

The Experience of Nurses Caring For
Young-Middle Aged Patients Dying of Cancer:
A Descriptive Study

by

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Abstract

Research has addressed issues which face the nurse caring for patients dying of cancer. However, this research has focused primarily on the older adult population. As a result, nursing issues with respect to the 20-45 year old patient group have not been examined. This study intends to address this gap in the literature by describing the experience of oncology nurses caring for young-middle aged (ie. 20-45 years old) patients dying of cancer. The conceptual framework guiding this study recognizes that this patient group presents unique and difficult nursing challenges. It is believed that insights into these issues may help to prevent the stress and burnout which these nurses experience.

A descriptive study design with convenience sampling was used. All of the fourteen subjects interviewed were registered nurses working in oncology who had cared for a young-middle aged patient within the past two years. Data analysis was concurrent with data collection, confirming the categories derived from the conceptual framework. The following areas were selected for analysis: issues in identifying with patients; issues in caring for families; and issues in shifting from a curative to a palliative focus.

Study findings and analysis revealed that oncology nurses find nursing young-middle aged patients dying of cancer particularly difficult and stressful. Patient identification appeared to be an important factor in creating this stress. In addition, the nurses identified the dependent children and the parents of their patients as particularly challenging. Further, they felt that they lacked expertise in providing palliative care and perceived a lack of support in their work environment for the provision of this care.

The nurses felt overwhelmed by the intensity of the sadness and grief they experienced when nursing the target patient group. They closely monitored the level of their patient involvement, often employing distancing strategies. However, the nurses also described the positive benefits and insights they gained from these patient relationships, despite the difficulties and grief they experienced.

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Chapter One - Introduction

Background to the Problem

Recent advancements in research and technology have lead to improvements in the treatment of cancer patients. However, it remains that for many patients, their disease will progress and result in death. The care of the dying patient is currently defined in terms of the concepts of hospice and palliative care (Scanlon, 1989). The literature recognizes that caring for the dying patient is primarily the work of nurses and thus palliative care is of particular concern to nursing (Davies & Oberle, 1990; Hull, 1989; Quint, 1972).

Research in palliative care frequently focuses on the difficulties inherent in providing this care. Nurses caring for dying patients have been observed to be vulnerable to a variety of stressors, including: stressors in their own inner experience, stressors related to their work environment, and stressors related to patients and families (Munley, 1985; Scanlon, 1989). In particular, a high degree of nurse-patient involvement is viewed as both integral to the provision of palliative care (Rovinski, 1979) and as a potential source of stress for the nurse (Scanlon, 1989).

Statistics describing the rates of cancer incidence and mortality indicate that the vast majority of patients developing cancer and dying from this disease are over the age of 45. Specifically, Canadian statistics reveal that only 10% of new cancer cases in 1987 occurred in patients under the age of 45, and only 5% of the total deaths attributed to cancer in 1989 involved patients under the age of 45 (National Cancer Institute of Canada, 1992). A small but significant number of such patients are children. The specialty of pediatric oncology addresses the issues involved in caring for children with cancer, while oncology and palliative care nurses care for adult cancer patients. However, as illustrated above, the patients who die from cancer between the ages of 20 and 45 years old represent only a very small portion of the practice of these nurses.

With the majority of patients receiving palliative care being over the age of 45, the palliative care literature and the research in the field predictably focuses on patients in this age group. However, recently the palliative care literature has begun to address the issues around patients dying with human immunodeficiency virus (HIV) disease who are frequently under the age of 45. The issues unique to this patient group are beyond the scope of this study; however it is

recognized that there may well be some common ground which can be made explicit by continuing research in the fields of both cancer and HIV palliative care nursing. Thus, this research study is intended to address the gap in the literature with respect to the experience specific to the nursing care of young-middle aged patients (20-45 years old) who are dying of cancer.

Problem Statement

Dying patients between the ages of 20 and 45 years old represent only a small portion of the practice of oncology and palliative care nurses. As a result, nursing care issues related to this patient group have not been effectively addressed in the literature. This gap in the literature reflects a gap in our understanding of the experience of the nurses caring for these patients. Insights into this experience may serve to guide nursing education and administration resulting in better support for nurses caring for these difficult patients. This study intends to address this problem by describing the experience of the oncology nurse caring for young-middle aged patients dying of cancer.

Purpose

The purpose of this study is to describe the experience of the oncology nurse when caring for young-middle aged patients dying of cancer.

Definition of Terms

The following terms are defined in an effort to make their meanings explicit in terms of the direction they provide for this research study. Thus, these definitions are intended to provide orientation and set boundaries for the study rather than serve as operational definitions (Sandelowski, Davis, & Harris, 1989).

- a) Experience: the sum of the feelings, emotions, responses, impressions, knowledge, and behaviours that describe the nurse's interactions with the patient.
- b) Care: those behaviours which the nurse employs in providing both emotional and physical support, and assisting the patient to achieve the highest level of wellness possible.
- c) Young-middle aged: refers to a patient between the ages of 20 and 45 years old.
- d) Dying patient: a patient for whom cure is no longer possible; where curative treatments have been replaced by palliative care.

