nurses stated they learned from each palliative patient, stressing that each patient was unique and required individualized nursing care. These behaviors illustrated that the nurse had defined a personal role in care of the dying. The nurses' skill and confidence in caring for the dying accumulated over time, resulting in an intuitiveness that is inherent to experts.

Defining a Personal Role in Care if the Dying

> You are able to care and relate on an emotional level and still not take the whole situation upon your shoulders, which I used to do at the start. I've learned how to remain healthy myself.

I: I think through the years, even as close as I get to them, I'm always preparing myself to accept the fact that they are not going to be here forever. They are not really my friend. I think there must be some kind of mechanism that nurses develop after a while. Because if you cry, I mean I cried after all of them, but it's not the same as the first time I met death head on as a nursing student or as a young grad. Then, it would take all my wits to pull myself together. But you soon learn.
R: What is the mechanism you're referring to?
I: I don't know. I've never really given it a name. It's a bit of a defense mechanism. You get really close but you don't go over the line.

Everybody is special in their own way. I learn something from every patient. Maybe it's qualities they bring out in me, maybe it's qualities I bring out in them or that I picked up in them. Qualities I think I would like to have if I was going through the same thing...I always learn, I always learn about people. People are never the same.

I don't feel anxious about looking after them or not knowing what to do. It's just whether they'll accept what I have to do. That they are ready for it. It doesn't matter how close a person is to death, they may not be ready.

The symptoms were well controlled, the family was present and participating in the care. Everybody was working as a team. The clergy visited; everything was done as the patient wanted. The patient died in their own bed, in their own home with their family and friends around them. The patient died fairly comfortable and with dignity. I would say for the majority of patients that I visit in the community, that is really what happens.

I may have been physically tired because some of the visits
took an hour and a half, two hours. Maybe at times it was a
little bit exhausting mentally too. I always enjoyed going to visit.
I felt comfortable talking about death and dying. Talking about
what life is. I don't have any trouble with that.

I think the important thing about nursing palliative care
patients is knowing that there is a time to cry and a time that you
have to be together. You have to be strong and guide them in the
right directions. The easy parts are monitoring the medications
and bowels, the different body systems and statuses. That is the
really easy part, the nursing part. The physical part is always
easy. I think what sets one nurse apart from another, is that it's
painful to get really involved with them. That's the hard part, but
I think, that's the part that will make the difference in the long run.

Intuition

The ability to understand and know without a rationale (Benner & Tanner,

1987) describes how the nurses in this study approached some situations. When

asked to explain how they 'know that', nurses were vague. They stated 'there is

a certain way that they look at you and let you know', 'you had to read between

the lines' and 'it was just a hunch'. Years of experience in care of the dying gave

nurses the ability to notice subtle changes.

You had to read between the lines and then you caught on. She
was never a lady to complain. I had to ask a lot of questions to
bring her out of that shell. I would ask specifically and she would
give a roundabout answer back. An unspecific answer. I had to
read between the lines and anticipate what the problem might be.
It was really difficult.

I never plan what I'm going to say. I just wait. I 'll know when the time
is right. Sometimes the opportunity is there and you take it.

Once you've been with them, you know. It could be your second visit
with one patient or it could be the fifteenth visit with another one, that
it would be the right time (to talk about death and dying). You know
when the time is right.

You understand the situation and then you get into a little bit more of the
dynamics. And at that point you sort of have to draw the line. To know
where your involvement is finished and where they have to take over.

In a situation where the family thinks they are protecting the patient,
they are, in their own mind. They are protecting them from hurt.
They're also reinforcing their own denial and justifying it.

A lot of times it's unwritten, you just have to know that you did a
good job.

Nurses received personal rewards, experienced personal growth and

became more cognitively aware of behaviour patterns as a result of their care

giving experiences. Differences in approaches to caregiving and in nursing skills

may have been related to the location of care, the community.

FINDINGS - CONTEXT

The category labelled context refers to the environmental factors

influencing the cancer patients' transition from living to dying. Patients explicitly expressed their greatest wish was to die at home, in their own beds. The environment emerged as a major influence on the patients' achieving their goal of dying at home and on their comfort during the dying process. The data revealed positive patient outcomes were related to the advantages of home care, whereas negative patient outcomes were associated with limitations in home care delivery.

Advantages of Home Care

The context in which community nurses provide care to the terminally ill cancer patient in the community is home care. Patients preferred to die at home for a variety of reasons. Comfort, familiar surroundings and people, privacy and fear of hospitals were cited. Community nurses were fundamental in fulfilling the patients request to die at home. Factors resulting in positive outcomes were the respect and autonomy provided by community nurses while they advocated for the patient and coordinated care.

> Basically, people say 'I'm happy to be at home. I'm glad not to be in that ratrace of a hospital. It's nice to lay in my bed and see people I know. It's nice to see surroundings I know. I don't have to call a nurse and wait for hours for something for pain. Everything I need is here'. Basically, that is what it's all about. That is the patients verbal response, how comfortable they feel. Some people are very frightened of a hospital.

When you're in the hospital, you're around other (unfamiliar) people.
This person liked to be at home because she could have friends
come over. They used to walk her down to the restaurant for coffee.
It was nice to be able to push her around in the wheel chair. She had
her wheelchair and the equipment that she needed. Having a wheelchair
was a big thing to her. Her mind was clear right up to the end. She
knew once she progressed to where she couldn't get out of bed,
the end was near...it's like they know, they can almost tell you...

Nurses also appreciated the home atmosphere. It allowed them to
become closer to their patients and the family.

When you are on home care you usually spend more time having
tea or coffee. In the hospital, I found it different, you don't get so
emotionally involved. In it's own way, each death is unique in the
hospital, but it's not as personal as in the home.

The patients' wish to die at home was not always fulfilled as there were
limitations in the delivery of home care.

Limitations of Home Care

Although the sample of community nurses studied provided nursing care

data from two distinct communities, the limitations cited by urban and rural

nurses were similar. Patients were hospitalized on the advice of the nurse for

pain control, poor nutrition, the inability of the family to cope with the physical or

emotional burden and out of respect for the family when they could not accept

the patient dying in the home. Lack of or limited family supports resulted in

hospitalization against the dying patient's wishes. When patients were

hospitalized, nurses gained their cooperation and acceptance of hospitalization

through explanations. Nurses stated that patients trusted their judgment and

advice because of the good rapport they had established during the early visits.

When some patients were hospitalized in a semi-comatose or comatose state,

nurses justified their actions by explaining that this patient would have accepted

their hospitalization as a logical decision, under the circumstances. At times,

negative patient outcomes occurred as a result of limitations in the referral

process and in funding for community services. Nurses expressed frustration

and concern for the welfare of their patients when bureaucratic delays or

limitations occurred.