Conceptual Framework

A conceptual framework refers to "a group of concepts which may or may not be related to each other, but which are believed to be important in understanding or explaining phenomena" (Menke, 1983, p. 416). The following conceptual framework outlines the assumptions orienting and directing this study as based on the researcher's nursing experience and understanding of the related literature.

The nursing care of young-middle aged dying patients involves challenges other than those faced when caring for older dying patients. These patients are frequently involved in establishing careers and building families. Their family members may include their young children, their parents, and their grandparents. In caring for these patients, the nurse may be directly involved with all of these family members. Frequently both patient and family demand information and support from the nurse. Some of the difficulties facing the nurse are associated with the often intense relationships that form, not only with the patient but with the family members as well.

In addition, the nurses caring for these patients are often accomplishing similar developmental tasks in terms of building families and careers. Thus, there may be significant identification with the patient on

the part of the nurse. However, regardless of whether the nurse can personally identify with the patient's situation, it remains that the death and dying of someone who has not lived a full life is seen as particularly tragic (Glaser & Strauss, 1964).

The concept of "social loss," articulated by Glaser and Strauss in 1964, acknowledges the difficulty nurses may have in caring for dying "patients in middle years [who] are in the midst of a full life, contributing to families, occupations, and society" (p. 119). Perceived social loss is believed to have a significant impact on the nurse's feelings, with the death of a high social loss patient being most upsetting to the nurse. The early work by Glaser and Strauss (1964) also suggested that high social loss patients received more than routine care while the opposite was true for low social loss patients. Thus, there is a tradition recognizing that death among different groups of patients may have different meanings for nurses.

Nursing young-middle aged dying patients presents unique stressors. For example, the nurse must deal with the stressors involved in intense family relationships because families are invariably coping with death before it is time. Further, there must be careful balancing between identification with, and

detachment from, the patient and family. The issues of caregiver stress and burnout are particularly significant in describing the experience of nursing these patients. "However, in the midst of this humanly difficult experience, nurses frequently speak of their work as rewarding, of their relationships with patients and families as meaningful, and of a desire to continue to work with dying patients" (Scanlon, 1989, p. 495).

The major assumptions which guide this study are summarized as follows. The nursing care of young-middle aged dying cancer patients is stressful. There are both similarities and differences when compared with the care of other patient age groups. However, there may well be stressors and difficulties which are unique to nursing the young-middle aged population. The issues involved in this area of oncology nursing have not been well studied. Insights and a deeper understanding of the nature of these issues may better prevent the symptoms of stress and burnout that are experienced by nurses caring for these patients.

Based on the above conceptual framework, the following categories for investigation have been identified and form the basis for the guided interview (see Appendix D):

1. Sources of stress in nursing young-middle aged patients dying of cancer.

2. Strategies for coping with the stress.
3. Positive aspects of caring for these patients.
4. Making sense of the experience.

Significance of Study

With the majority of cancer deaths occurring in patients over the age of 45, there is a gap in the literature with respect to the nursing care of young-middle aged dying patients. This research study addresses this gap. The research findings will describe the experience of oncology nurses caring for young-middle aged patients dying of cancer. The researcher believes that insight into this experience could guide nursing education and administration such that nurses might be better able to cope with the aspects of providing care to this patient group which prove difficult, and subsequently improve the quality of patient care.

Summary

This thesis is organized around six chapters. Chapter One is an introductory chapter. It describes the nature and significance of the problem, explains the conceptual framework which guides the study, and includes the study's defining problem statement and purpose. Chapter Two is a review of the relevant

literature with respect to the issues involved in nursing dying patients. Chapter Three outlines the research methodology used in this study including a description of the sample. Chapter Four presents the study's findings from the interviews. Chapter Five discusses and analyzes these findings. And, Chapter Six provides a summary, conclusions, and discussion of the implications arising out of the study.

Chapter Two - Review of Related Literature

Nursing dying patients presents unique demands. The repeated exposure to suffering and death requires sensitivity, understanding and compassion on the part of the nurse (Scanlon, 1989). A variety of stressors makes this care difficult and may lead to burnout.

The following literature review examines several issues with respect to the care of the dying patient. It begins with a general discussion of the nature of the caring or supportive role of the nurse as outlined in the literature. A discussion of the nursing behaviours critical to providing this care, both as perceived by the nurse and by the patient and family, follows. Some of the difficulties nurses face in caring for dying patients, particularly in terms of stressors, are examined. And finally, ways of addressing these stressors and preventing burnout will be discussed.

General Nursing Care of the Dying Patient

In describing the role of nursing in palliative care, the terms "support" and "care" frequently appear in the literature. Benoliel (1976) constructed an early definition of care using components which closely parallel the dimensions of Davies and O'Berle's (1990) Supportive Care Model. Scanlon (1989) uses the term

"emotional support" in describing an integral part of the nurse's role in caring for the palliative patient. And, Larson (1986) defines the nursing behaviours central to nursing dying patients as "caring." Thus, the terms support and care are used virtually synonymously in describing the essence of palliative care.