> His condition was so bad that he put all his energy into staying home.
> I showed up on Friday. We couldn't arrange for a nurse to see him on
> the weekend and no health care aide was available. They were all
> booked and this was Friday. I looked at him and tried to reason
> with him. He was telling me 'I want to stay home'. But it would be
> cruel and inhumane to leave him home alone.

> For whatever reason referrals are being missed or they (patients)
> are not getting on to the system in time. You don't have a lot of
> time to develop a rapport with them. Palliative care takes time;
> time in days, weeks and months and it takes time for individual
> visits.

> I can think of one case where the mother was dying. To this day
> I've never met her husband. By the time I got the referral to go
> in, the woman had metastasis to the brain....This boy gave
> up his first year of university to be home with his mom because
> he had promised his mom that he would do it. For a seventeen

year old boy to give his mother a bed bath, that's something else.
It was hard because I never really got to first base. The boy
didn't know how to manage his grief, didn't know how to handle
caring for his mom, although he was willing to learn. I didn't feel
very fulfilled.

I was called to go in to see her because she was very sick. I got
to the door and she was gone (deceased). So we had the police
there, and all the others because we had not been given the
referral in time to do the DNR letter. The son had called the
ambulance before I got there. I had phoned ahead that I was
coming but within a half hour this all happened. I felt awful that
I couldn't have been there for her. She had been my patient for
a brief period when she had surgery. After her incision healed I
was advised to discharge her from my caseload because 'she no
longer required nursing care'. I had suggested to the doctor that
if the patient required further nursing care a new referral would
be required. Somehow that didn't happen until it was almost too
late. It would have made everything much easier for the patient
and family if they had some guidance and support from a palliative
care nurse.

They've cut out bereavement visits in the last year or year and a half.
Essentially we make the visits on our lunch hour or on our own time
because they are crucial. We don't get paid for doing them, but we
do them. You just can't leave a family, you can't 'not go back', not if
you've been involved with them.

She was very angry because she knew she had a lump. She went
to the doctor, but the doctor did nothing about it. He said 'you're
pregnant, what do you expect'. She found the lump when she was
four or six months pregnant, so there was lots of anger. They didn't
do anything about it, then they started her on chemo. They had
to do a mastectomy. There was a lot of anger on her part. She had
poor access to her family. Her mother and father were divorced.
Her father was living with another woman whom she didn't know
very well, or didn't like. The mother lived far away. There was no

family except for her husband, who was trying to make money to put bread on the table. He was trying to keep the family together and manage with newborn twins.

The data revealed patients preferring to die in their own homes were empowered by the security of their environment, however community nurses encountered limitations in providing palliative care. Overall, analysis of the context of care provided only a thin description of the advantages and limitations to home care as the data revealed infrequent and varied references the home environment.

Conclusion

Chapter five discussed the characteristics of the sample and the data. Two major categories emerged from the data, nurse behaviors and context. Major themes within the categories were evident. The operational definitions that were drawn from data will contribute to a model of nurse behaviors in care of the dying.

CHAPTER VI

DISCUSSION OF THE FINDINGS

The findings will be discussed as they relate to a) the theoretical framework of the study and, b) the research questions cited at the onset of this study, including the findings of Degner et al (1991) and McClement (1993) on critical nurse behaviors in care of the dying. A discussion of the findings as they relate to implications for nursing practice, education and research will conclude the chapter.

a) Theoretical Framework

The two conceptual frameworks used for this study were Pattison's (1977) Living-Dying model and Benner's (1984) Novice to Expert model based on the Dreyfus model of skill acquisition. The Living-Dying model was a useful framework for the examination of nurse behaviors, the first major category to emerge from the data. According to the model, nurses function in two interrelated roles, 1) as a problem-focussed support system for the person with cancer and family members and 2) as a communication link between the patient/family support system and community services. In a problem-focused support system role, the nurse "assists the dying person and members of the family in coping with stresses and strains imposed on their lives by the demands of terminal illness" (Thornberg et al., 1984. p.132). The respondents in this study revealed support for this concept. They provided comfort to the patient and

responded to family's needs after they had built a trusting relationship in the home. Although nurses bring expert knowledge and skill to the situation, the effectiveness of their care depends on an environment of trust and a willingness to be available to the patient and family when they are in most need of help (Benoliel, 1985). Nurses stated that their respectful, supportive behaviors were instrumental in promoting patient autonomy. According to Saunders & McCorkle (1985) the Living-Dying model is based on the belief that the patient is an active participant in self-care and in decisions affecting their illness.

In the Living-Dying model, the second interrelated nursing role was that of a communication link between the patient/family system and the community health care system. Similarly, nurses in this study acted as liaisons coordinating the care in the home by seeking resources in the community. Pattison's model was based on community health care and this concept emerged as the second major category in this study. Under most circumstances the community environment was found to have a positive effect on patient outcomes, however limitations resulted in negative outcomes for some dying patients and their families. The respondents in this study were knowledgeable about the resources available in the community and were willing to access the resources to promote improved quality of care for the patient and family. Nurses coordinated the care in the home by contacting doctors, hospitals and by requesting home health personnel and equipment as required. Nursing activities and interventions that promote access to relevant information, collaboration in reaching decisions and

coordination of activities ensures patient centered care (Tornberg et al., 1984).

The findings revealed that providing information to both patient and family were

important nursing interventions in home care. The original figure for this study

(see Figure 2, p. 36) was modified to reveal the nursing behaviors that emerged

from the findings of this study (see Figure 3).

CRITICAL NURSE BEHAVIORS IN CARING FOR THE DYING IN THE COMMUNITY

Figure 3
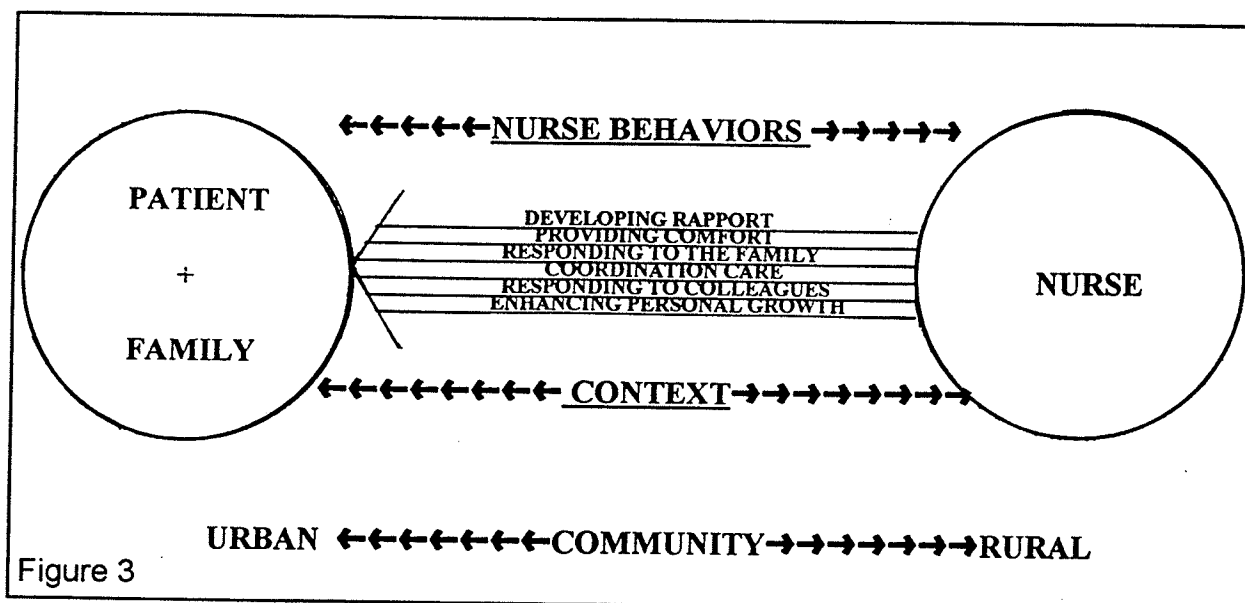
Benner's Novice to Expert model was the second framework used in this

study. Expert behaviors as described in Benner's (1984) model and the Dreyfus

& Dreyfus (1986) model of skill acquisition are reflected in the findings of this

study. The basic premise of the Dreyfus model is that acquisition of skills evolve

over time, from a context-free rule following approach to an involved pattern

recognition of entire situations based on previous experience (Belongia Le

Breck, 1989). Despite practicing as generalists, the community nurses

participating in this study had an average of 11 years experience in caring for the dying in the community. They reported they 'interpreted' and 'read between the lines' when communicating with patients and families. Nurses searched for opportunities to discuss the patients' self-preparation for death. They were vigilant, waiting for the right moment. They stated 'I never plan what I'm going to say, I just wait. I'll know when the time is right'. Nurses intuitively understood the meaning of the dying patients' behaviors stating 'there is a certain way that they look at you or let you know'. According to Benner (1984), the expert nurse with enormous background experience has an intuitive grasp of each situation and zeros in on the accurate region of the problem without wasteful consideration of a large range of unfruitful solutions. Experts unconsciously associate patterns of salient features with correct actions (Belongia Le Breck, 1989). The community nurses reported that their learning to care for the dying accumulated over time. They learned from each situation but were explicit and emphatic in stating they avoided generalizing, preferring to respond to the unique needs of the individual and the family.

To identify the pattern recognition process characteristic of expertise, nursing judgements must be studied in their particular context (Benner, 1984; Dreyfus & Dreyfus, 1985). The nurse's recognition of their precarious position in the patients' homes resulted from their experiences as novices when they had almost or had been asked to leave the home. They stated they were quick to 'quietly learn and respect the home rules'. The home care environment

empowers the dying patient, not the caregiver as the patient is in a position of authority and can exercise autonomy in making decisions affecting their care.

Providing nursing care in the community extends the nurses' responsibilities. Their knowledge of health related resources places them in the role of care coordinator. Their knowledge of the health care system and individual physicians' practices enabled the nurses to make contacts that ensured positive results for their dying patients. Nurses interceded on behalf of the patient with physicians for changes to analgesics and for DNR letters. Urban nurses disputed a proposed change to decrease visiting time for the terminally ill on weekends, stating that the dying could not arrange their death to occur between nine and five, Monday to Friday. Diplomatic negotiation with superiors and community resources was the norm, as nurses stated their collegial relationships resulted in improved patient outcomes.

Nurses tended to focus nursing care on the 'micro' level of practice although the structural/policy issues that affect their caring behaviors at the 'macro' level were not consistently addressed. Formation of a nurse support group and challenging the 'no bereavement visit' rule would have beneficial effects for the nurses themselves that would result in improved patient care. Supervisory/management personnel would be in pivotal positions to advocate for community nurses and terminally ill patients.

During the interviews, nurses stated that they had described only the most recent cases in care of the terminally ill with the researcher, as their recall

was impeded by time and the large number of cases. According to Benner

(1984) experts have a problem telling everything they know. One nurse stated

that 'at any time, 50% to 80% of my caseload are dying' and that her coworkers

asked `how do you manage?' This nurse expressed surprise that the number of

palliative care patients on her caseload was different from her coworkers.

Although nurses in this study had been nominated by their peers as 'experts' in

care of the dying, they did not perceive themselves as different or special. They

shared the most salient features of their most memorable patients but were

modest when their behaviors were referred to as critical to care of the dying. The

nurses perceived their behavior as commonplace. Dreyfus & Dreyfus (1985)

state that as the performance becomes fluid, flexible and highly proficient, the

performer is not aware of the features and rules.

The novice to expert model was appropriate for this study as it allowed

the researcher to capture the complexity of real clinical situations (Benner, 1985)

experienced by community nurses. Nurses used paradigm cases to guide them

in clinical practice in care of the dying. Paradigm cases enable nurses to add

'know how ', knowledge developed through clinical experience in the practice of

the discipline to 'know that', knowledge of theories that is based on scientific

explanations (Benner, 1984). Experts develop skills using both types of

knowledge. The combination of Pattison's (1977) and Benner's (1984) models

were useful to identify critical nurse behaviors and the context of care in this

study.

b) <u>Research Questions</u>

The overall purpose of this study was to describe behaviours that nurse experts identified as critical to care of the adult patient dying of cancer at home. The following research questions were addressed:

1. What are behaviours that community nurses describe as critical to care of the adult dying at home that have a positive effect on the cancer patient and family?

2. What are behaviours that community nurses describe as critical to care of the adult dying at home that have a negative effect on the cancer patient and family?

3. How do the behaviours identified by community nurses in this study compare with 1) the seven categories of nursing behaviours identified in Degner, Gow and Thompson's (1991) qualitative studies of palliative care nurses and nurse educators and 2) McClement's (1993) replication study of ICU (intensive care unit) nurses ?

A discussion of each question follows.

<u>Question 1:</u>

The behaviours that community nurses describe as critical to care of the

adult patient dying of cancer at home that have a positive effect on the patient

and family emerged as the first major category of the data and was labelled

nurse behaviors. Six themes of nursing behaviors were evident in this category

1) developing rapport 2) providing comfort 3) responding to the family

4) coordinating care 5) responding to colleagues and, 6) enhancing personal

growth. The characteristics of each theme were delineated in the operational

definitions (see Table 2&3). A review of nursing behaviors in the literature

supported the findings in this study, however they were not specific to nursing

care of the dying in the community. General nursing behaviors in the literature

that related to physical, emotional/ psychological, and information needs were

identified at the onset of the study (see Table 1).

Two studies on nursing care of the terminally ill in the community that

were relevant to this research were found in the literature 1) Dobratz (1990) and

2) Davies & Oberle (1990) . In her examination of the hospice literature, Dobratz

(1990) identified four categories of nursing behaviors that paralleled the findings

in this study. The categories Dobratz described were 1) intensive caring,

2) collaborative sharing, 3) continuous knowing and, 4) continuous giving.