In an attempt to clearly define the concept of support in relation to the supportive role of the nurse in caring for patients with advanced cancer, Davies and Oberle (1990) developed a Supportive Care model. However, they were unable to distinguish between the concepts of support and care, and concluded that their model may, in fact, describe all nursing care (Oberle & Davies, 1992).

The literature describes caring as central to the practice of nursing (Scanlon, 1989; Watson, 1988). Caring is viewed from a holistic approach including: understanding the disease process, alleviating suffering, and understanding the patient both as an individual and as part of a family (Scanlon, 1989). In addition, Watson (1988) notes that not only does the patient benefit from the caring relationship, the nurse benefits as well.

While a holistic approach to care is essential to the care of all patients, it is particularly

significant in providing palliative care. The goals of palliative care address the physical, emotional, and spiritual needs of the patient and extend to the family as well (Rovinski, 1979; Scanlon, 1989). Thus, palliative care lies primarily in the domain of nursing with its focus on providing comfort and alleviating suffering (Scanlon, 1989).

Providing palliative care and nursing the dying requires the highest skills. Saunders (1978) observes that the nurse must be deft, dexterous, observant, vigilant and sensitive to the needs of both patients and relatives. Further, it is the actual caring behaviours that are required, rather than good intentions and offers (Rovinski, 1979). Thus, the general literature describes a nursing role that is holistic in its "caring" and "support" and provides clinically competent interventions.

Nursing Care Behaviours Research

Nursing care behaviours in relation to dying patients have been the focus of several studies in the literature. Studies have examined the nature and effectiveness of these behaviours from the perspectives of nurses, patients, and families.

Different populations of nurses have been studied with respect to variations in care behaviours towards

the dying. A study by Waltman and Zimmerman (1991) examined whether there were differences in the behavioural intentions of nurses towards dying patients related to differences in the age, educational level, place of employment, area of work, and the nurses' personal experiences with death. Data were obtained from a convenience sample of nurses responding to a questionnaire. The results indicated that nurses across different settings were all found to spend more time with dying patients than non-dying patients. However, demographic differences were observed with younger nurses, nurses with master's degrees, full-time nurses, and those employed in schools of nursing being more likely to openly communicate with dying patients and families. In contrast, older nurses, nurses working in areas other than critical care, and those with personal death experiences were most likely to provide continuing care for bereaved family members.

In addition to examining the nature of, and variations among care behaviours of nurses, a number of research based studies have examined whether these behaviours do, in fact, meet the patient's perceptions of their care needs (Larson, 1986; Lev, 1991; Waltman & Zimmerman, 1991). Larson (1986) questioned whether there was agreement between nurses' perceptions of caring and patients' perceptions of caring. While

nurses ranked behaviours in the affective domain as those most important in making the patient feel cared for, the patients ranked the nurse's availability and professional knowledge as most important.

Larson (1986) acknowledged limitations of this study based on its forced-choice format. However, a later study by Lev (1991) using a qualitative method interviewing both patients and family members about their concerns revealed similar findings. Lev (1991) suggested that what constitutes appropriate supportive care of patients and families may be perceived differently by patient groups and nursing groups. These findings suggest a need to define the nature and context of nursing care behaviours, and to clarify that these behaviours do, in fact, accurately address patients' needs.

Kristjanson (1986) also studied the supportive care of dying patients. She identified those care behaviours that were ranked as most important to the families of cancer patients with advanced disease. This research study involved a qualitative phase identifying indicators that families of dying cancer patients perceived to be important in patient care and a Q-Sort methodology to obtain relative rankings of the items identified. The sample included patients in home care, acute care, and palliative care settings. While

some differences were observed between settings with respect to the five most important items, the item ranked as highest in importance for the total sample was the relief of patient pain. Another highly ranked item involved caregivers communicating information in a straightforward manner.

Similarly, Hull's (1989) review of the literature with respect to family needs and supportive nursing behaviours with dying cancer patients concurred that patient comfort was of primary importance. Nursing interventions consistently identified as least supportive to family members included behaviours designed to encourage ventilation of feelings. Hull observed that this finding was contrary to widely held professional opinion. She suggested that while some studies did link family needs and supportive nursing behaviours, families clearly indicated their preference for patient-centered information and their wish to focus attention away from their own emotional needs, especially when nurses were perceived as busy and having limited time.

Clearly, it is vital to understand what the patient and family perceive as critical nursing behaviours in the care for the dying. That there are discrepancies between what nurses perceive as supportive and what patients and families perceive as

supportive has been well identified in the literature (Hull, 1989; Larson, 1986; Lev, 1991). However, there is also considerable consensus within the literature. The literature identifies that patients and family members equate effective caregiving with effective communication skills (Hull, 1989; Kristjanson, 1986; Lev, 1991). Further study addressing the discrepancies is important in increasing nursing's effectiveness in assisting patients and families through this very difficult experience.