Intensive caring was described as nurses managing the physical, psychological,

social and spiritual problems of the dying person and their families. This

corresponded with two nursing behaviors identified in this study, providing

comfort and responding to family. Dobratz's description of collaborative sharing

was very similar to coordinating care as described by the respondents in this

study. Continuous knowing, Dobratz's next category was related to communication and teaching skills and resembled the communication and teaching skills that were subsumed under information needs for both patients and family in this study. The final category Dobratz described was continuous giving. It referred to the nurses' own self-care needs that resulted from repeated death encounters. Responding to colleagues and enhancing personal growth were the two self-care needs identified by the subjects in this study that may be analogous to Dobratz's continuous giving category. Although Dobratz's review is a helpful guide, it is unclear if the data was collected from nurses practicing in home hospice care. References to developing rapport and responding to the family were not included in Dobratz's study.

In the present study, developing a rapport emerged as the basis for future nursing interventions. McMurray (1992) lists this nursing behavior as establishing contact/rapport in her model of community health nursing practice but the behavior is not described. The nurses in this study, without exception stated that building and maintaining a rapport was crucial to their continued warm reception in the home. Their initial assessment occurred concurrently with 'developing a rapport'. During some palliative care visits to homes the nurses did not implement physical nursing interventions. They spent time listening to the patient in an attempt to understand their patient's unique personality and to provide emotional support to the patient and family. Attending patients with incurable disease at times of extreme distress leads the nurse to a deeper

understanding of patients and seeing them as distinct and unique (Copp, 1986).

In a qualitative study on the practice of health visiting in England, Luker and

Chalmers (1990) report that nurses implement similar behaviors in gaining entry

to the client/family situation. Data from the study suggest that 'entering the

client/family situation' is a process that involves gaining access to their

environment and entering/re-entering into the client situation more fully to

continue the health visiting work. In this study, respecting patients and promoting

autonomy were priorities for the respondents in this study and emerged as

subthemes in 'developing rapport'.

The second study found in the literature that reported on caring for the

terminally ill in the community was that of Davies & Oberle (1990). The purpose

of their study was to describe the knowledge, skills and personal coping

strategies essential to successful provision of supportive care to the patient with

advanced cancer. Their category labelled 'connecting' - defined as establishing

a rapport, sharing secrets and giving of self - was similar to the properties of

'developing rapport' as described by the respondents in this study. Although the

remaining dimensions described by Davies & Oberle (1990), empowering, doing

for, finding meaning and preserving own integrity were parallel to the nursing

behaviors identified in this study, some differences existed.

Davies & Oberle's (1990) data was from 10 cases as described by one

'expert supportive care nurse'. The authors admit collecting data from one

informant is an unorthodox approach. Although similarities between the findings

of this study and Davies & Oberle's (1990) study exist, differences in the number of respondents, length of interviews and operational definitions may account for the dissimilarities in the findings.

Question 2:

The behaviours that community nurses describe as critical to care of the adult dying at home that have a negative effect on the cancer patient and family was the second question asked in this study. Although nurses referred to negative patient outcomes, the data revealed that nursing behaviors were not contributing factors. Some nurses reported incidents early in their practice as community health nurses resulted in the patients' asking them to leave the home and to not come back. These breakdowns motivated nurses to quickly learn how to nurture the relationship with patients and families. The emergence of 'developing rapport' as an important nursing behaviour in this study may have been related to the nurse's previous negative experiences. The nurses may not have felt at ease describing to the researcher their behaviors that resulted in negative patient outcomes, however it is unlikely that all 10 nurses, unknown to the researcher and each other would react in a similar manner to the research question. Research on novice community nurses caring for the dying in the community may elicit nursing behaviors with more diverse results.

Negative patient outcomes did emerge from the data. In the second major category revealed in this study, labelled context, positive and negative outcomes

were evident. For the purposes of this study context referred to the community

(see Table 3). Contextual conditions that resulted in positive patient outcomes

were described as the advantages of home care. Whereas the second

component was the limitations that related to a community environment.

Limitations in home care resulted in negative patient outcomes. Patients

experienced negative outcomes as a result of late referrals, breakdown in

communications, insufficient pain control, lack of a DNR letter, lack of

caregivers, or families' inability to cope with the patient dying at home.

Question 3:

The third and last question of this study was to examine how the

behaviours identified by the community nurses in this study compared with the

seven categories of nursing behaviours identified in Degner, Gow and

Thompsons' (1991) qualitative study of palliative care nurses and nurse

educators, and the six categories of nurse behaviors reported in McClements'

study of ICU nurses. Similarities and differences between the findings in the

Degner and colleagues' study, Mc Clement's study and the findings in this study

were evident. The similarities will be discussed first.

The Similarities

Providing comfort, responding to the family, responding to colleagues and

enhancing personal growth were the nursing behaviors that were found in each

of the three studies. Although the categories were similar, slight differences in the operational definitions between the studies were apparent. Each category will be discussed and compared.

'Providing comfort' was operationalized in all studies as nursing behaviors that promote physical comfort. In the present study and in McClement's ICU study it also included pain reduction. Community nurses reported that they supported the patients' spiritual and information needs, whereas these behaviors were not evident in either the Degner et al. (1991) or McClement (1993) study. However, the differences may be attributed to the context of the nurse patient relationship. Community nurses become acquainted with their patients in their own homes in long term relationships while hospital nurses become intensely involved with patients for a relatively shorter period of time. Some patients in the community were independent for self-care during the process of dying. They refused the assistance of home health aides, or at times allowed the aides to come into their residence only to cook and clean. Patients preferred to be self sufficient for their personal care and medications. However these patients needed information and welcomed the nurse as a resource. They also insisted that the nurse come to the home regularity, if only to talk. Community nurses reported that in some homes they visited, their singular responsibility was to listen to the patient/ and or family. In other homes they were consultants, providing information on the disease process, medications, and the behaviors that would precede death. Nurses reported their spirituality and sense of comfort

with death gave them confidence to discuss life after death with their patients and to calm their patients' fear of death. 'Providing comfort' as reported by the nurses in this study not only included physical and emotional comfort but also comfort related to information and spiritual needs. Not only do nurses need to know the histology and physiology of numerous cancers, their patterns of metastasis, the recommended treatment protocols and the side effects, but they also need to have a good understanding of the techniques of family counselling, communication theory, ethics, management principles, psychosocial responses to illness and the spectrum of community resources that are available (McCorkle & Germino, 1984).

The second nursing behaviour that was evident in all studies was 'responding to the family'. There was congruence in providing information and in promoting family behaviors that reduced their potential for future regret in the studies. However Degner et al. (1991) reported 'behaviors that include family in care or relieve them of this responsibility according to what is best for the family', that were not found in the present study. Family members were usually the primary caregivers in the home, with supplemental help from home health care aides. Behaviors found by Degner et al. (1991) may not have emerged in this study as the community nurses encouraged patients and families to decide the amount and type of supplemental care they required, thus relieving nurses of the responsibility of deciding for the family.