Stressors Involved in Caring for the Dying Patient

Issues of work-related stress and burnout are central to discussions of palliative care. Munley (1985) identified that hospice staff are susceptible to three levels of stressors: those evoked by patients or family members; those occurring in their own inner experience; and those related to the hospice work environment.

Vachon (1987) conducted a major study of occupational stress related to caring for the critically ill, the dying, and the bereaved. Approximately 580 caregivers, representing a wide variety of disciplines, were interviewed with the majority of these caregivers being nurses and physicians. Contrary to expectations, the findings

revealed that caregivers felt that more of their stressors emerged from their work environment and from their occupational role than from their direct work with dying patients and their families.

Similarly, Munley's (1985) qualitative study of stress among hospice staff revealed significant occupational role and work environment stressors. Occupational role stress was found in staff interactions as a result of the high expectations hospice staff have of one another. Also, stress was experienced from being involved in a work context that values sensitivity and being onstage as a giver at all times. Stressors related to the work environment included working under tight budget constraints with resultant inadequate resources and staffing difficulties (Munley, 1985; Vachon, 1987).

While Vachon's (1987) results clearly reveal the significance of occupational role and work environment related stressors, much of the literature addresses stressors related to patient and family variables. Specifically, Vachon found that stressors related to patient and family variables accounted for 22% of the occupational stressors mentioned during interviews. She suggested that at least some of the stress caregivers reported in response to occupational role and work environment stressors was a displacement of

the stress experienced in caring for dying patients and their families. The remainder of this section of the literature review will focus on these stressors.

Patient-family stressors are most common in settings where caregivers have long-term relationships with patients and families, such as oncology (Vachon, 1987). The stress arises from the caregiver identifying with the suffering that patients and families experience. The sustained intimacy that characterizes the concept of palliative care and hospice leaves the nurse particularly vulnerable to stresses associated with over-investment and over-involvement (Munley, 1985).

Scanlon's (1989) discussion paper identifies the danger of over-involvement with patients and families in providing palliative care, and suggests maintaining a healthy detachment balanced by a commitment to non-abandonment. The idea of balanced caregiving is also examined in an article by Larson (1992). He cautions against using the increasingly popular and increasingly negative term of "codependent nurse," and instead maintains that the major source of the problem is in the situation or context rather than in the caregiver. Further, in an overview of hospice nursing, Rovinski (1979) asserts that a high degree of nurse-patient

involvement is, in fact, integral to providing palliative care.

The intense relationships that develop between nurses and dying patients prove stressful for several reasons. By becoming too attached, nurses may fear becoming too involved in the suffering as well. These overwhelming feelings may limit the ability of the nurse to support the patient (Zelevsky & Birchfield, 1992). In addition, nurses who become over-involved with their patients may also become over-protective and have difficulty relinquishing care to other caregivers. Clearly, the balance between involvement with the patient and distance from the patient is a crucial factor in providing care.

Certain types of patients and families are identified as being more stressful to care for than others. For example, patients experiencing pain are often stressful to nurse (Munley, 1985). Vachon (1987) describes a variety of stressful patients and families: those who act in an unexpected way; those with whom caregivers have difficulty communicating; those who become extremely depressed, angry, withdrawn, or psychotic; those in denial; those who act out by using alcohol or drugs; and those engaged in avoidance behaviour.

Cancer patients have been identified as being very stressful to nurse (McElroy, 1982; Vachon, 1987). Some of the difficulties these nurses face include: close involvement with the patients over an extended period; a sense of repeated failure with frequent deaths; and difficulty in deciding what message to give patients and families when the trajectory of the illness is so unpredictable (Bolle, 1988; McElroy, 1982; Scanlon, 1989).

In addition, patients may be viewed as being particularly stressful to work with because of their age. For example, the nursing care of dying children presents unique stressors. Nurses may experience feelings of helplessness in trying to relate to the dying child, and there may be an uncertainty in determining the extent of the child's understanding of death. Coody (1985) notes that it is instinctual to try to protect children and carry their burdens for them. In contrast, some nurses find older patients serve as a source of stress. Nurses empathize with their loneliness and feel particular sympathy for those patients who die alone, having outlived their relatives (Vachon, 1987).

The literature has not investigated the young-middle aged patient group as an independent group in terms of caregiver stress. However, this patient group

has been identified as being uniquely stressful as part of studies or discussions of larger populations. For example, Vachon's (1987) study found that, although caregivers identified stressors in patients throughout the lifespan, the young-middle aged patient group was viewed as being uniquely stressful.

Similarly, Alexander's (1990) quantitative study measuring the major sources of stress for palliative care nurses found that dealing with illness and death in patients below the age of 40 years was consistently a greater source of stress than dealing with patients in older age groups. He theorized that the principal reason for this difference lay in the nurse identifying with the younger patients and experiencing a greater sense of injustice regarding their deaths. Vachon's (1987) results indicated that the stress lay in watching the suffering of these young patients rather than in identifying with them. She also found that caregivers questioned the injustice in the suffering and death of these patients.

While the results of these studies may differ with respect to the role that patient identification plays in caregiver stress, they do agree that nurses are vulnerable to stress when they identify with certain patients and their families. When identifying with particular patients, nurses are more likely to invest

their emotional energy in the nurse-patient relationship, and thus they are at risk for developing stress responses when these special patients deteriorate and die (Vachon, 1987). "Certain patients are most apt to evoke these responses: 'socially valued patients' such as children, young people, or those who will be leaving young families; intelligent and cooperative patients; those who are similar in age, social class, or lifestyle to the caregiver; those with prominent positions in the community; [and] those who have responded well to treatment" (Vachon, 1987, p. 100).

Caring for the young-middle aged dying patient is inherently stressful. However, as previously stated, this patient group has been studied only as part of investigations of larger patient populations. A greater understanding of the stressors specific to the nursing care of young-middle aged dying patients would contribute greatly to the existing knowledge base.

Addressing the Stressors

Nursing research has centered not only on identifying the stressors in providing nursing care to the dying, but also on addressing and preventing the burnout which may result from these stressors. It has been recognized that nurses who work with the dying are

especially vulnerable to professional and emotional burnout (Larson, 1992). These nurse have advanced skills and high expectations of themselves and each other. Their stressors and challenges are often rewarding but may also cause distress and eventually burnout (McElroy, 1982; Scanlon, 1989). While the research has not addressed the issues of caregiver stress and burnout specifically in terms of the young-middle aged dying patient, the following discussion applies to this group as it is part of the general population of dying patients.

Caregiver stress is manifested in psychological, behavioural, and physical symptoms. Vachon (1987) notes that the most frequently reported symptoms of stress include: feelings of depression, guilt and grief; staff conflict; marital and family problems; feelings of helplessness, inadequacy, anger, and irritability. Physical symptoms of stress among palliative care nurses included changes in eating patterns and sleep disturbances. She found that feelings of depression, grief, and guilt constituted the single greatest manifestation of stress in all care settings.

McElroy's (1982) literature review observes that the most common symptoms of burnout in the literature are exhaustion and fatigue, with impaired problem-

solving and decision-making abilities. Unchecked, these symptoms lead to anger, resentment, and a build up of apathy with the caregiver becoming detached from patients and colleagues (Bolle, 1988).

The literature has addressed ways of dealing with the stress of caring for dying patients. While young-middle aged dying patients have not been studied as an independent patient group, the literature on other patient populations and dying patients in general has applications for nursing the young-middle aged patient group.

For example, the literature has addressed the stress of caring for dying children. In particular, nurses caring for children with AIDS face the added stress of the very poor prognosis associated with this disease. To prevent feelings of hopelessness and helplessness, nurses develop care plans which combine both aggressive medical treatment and palliative care. A balance between these care measures helps to maintain the distinction between cure and treatment (Gary, 1992).

In caring for dying children, nurses must come to terms with their own views about death and about children (Coody, 1985; Gary, 1992). This allows the nurse to view the child as independent and helps the nurse to function as a partner rather than a protector.

The level of involvement of the nurse must be carefully balanced in these partnerships. The level of involvement and intensity of the relationship of the nurse with the young-middle aged dying patient requires a similar balancing of the nurse's roles.

Zelewsky and Birchfield (1992) describe a different method of coping with the attitudes and feelings which accompany nursing dying patients. Their discussion paper with respect to strategies for coping with the inherent stressors of caring for the terminally ill was based on their collective experiences with dying patients in general and patients affected by human immunodeficiency virus disease. They encourage nurses to become more comfortable with the discomfort of their own mortality and the experience of working with the dying. The premise of this approach is that "only when we face and accept the difficulty of being with and caring for the dying will we be able to be with them and care for them" (p. 16).

An early observation by Quint (1972) describes nurses as using "composure tactics" as a defense mechanism against the difficulties of nursing dying patients. However, recent literature supports nurses being highly involved with dying patients while employing mechanisms of self-protection. For example, Davies and Oberle (1990) identify "preserving own

integrity" as the core concept in their Supportive Care Model.

Vachon (1987) describes strategies for coping with the stressors in terms of problem-solving mechanisms and emotion-regulating mechanisms. Examples of problem-solving mechanisms include: staffing policies, and good orientation and ongoing educational programmes. Examples of emotion-regulating mechanisms include: having a sense of competence, control or pleasure in work, and developing a personal philosophy of illness, death, or one's role. Similarly, Bolle's (1988) article lists education, regular support group meetings, and multidisciplinary team meetings as strategies for preventing burnout.