McClement (1993) reported nurse behaviors that 'facilitate the transition

from cure to palliation' in her study. In the present study, not all patients acknowledged that they were terminally ill, but nurses revealed they all had been told by their attending physicians or oncologist that their cancer was fatal. Some patients were actively seeking treatment for their cancer, however the community nurses caring for these patients reported no changes in their nursing approaches. Differences in the context of care may account for the differences in findings in the McClement and in the present study. Nurses initially focus their care on cure in the ICU and have limited time to refocus the patient to palliative goals, whereas community nurses usually have more time to prepare their patients for death if treatment is not effective.

One behavior that emerged in this study that was not evident in Degner's et al. (1991) or McClement's (1993) study was that of providing emotional support to the family. Community nurses reported that they provided emotional support to the family under a variety of circumstances. Some family members were totally involved in patient care while others rarely contacted the dying patient. Family members telephoned community health nurses at home to ask their advice and to seek information. The nurses gave their telephone number to people they trusted not to abuse the privilege, although their supervisors advised against the practice. The literature supports this finding. McGinnis (1986) used a Q-sort methodology to study the effect of nursing behaviors on the quality of life of the terminally ill and reported caregivers ranked direct support and information as most helpful nursing behaviors. Reimer (1991) concurred

stating nurses can help families come to terms with their circumstances by discussing their beliefs, feelings, fears, hopes, wishes and dilemmas. Providing emotional support for family members may have been subsumed under the nursing behaviour category of 'responding to the family' in the Degner et al. (1991) study, however it did not appear as a unique entity in the operational definitions.

The two remaining nursing behaviours that were similarly operationalized in the three studies related to the nurses' self preservation behaviors, 'responding to colleagues' and 'enhancing personal growth'. Community nurses responded to colleagues in the present study in the same manner as was reported in the two previous studies. They provided emotional support and critical feedback to their peers, stating that their therapeutic role in caring for the dying depended on peer support and mutual understanding. Nurses working independently in the community did not have the collegial hospital network to rely on, therefore they met with peers at the office, for lunch or telephoned each other after working hours.

Nurses reported their personal growth was enhanced by exchanging support with their peers. It was apparent that community nurses had defined a role for themselves in care of the dying. Their comfort and confidence in providing palliative care to the patient and family was obvious. They stated experiencing the deaths of many patients and learning from each situation helped them to develop a philosophy and specific approach in caring for the

dying. Although not reported in either Degner's et al. (1991) or McClement's

(1993) study, the community nurses in this study revealed intuition guided their

decisions on when and how to approach the patient and family about sensitive

issues. The nurses waited for appropriate opportunities or created their own

openings to discuss the approaching death, the patient's will, the DNR letter and

arrangements for the funeral. According to Benner and Tanner (1987) nurses do

not lack knowledge or adequate judgment in dealing with problems, rather, the

inexactitude of the situation requires that the nurse consider all possibilities

before proceeding. Benner (1984) states that expert nurses develop a

perceptual awareness that leads them to follow their hunches. Community

nurses recognized and respected denial as a method patients and families

employed to cope with the burden of death. Nurses stated during early visits

they would circumvent pertinent questions, while assessing the readiness of the

patient and family to openly and honestly discuss death. When a family explicitly

asked the nurse not to tell the patient that the illness was terminal, nurses

complied with the family's request although they were convinced they were doing

a disservice to the patient. Despite their misgivings, they intuitively knew that

their ability to help the dying patient would be compromised if they did not

respect the families' wishes. Although Mitchell (1994) states that intuitive

knowing is a myth in the development of nursing theory, Rew (1986) maintains

that "intuition should be considered a resectable cognitive skill characteristic of

the science of nursing" (p. 27).

The Differences

Both the Degner et al. (1991) and the McClement (1993) studies revealed positive and negative nurse behaviors, whereas the data in this study revealed only positive nurse behaviors. Four reasons may account for the difference in the findings. The first reason is that the respondents in this study had provided care in the community for an extended period of time and the nurses stated that they had learned early in their careers that they would not have access to the home if their interventions were not supportive to the patient and family. The second reason may be that nurses are reluctant to talk about behaviors that resulted in negative patient outcomes. Further research is needed to identify negative outcomes from the patient and family perspective. The third reason may be related to the context. In this research study the community environment emerged as the context of care and it had positive and negative effects on patient outcomes. The findings in the two previous studies of critical nurse behaviors did not reveal the context of care as a separate category. Comparatively, the context of Degner's and McClements' studies were within a controlled environment, as the studies were based on nurse educators, palliative care nurses and ICU nurses working in hospitals.

For similar reasons coordinating care emerged as a separate nursing behaviour in this study, but not in the previous studies. Coordination of patient care is an internal function of a hospital system, whereas in a home care

situation, coordination of care is external to the home. The literature supports

the coordination of services as a component of caregiving in the community,

although terminology and descriptions varied. Coordination of services (Decker,

1991; Higginson et al., 1990; Kristjanson, 1993) was referred to as knowledge of

community resources by Reimer et al., (1991) while Hinds (1985) and Mayer

(1987) described a need to arrange respite. Community resources were also

described as resources to aid in care giving by Stetz and Hanson (1992). Other

components of coordinating community resources were described as: arranging

transport (Blank, et al., 1989; Rose, 1976), getting physicians' orders (Longman

et al. 1992) and household management (Stetz & Hanson, 1992). Differences

between a community environment when compared to a hospital environment

may have prevented coordination of care from emerging as a separate nursing

behaviour in the Degner et al. (1991) and the McClement studies as total quality

management programs ensure that patient care is well coordinated in hospitals.

In this study coordination of services emerged as an added nursing

responsibility. Similarly, the behaviors involved in 'developing rapport' with

patients and family may have emerged as a separate theme of behaviors in

community nursing.

Nurses unanimously described 'developing rapport' as a behaviour that

was instrumental to providing care to the dying patient and family in the

community. The three major components of developing rapport were nurse

behaviors that 1) build relationships, 2) show respect for patient and family and,

3) promote patient autonomy. Building relationships depended on the trust a patient had in the nurse. Benoliel (1976,1985), Tornberg et al. (1984) and Zerwekh (1994) support these findings, indicating that developing trust was a necessary nursing intervention in caring for the dying. The community nurses were aware of the tenuous situations in many homes, and that without a trusting relationship they would not be allowed to provide even basic nursing care. Nurses established and sustained trust by respecting patient and family wishes and the 'habits' or patterns of interaction in each home. Nurses in cancer care occupy powerful positions in fostering health care services that respect the personal integrity and human needs of patients and families (McCorkle & Hongladrom, 1986). In a replication study of community nurses caring for the dying, Seale (1992) revealed that the need to build a good relationship with family members was accorded equal priority with relief of the patients' physical symptoms. Sullivan, Weinert and Fulton (1993) concur, stating that a major source of difficulties for people living in rural areas are ineffective communication skills in relating to and interacting with health care professionals. According to Woodward and Thobaben (1994), of all the issues in dealing with patients with cancer, none is more crucial than community nurses knowing when and how to talk with families.

Developing rapport included showing respect for the patient and family. Most nurses were discriminate in their communications, knowing when to keep their opinions and values secondary to the patients'. Showing respect included

the nurse asking a dying patient's husband to bring home a 'whistle dog' from a local fast food restaurant, although the nurse and patient were aware that regurgitation would follow quickly after the hot dog was ingested. Nurses showed respect for the patient wishes when the patient refused to acknowledge their imminent death to their children. According to Ness (1991), "we must respect their way of coping even if their judgement seems poor" (p. 59). Similarly, Longman et al. (1992), found an important patient need was to 'convey respect for me when giving me care' in their study of the needs of home-based cancer patients and their caregivers. Nurses in this study were receptive to the patients' need to discuss their feelings toward hope, spiritual ideology, and life after death. This theme is similar to the nursing behaviors identified in Degner's et al. (1991) study, operationally defined as 'enhancing the quality of life during dying', where nurses "could get past the idea that the patient was dying, focusing instead on important aspects of living" (p. 250).

The last aspect of developing rapport involved nursing behaviors that promoted patient autonomy. Nurses illustrated how they empowered their patients when they said 'it's your choice', 'I let him make the decisions', 'I let them take the lead', 'give them the freedom to decide', 'it's important for the patient to have control'. Nurses, sensitive to the many losses the patients had experienced, promoted autonomy while remaining cognizant of the patients' safety. One nurse stated 'an important part of cancer nursing is letting them decide', still another said 'give them as much freedom to make decisions as they

want, so they still have autonomy...as long as it's safe and they're comfortable with it'. As an incurable disease progresses and the patient becomes more debilitated, the nurse's role is integral in assisting the individual to recognize their limitations and to maximize their independence where possible (Benoliel, 1986; Penn, 1994; Ryan, 1992; Skorupka & Bohnet, 1982; Zerwekh, 1994). 'Promoting autonomy', a theme in this study, is reflected in a category in Degners' (1991) study, that of 'enhancing quality of life while dying', however it did not emerge in the McClement (1993) study.

Two categories in Degner's (1991) study that were not evident in this study were 'responding to the death scene' and 'responding to anger'. Nurses in this study reported that while they were prepared to stay with a dying patient, they were most often not present during the death scene. Reasons for their absence during the death scene were related to the patient's death not occurring during the nurse's visit. Nurses reported that if signs of imminent death were apparent they would stay with the family. In some cases family members telephoned nurses to come to the home after death had occurred. Nurses stated that although they were paged to go to a patient's home, communication lag time often meant their arrival was not in time to be with the family during the moments preceding the death. The nurses reported that another reason for their absence at the death scene was the length of time nurses are expected to visit in the home is dictated by economic considerations. A lengthy death scene often does not fit within the allocated time. However, nurses stated if they knew the patient

was dying they would stay with the patient and family and not claim the time on their work report sheets. Although some nurses reported that they were present at the death scene, most nurses were not present, therefore behaviors related to 'the death scene' did not emerge as a theme in this study. The rapid changes in patients' conditions in the ICU led McClements' (1993) study to reveal a category describing nurses 'responses after death had occurred'. These behaviors were not evident in this study.

The last difference between the nursing behaviors in the present study and those reported in Degner's (1991) study and McClement's (1993) study was the category of 'responding to anger'. Experienced nurses showed empathy and respect toward angry patients and family members in the Degner and McClement studies, however those behaviors were only alluded to in the present study. One nurse stated that although family members directed their anger and frustration toward the nurse, the nurse understood that the anger was at death and not at the nurse as a person. One nurse described a terminally ill patient's behaviour as angry and abusive, however she kept a therapeutic perspective during the patient's transition from living to dying. She described the incident:

> We knew each other quite well. She would be storming and
> tantrumming. I would have to duck bottles of whatever was
> being pitched, leaving holes in walls. But I felt I did some good
> in that home, while at the same time I felt totally exhausted and
> at times so frustrated. Sometimes I felt as though it was a battle
> of wills (chuckles). But again, we did know each other well.

In this study community nurses did report responding to anger, however the occurrences were reported so rarely they could not be considered a theme in the category of nursing behaviors.

Conclusion

Six nurse behaviors and the positive and negative aspects of the community environment that emerged in this study were compared to the results of two previous studies on critical nurse behaviors. According to McMurray (1992), research on community health nursing practice has been under represented. This study will contribute to the growing body of knowledge on nursing care of the terminally ill and community nursing practice and nursing expertise.

Implications of the Study

The findings of this study have implications for nurse educators and nursing education, nursing research and, nursing practice. Each area will be discussed in point form.

Recommendations for Nurse Educators and Nursing Education

1. That education on death and dying be taught as a separate course rather than be integrated with general nursing courses.

2. That student clinical experience in care of the dying coincide with theoretical course content as closely as possible.

3. That the clinical teacher be confident and comfortable in approach behaviors to the dying patients prior to teaching in the clinical area.

4. That context of nursing care become integrated with critical nurse behaviors in care of the dying.

5. That educators expose students to experts in care of the dying in a variety of settings, eg. medical-surgical, palliative care units, ICU, pediatric, community, nursing home. The progressive development of expertise is facilitated through role modelling expert behaviors in care of the dying.

6. That educators provide students with opportunities to learn coordinating skills outside of a hospital setting.

7. That student nurse experiences focus on emotionally supporting patients and families through the therapeutic use of self.

8. That nurse educators encourage students to discuss care for the dying in a group setting to provide students with an opportunity to observe role modelling of emotional support and critical feedback.

9. That nurse educators have previous experience and a comfort level prior to teaching care of the dying to students in the classroom or in the clinical area.

10. That a continuing education certificate course in care of the terminally ill be available to nurses working in all health care settings.

Implications for Nursing Practice

1. That nurse coordinators support community health nurses in their request for re-imbursement for bereavement counselling with the family.

2. That nurse coordinators support community health nurses in the provision of emotional as well as physical care.

3. That community nurses with palliative patients be encouraged and funded to start a peer support group.

3. That nurses have access to a post-diploma palliative care course.

4. That health care planning and funding bodies consider the dying patient together with the family as the unit of care in the community.

Implications for Nursing Research

1. The results of this study revealed only nursing behaviors that resulted in positive outcomes. Replication of this study with novice community nurses may reveal nurse behaviours that result in negative outcomes.