Strategies have been identified for coping with the stressors surrounding a difficult death. Following a death where there has been an intense involvement, Coody (1985) notes that it is the nurse's responsibility to take a break from intense patient involvement. Some form of ritual or remembrance may also prove helpful in assisting nurses to move on from these particularly difficult deaths (Gary, 1992; Hammer, Nichols, & Armstrong, 1992). Clearly, a wide variety of mechanisms for coping with stress emerges from the literature. Nurses' support of each other, both formally and informally, is frequently

acknowledged (Munley, 1985; Rovinski, 1979; Scanlon, 1989). In addition, maintaining feelings of self-esteem and self-worth are identified as successful and important mechanisms for dealing with the stress of nursing dying patients (Davies & O'Berle, 1990; Larson, 1992; Scanlon, 1989). Zelewsky and Birchfield (1992) concur that the individual nurse must develop a life outside of work that nourishes and fulfils self.

The prevention of burnout symptoms involves consciously monitoring whose needs are being met and avoiding the pitfall of viewing oneself as a "saviour" (Munley, 1985; Scanlon, 1989). Munley (1985) cautions nurses not to dwell on the difficult deaths but rather to think and talk about success stories. She observes that "when nurses interpret their work as having intrinsic value and they experience sacred moments in caring for the dying and their families, the rewards of their role can more than balance the costs" (p. 356).

In conclusion, the literature identifies a variety of methods for addressing the stresses and avoiding burnout when nursing dying patients. For example, recommendations include having support within the system or work environment. Further, the literature recommends that nurses develop a philosophy of death and an understanding of their role in nursing the dying.

patients. Thus, strategies for preventing burnout target both the work environment and the individual.

Summary

In summary, the literature identifies the need to clearly define the nature and context of the nursing care behaviours which most appropriately meet the dying patient's needs. With the variations among nurses in terms of their care behaviours, it is vital that nurses understand what patients and families most value in their nursing care. In addition, the literature identifies the care of certain patients and families as being particularly stressful. Finally, this literature review addresses how the stressors inherent in this type of nursing are addressed with the goal of preventing burnout.

There is consensus among both the research based and opinion based literature that nursing dying patients is stressful, and that these nurses are particularly vulnerable to burnout. Patients under the age of 40 have been identified as being particularly stressful within the larger population of dying patients. While there is a common assumption that young-middle aged dying patients are inherently stressful and as a result difficult to nurse, there has been no independent study of nursing issues as related

to this population. The nurses who care for these patients are the focus of this research study. There is sufficient evidence in the literature to conclude that they do encounter difficulties and therefore would benefit from a body of knowledge that can facilitate recognition of their special challenges and help them to prevent burnout.

Chapter Three - Methodology

The following chapter describes the methodology used in completing this research study. It outlines the study design, sample selection, data collection and analysis procedures, as well as ethical considerations and limitations.

Research Design

"Factor-searching studies are the most basic that can be done" (Diers, 1979, p. 102). They include descriptive, exploratory and formulative study designs (Diers, 1979, p. 100). These designs are appropriate "when the problem is to describe, or name the parts of, a given situation or event" (Diers, 1979, p. 100). Polit and Hungler (1991) note that descriptive studies "do not focus on relationships among variables," rather "their purpose is to observe, describe, and document aspects of a situation as it naturally occurs" (p. 175).

Thus, a descriptive design is the method of choice for this research study. A descriptive study functions to classify or conceptualize situations "when there is no usable information about a particular phenomenon available" (Diers, 1979, p. 100). Field and Morse (1985) concur that descriptive studies are appropriate for addressing the question, 'What is this

phenomenon?" (p. 9). The use of the descriptive study design is appropriate in light of the identified gap in the literature with respect to the experience of the nurse caring for young-middle aged dying patients.

Sample Selection

Convenience sampling was used to select research participants. Although the research proposal predicted that the sample would consist of 20 subjects, 14 interviews were completed because of time restrictions. Because the process of analysis was on-going with the data collection, the researcher was able to observe a richness in the data indicating that the categories derived from the conceptual framework had been well addressed. Thus, the researcher felt that a sample of this size, though representing a limited number of experiences, would still be sufficient to achieve the desired study results.

All of the participants met the following criteria: (1) be a registered nurse working in oncology, and (2) have cared for a young-middle aged patient dying of cancer within the past two years. Letters of introduction to potential participants (see Appendix A) explaining the study were given to Nursing Unit Managers at the British Columbia Cancer Agency (BCCA) for distribution during staff meetings.

Additional letters were placed in each nurse's unit mailbox. In addition, copies of the letter were mailed out to the provincial membership of the B.C. Oncology Nurses Group. However, all of the nurses who volunteered to participate were employed at BCCA.

Interested nurses informed their Unit Manager who kindly let the researcher know on which days these nurses would be working. Some nurses volunteered directly after discussion with the researcher. At least two interviews were conducted on a given day, thus not all nurses who had initially expressed an interest to their manager were able to participate. The identity of those nurses who did participate was known only to the researcher. All subjects signed a consent form (see Appendix B) before being interviewed. Basic demographic information with respect to the subject's age, nursing education and experience was also obtained (see Appendix C).

Sample Description

The study sample consisted of 14 staff nurses, including two male nurses, employed at the BCCA. These nurses differed in terms of age, education, and nursing experience. Nine of the subjects were 31-40 years old, three subjects were 20-30 years old, and two subjects were over 51 years old. Thus, 85% of the sample was

within the age range (ie. 20-45 years old) of the patient population targeted in this study.

The educational backgrounds of the nurses interviewed ranged from preparation at the diploma level to preparation at the master's level. Nine nurses (ie. 64%) were prepared at the diploma level; four nurses (ie. 29%) were prepared at the bachelor's level; and one nurse (ie. 7%) was prepared at the master's level. In addition, some of the subjects reported having completed some specialty training in the areas of obstetrics, pediatrics, ICU/emergency nursing, and palliative care.

The sample represented a range of nursing experience with the total number of years in nursing ranging from two to 30 years. The average length of time in nursing was 10 years. The number of years worked in oncology ranged from two to 14 years, with the average length of time specializing in oncology nursing being six years.

Data Collection Procedures

Data collection was completed through guided interviews of approximately one hour in length. A guided interview (see Appendix D) was used because "this technique ensures that the researcher will obtain all information required (without forgetting a

question), while at the same time permitting the informant freedom of responses and description to illustrate concepts" (Field & Morse, 1985, p. 67). The interview guide was designed specifically for this study from the themes which emerged from the conceptual framework. It was reviewed by thesis committee members before being used.

Twelve of the interviews were conducted in offices or staff rooms at BCCA. These nurses were allowed time during their work shift to participate in the interviews. The remaining two interviews were conducted at the subjects' homes at mutually convenient times for subject and researcher.

All interviews were tape recorded to ensure accuracy of data collection. Two of the subjects expressed concerns about identifying specific patients by name during the taped interviews. They were reassured, as stated on the consent form, that initials only would be used in transcription of the interviews, and that the interview tapes would be erased following transcription. Aside from this concern, subjects appeared to speak freely and comfortably during the interviews. Subjects responded directly to the interview guide questions, as well as digressing to discuss any aspects of their nursing experiences that they felt were relevant to the interview. The subjects

all took advantage of the opportunity to add any information at the conclusion of their interview that they felt should be included in the discussion.

Data Analysis

The following categories, based on the conceptual framework for this study, formed the basis for the initial process of organizing and analysing the collected data: sources of stress in nursing young-middle aged dying patients; strategies for coping with the stress; positive aspects of caring for these patients; and making sense of the experience. Thus, the conceptual framework as developed from assumptions drawn from the related literature and the researcher's experience formed the basic structure directing the analytic process.

Within this basic structure, an inductive approach was taken in analysing the interview data. During the interviews, the researcher listened carefully to the ideas and themes emerging and compared these with previous interviews questioning what might have been happening for subjects who related similar and dissimilar experiences. As noted by Diers (1979) "the "processing" of data takes place in the investigator's head literally" (p. 115) and "a self-conscious monitoring of one's own thinking process is maintained"

(p. 115) during data processing and analysis. Thus, each interview was built on those preceding it, with the researcher using the initial analysis of preceding interviews to guide the approach and questions in subsequent interviews.

At the completion of the interviews, the researcher listened to each of the interview tapes making notes to identify particularly pertinent and interesting subject comments with respect to the categories identified from the conceptual framework. Each tape was then listened to a second and sometimes third time to transcribe these sections. Following this each tape was erased.

The data from these transcribed tapes was then sorted and organized into the categories identified in the conceptual framework. The categories were then reworked by subdividing or combining categories. For example, the category of "sources of stress in nursing young-middle aged dying patients" proved to be too general. It was subdivided to acknowledge the importance expressed during the interviews of the family as a source of stress during the interviews. The reworking of categories was repeated "until a set of categories [evolved] which [did] encompass all the data meaningfully" (Diers, 1979, p. 117). "Reworking the categories over and over constitutes the major

portion of data analysis for this kind of factor-searching study" (Diers, 1979, p. 117). Finally, the researcher integrated insights from all of the interviews into a description of the nurse's experience in caring for young-middle aged dying patients.

Ethical Considerations

In order to protect the rights of all subjects, permission to carry out the proposed study was obtained from the Ethics Committee of the University of British Columbia. All subjects received a copy of the letter of introduction providing basic information with respect to the purpose and nature of the research study. Prior to the interview, each subject was required to sign an informed consent.

Limitations

The primary limitation of this study lies in the fact that theoretical sampling was not used. Dier (1979) observes that "the ideal in factor-searching studies is the Glaser and Strauss method of gathering data, beginning to construct concepts, sampling theoretically, gathering more data and so on until the concepts are fully saturated" (p.111). Because of time restrictions a smaller sample was used without theoretical sampling, thus sacrificing some of the

richness and subtlety of the concepts (Dier, 1979, p. 111). Future study to further develop the categories could increase their precision and sensitivity as other groups of data are collected. In addition, study findings are not generalizable beyond the group studied. Generalizability is limited by the fact that the subjects are representative of only one institution.

Summary

A descriptive research design was used to collect data for this study. Fourteen subjects were interviewed, using a semi-structured interview guide, about their experiences nursing young-middle aged dying patients. The tapes were reviewed and the information was organized into categories as identified in the conceptual framework.