2. Skills critical to effective teaching of nursing behaviors in care of the dying have not been investigated.

3. To date, critical nurse behaviors in care of the dying adult and pediatric patient have been studied. Critical nurse behaviors in the adolescent age group need to be explored.

4. A prospective, longitudinal, multi-site evaluation of patient and family palliative care outcomes of care provided by students exposed to an integrated approach to learning care of the dying, compared to students exposed to a separate course in care of the dying, would contribute to the growing body of knowledge in care of the dying.

Summary

The context of care and nursing behaviors identified in this study together with the nurse behaviors reported by Degner, Gow and Thompson (1991), McClement (1993), and two studies in progress 1) on terminally ill pediatric patients and 2) adults on a medical-surgical unit will provide nurse researchers with a more complete list of critical nurse behaviors in care of the dying. The critical nurse behaviors identified in the five studies will define a model of expert nursing practice in care of the dying. The resulting model will provide the framework for educating student nurses in care of the dying. Expected benefits are improved outcomes for the patient and family and a more positive, accepting attitude to death and dying in our society. There is a growing acceptance of palliative care in the community. Although some nurses had difficulty articulating exactly what services they provided in the home, community nurses were well received. One nurse explained 'we are invaluable in their eyes'.

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TABLE 1
NURSING BEHAVIORS IN CARE OF THE DYING ADULT PATIENT AT HOME
DESCRIPTIONS IN THE LITERATURE

GENERAL BEHAVIORS	SPECIFIC BEHAVIORS	SOURCES OF SPECIFIC BEHAVIORS
PHYSICAL CARE	Nursing care skills	Stiles, 1990
	Care related to physical decline, weakness & respiratory distress	Petrosino, 1985
	Providing comfort	Degner & Gow, 1991
	Control of physical symptoms	Hunt, 1992
	Physical care	Heslin & Bramwell, 1993, Lewandowski, 1988, Masters & Shontz, 1989, Mulhern, 1986, Peruselli, 1992, Wingate & Lackey, 1989

GENERAL BEHAVIOR	SPECIFIC BEHAVIORS	SOURCES OF SPECIFIC BEHAVIORS
PSYCHOLOGICAL NEEDS	Listen to the patient, allow expression of feelings	Mayer, 1987
	Give patient time to assimilate changes, enable patient to be as independent as possible, assist family to sort out expectations, recognize families' fears and concerns	Reimer, 1991
	Provide support to family in emotional difficulty	Petrosino, 1985
	Help patient with fear to safely vent anger, sadness, anxiety	Ryan, 1992
	Psychological needs	Masters & Shontz, 1989 McGinnis, 1986;Wingate & Lackey, 1989
	Psychosocial needs	Heslin & Bramwell, 1989; Kristjanson, 1993;Masters & Shontz, 1989; Mulhern, 1986

GENERAL BEHAVIOR	SPECIFIC BEHAVIORS	SOURCES OF SPECIFIC BEHAVIORS
INFORMATION NEEDS	Knowledge of community resources	Mayer, 1987; Reimer & Davies, 1991
	Information needs	Lewandowski, 1988 McGinnis, 1986 Mulhern, 1986 Stiles, 1990 Wingate & Lackey, 1989
	Pain control	Petrosino, 1985 Stiles,1990
	Teach caregiver	Ryan, 1992 Stiles, 1990
	Legal/financial resources	Wingate & Lackey, 1989
	Arrange respite	Mayer, 1987 Hinds, 1985

GENERAL BEHAVIOR	SPECIFIC BEHAVIOR	SOURCES OF SPECIFIC BEHAVIOR
	Be available 24 hours a day 7 days a week	Brown, 1990; Kristjanson, 1993; Ryan,1992;Skorupka & Bohnet, 1982;Stiles, 1990
	Answer questions honestly	Lewandowski, 1988 McGinnis, 1986 Ryan, 1992 Stiles, 1990
	Include patient & family in decision- making	Mayer, 1987 McGinnis, 1986
	Support/ spirituality/ provide hope	Heslin & Bramwell, 1989 Hunt, 1992 Wingate & Lackey, 1989 Lewandowski, 1988
	Anticipate needs	Mayer, 1987

TABLE 2
CRITICAL NURSE BEHAVIORS IN CARE OF THE DYING
IN THE COMMUNITY

<u>Nurse Behaviors</u>	<u>Operational Definitions</u>
Developing rapport	Behaviors that build relationships with the patient and family.
	Behaviors that show respect for the patient and family
	Behaviors that promote patient autonomy
Providing comfort	Behaviors that reduce physical, psychological and emotional pain.
	Behaviors that support patients spiritual and informational needs.
Responding to the family	Behaviors that respond to the family's need for information.
	Behaviors that provide emotional support to the family
	Behaviors that reduce the potential for future regret
Coordinating care	Behaviors that illustrate the nurses' knowledge of available resources and willingness to access them
	Behaviors that demonstrate the nurses' confidence in advocating and decision-making
Responding to colleagues	Behaviors that provide emotional support and critical feedback to nurses
Enhancing personal growth	Behaviors that show the nurse has defined a personal role in care of the dying
	Behaviors that show the nurse is intuitive in care of the dying

TABLE 3

Context-Community	
Operational Definition	
Positive	Negative
Advantages of home care, environmental factors that result in positive patient outcomes.	Limitations of home care, environmental factors that result in negative patient outcomes.

Appendix A

Tool for Identifying Nurse Experts

Disclaimer

My name is Pat Helwer and I am a student in the Masters of Nursing Program at the University of Manitoba. The title of my research is "Critical nurse behaviors in care of the adult patient dying of cancer at home". The purpose of this study is to identify nursing behaviors that have positive or negative outcomes for the adult patient dying of cancer at home and/or their family.

Prior to beginning this study I will have obtained ethical approval from the Ethical Review Committee of the Faculty of Nursing at the University of Manitoba and access approval from the Research Review Committee of Manitoba Health. Your agency will have agreed to have you participate in this study but your participation is completely voluntary. You have been chosen because you are a registered nurse providing care in a community setting.

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 are asked not to sign your name on this form. You may choose not to respond to one or all of the paragraphs, if you so desire. Whatever you decide, your employment will not be affected in any way. Any questions you have will be answered and you may withdraw from the study at any time. There are no known risks to you should you decide to complete this form. The information on this form is confidential, only the researcher (Pat Helwer) and the Chairperson of the committee (Dr. Leslie Degner) will have access to this information. Members of the committee, Dr. Karen Chalmers, Internal Member, J. Honer M.A. and Dr. M. Harlos, External members as well as Dr. Degner may be contacted for further information on this study. Telephone numbers will be provided on request.

Instructions

Please read each paragraph carefully and indicate the name(s) of the VON/Home Care nurse(s) you work with that <u>best</u> fit each description. <u>The nurse must have had three or more years of experience in community, palliative care nursing, and presently be involved in patient care.</u> 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 that supports the relatives in care of their family member as much as possible. Because they appear to have an intuitive grasp of the needs of dying patients and the 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 the families may express. They seem to be able to zero in on the support needs of the patient and family.

Name_____

Name_____

Name_____

Appendix B

Semi-structured Interview Guide

Semi-structured Interview Guide

The nurse will first be asked to remember a situation involving nursing interventions that resulted in a positive outcome for the dying patient and/or family. Later, the same approach will be repeated, but the nurse will be asked to remember a situation that resulted in a negative outcome for the dying patient and/or the family. A critical incident may be described as:

.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 is all about.

Information that needs to be elicited from respondents:

.The content of the incident (eg. location, time of day, family resources).

.A detailed description of what happened.

.What were the nurse's concerns at the time?

.What was the nurse thinking about while caring 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. p. 300-301.

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Appendix C

Biographical Data Collection Form

Structured Data Collection

I.D.#_____   **Date_____**

1.<u>Years of experience in nursing</u>

Years_____

2.<u>Years of experience in palliative care</u>

Years_____

3.<u>Most recent level of nursing education completed</u> (CHECK ONE)

a) Registered Nursing Diploma_____

b) Post-diploma degree in nursing_____

c) Baccalaureate degree in nursing_____

d) Master degree in nursing_____

5.<u>Have you completed a specialized Palliative Care course?</u>

Yes_____

No _____

Appendix D

Consent Form

CONSENT FORM

STUDY TITLE: Critical nurse behaviors in care of the adult patient dying of cancer at home.

My name is Pat Helwer and I am a student in the Masters of Nursing Program in the Faculty of Nursing at the University of Manitoba in Winnipeg, Manitoba.

The purpose of this study is to identify nurse behaviors that result in positive or negative outcomes in care of adults dying of cancer and their family in their own homes.

You are being invited to participate because you have been nominated by your peers as providing "expert" nursing care to the terminally ill. The nurses you will be asked to nominate will have provided palliative care in the community for three or more years. The nurses demonstrate superior nursing skills in caring for adult patients dying of cancer at home. They are respected and consulted by their peers and case coordinators in caring for the terminally ill. Approximately ten nurses will be involved in this study.

If you are nominated and agree to participate, I will ask you to take part in one interview lasting 45-120 minutes. During the interview I will ask you to recall situations from your nursing practice that have resulted in superior, positive outcomes for your patients and their families. As well, I will ask you to identify situations that resulted in negative outcomes for the adult patient dying of cancer and the family. I will ask you to recall how and why the situations evolved and your feelings during the event. Later, I may contact you by telephone to clarify my impressions of the information you gave me during the interview. The telephone interview may last up to 15 minutes. Later, you will be contacted by mail to validate the data that has been collected, to ensure that what you said has retained its context and meaning.

The interview will be scheduled for a time that will be convenient to you. It will be audiotaped on a tape recorder and I will take some notes. The tapes will be kept in a locked drawer and will be heard by me, the chairperson of the committee, Dr. Leslie Degner and the person hired to transcribe the tapes. The tapes will be coded using numbers so that neither you nor your patients or their family can be identified. Names and identifying information will not appear on the transcripts. At the end of the study the recordings on the tapes will be kept in a locked file for 7-10 years in keeping with established procedures. Later they will be destroyed by taping over the interview. There is no monetary compensation for your participation in this study.

Some people may become uncomfortable or saddened when asked to recall sensitive information. If you wish to stop the interview for any reason, at any time, we will do so.

Reflection on previous experience may be helpful to some nurses. Participating in this study may give you a sense of satisfaction in knowing that you have helped me to identify nurse behaviors critical to caring for the dying adult and the family in their own home.

This study will have been approved by the Ethical Review Committee at the University of Manitoba, and access approval will have been obtained from the Research Review Committee of Manitoba Health. No information that can identify you will be given to anyone at the agency where you work. If you are nominated by your peers, your supervisor will be asked for a list of all the nurses' telephone numbers so that your name will be known only to the interviewer. Your employment will not be affected in any way should you agree or disagree to participate in this study. Information that can be identified with you that was obtained in this study will remain confidential.

If you decide to participate, you are free to discontinue your participation at any time. This project is being supervised by Dr. Karen Chalmers, internal member, Dr. Mike Harlos and Joan Honer, external members. If you have any questions, please contact me at   my thesis advisor Dr. Leslie Degner at   You will be offered a copy of this form to keep.

Participant's signature   Date

Researcher's signature   Date

Appendix E

Description of the Study

Description of the Study

Title: Critical nurse behaviours in care of the adult dying of cancer at home.

My name is Pat Helwer and I am a student in the Masters of Nursing Program in the Faculty of Nursing at the University of Manitoba in Winnipeg, Manitoba.

The objective of this study is to identify nurse behaviors that result in positive or negative outcomes in care of adults dying of cancer and their family in their own homes. You are being invited to participate because you have been involved in community nursing. The nurses you will be asked to nominate will have provided palliative care in the community for three or more years. These nurses demonstrate superior nursing skills in caring for adult patients dying of cancer at home. They are respected and consulted by their peers and case coordinators about caring for the terminally ill and their family members. Approximately ten community nurses will be involved in this study.

Description:

Following this explanation of the study you will given a form with three descriptions of "expert" nurses and asked to nominate palliative care nurses that best fit the descriptions. My telephone number will be left with the coordinators if nurses not present at the meeting wish to participate in the study, or if nurses have questions about the study. An envelope for the nominations will be placed in a location identified as confidential and will be convenient to the nurses. The envelope will be collected by the investigator approximately two weeks following the staff meeting. The forms will be reviewed by the researcher to identify the individuals nominated as "expert" by three or more of their colleagues. The coordinators will be asked to supply the names and addresses of all nurses participating in the study. To maintain anonymity, I will request privacy to copy the addresses and phone numbers of the nominated individuals.

Individuals nominated by their peers will be contacted by telephone to determine their interest in participating in the study. The nurse will select the location of the interview. Mutually agreed upon times for the interview will be arranged. The interviews will take place after a consent form (see Appendix D) has been read and signed. The nurse will then be asked to complete a sheet designed to collect information related to educational background and work experience (see Appendix C). Participation in the study is voluntary, the collected data will be confidential, and the research findings will be reported in a manner that maintains anonymity of the participants.

The interviews will take from 45-120 minutes and will be tape recorded. During the interview the nurse will be asked to reflect on a past incident related to caring for the dying. I may take notes during the interview to track themes and key terms. Later, I may contact you by telephone, to clarify unclear statements made during the interview. The telephone contact may take up to 15 minutes. After the data is transcribed, collated and categorized it will be sent to you for validation. You will be asked to return the data with your comments in a stamped envelope addressed to the researcher.

Your employment will not be affected in any way should you agree or disagree to participate in this study. Any information that is obtained in connection with this study and can be identified with you will remain confidential. If you decide to participate, you are free to discontinue your participation at any time.