Chapter Four - Presentation of Findings

Chapter four summarizes and describes the data obtained in 14 interviews with nurses from the B.C. Cancer Agency. The discussion is organized around the following categories: general responses to the experience; comparisons with older patients; the family as a source of stress; other stressors; coping with the stress; positive benefits; making sense of it. These categories and their sub-categories are directly related to the conceptual framework from which the interview guide was developed. The nature of the data obtained through the interviews required that sub-categories be created within the categories of 'stressors' and 'coping with the stress.' In addition, the subjects discussed the family as a source of stress to such an extent that it required the creation of a separate category in the presentation of the findings. An analysis of findings follows in chapter five.

General Responses to the Experience

Each of the 14 interviews opened with the subjects being asked to describe, in general, what the experience of nursing young-middle aged dying patients has been like for them. While the responses differed between subjects, they all reflected the impact that this patient group has on them. As one subject

described, "very overwhelming, they stand out in my mind. I take them home in my mind an awful lot when I don't want to." Several of the subjects described the experience as difficult and painful. One subject stated that "it's been overall very difficult, very difficult." While another subject remembered that "there was a lot of painful times with it. There was a lot of grieving."

A variety of factors were identified which the subjects attributed to the pain and difficulties they experienced in nursing these patients. One subject described that she found the experience difficult because she had never nursed this patient group before. She said, "It was very hard for me to deal with, and my initial reaction was to run away from it because I didn't want to face it." Another subject found her feelings of helplessness made nursing these patients difficult. A third subject described feeling inadequate and uncomfortable recognizing that while she was healthy her patients were "facing this horrible, horrible burden." In addition, patients with young families were identified as being difficult to nurse. As one subject stated, "when they have families, and they are young families it just tears your heart out and you want to help them even more."

Several of the subjects related the age of the patient to the difficulties they experienced in nursing them. For example, one subject stated that it's "more stressful because the patients are young." Another observed that "especially the closer you get to the bottom rung of that ladder, the younger people, I find it very frightening." Further, one subject stated that "whenever I see an age under what seems to be a reasonable life span, before I even enter the room I feel heavy hearted . . . most of the time it's pretty sad."

While feelings of pain and helplessness were central to most of the subjects' initial responses with respect to their experience nursing young-middle aged dying patients, there was also considerable discussion of the rewards and benefits of this type of nursing. For example, one subject stated that "it's difficult in certain ways but it's also the most challenging and the most rewarding." Despite the difficulties and pain they experience the subjects indicated that they choose to nurse these patients. As one subject stated, "I would probably go for that patient even knowing that its going to be hard because even though its difficult it can be the most rewarding kind of nursing too." Another subject agreed, "It's a privilege to be involved with these people. I jump at the chance."

Clearly, the subjects described nursing young-middle aged dying patients as a very difficult yet rewarding experience.

Comparisons With Older Dying Patients

Following a general discussion of the subjects' experiences nursing young-middle aged dying patients, the subjects were asked to compare this patient group with the older patients that they nurse. A variety of differences were identified. The subjects emphasized differences in the ways that these two patient groups face their illnesses and deaths, differences in the family structure and involvement, and differences in the approach and role of the nurse.

All of the subjects viewed older patients as being more accepting of their illnesses and eventual deaths. As one subject stated, "with an older population . . . they'll say something like I've lived my life to the fullest, I just don't want to be in pain now and it doesn't matter if I go now, things are fine." This acceptance was linked with the idea that the older patient has lived a long and full life on which they can reflect with some satisfaction. For example, one subject said, "with an elderly person they can talk about what a good life [they've] had and the experience that they've had and they've something to draw on."

The older patient's acceptance of illness and death was also seen to be linked to having faced difficulties and crises during their lives:

I think the older people generally confront their eventual death in a different way than a younger person is going to just because they have had more life experiences to draw on and they've probably had more crises in their lives where they've had to cope and get through . . . some of these older people have had children that have died already.

And finally, this acceptance of death on the part of the older patient was described in terms of viewing these deaths as "natural." As one subject stated, "It's just something that is natural, you know, we die, that's just part of life."

In contrast to describing the older patient as accepting of death, the subjects described the younger patient as frequently having difficulty accepting their illness and eventual death. One subject observed that "they are probably more angry, more intense than somebody who's older," while another subject observed that "its a lot harder for them to let go."

Several of the subjects discussed the importance of dealing with crises and having significant life experiences in enabling the older patient to accept death. In comparison, they also discussed the effect that the lack of these experiences has on younger patients. As one subject observed, the younger patients "need more support because they've not

necessarily gone through crises already." Another concurred that "there isn't that long range of experiences that there is for other people in an older age group that seems to be a source of great comfort to them." More specifically, one subject noted that it was the development of a life philosophy or particular belief system that guided the older patient through illness and death. Not having had the time to establish such philosophies or beliefs leaves the younger patient without "the same kind of equipment" to face their illness and death.

In comparing the older and younger patient groups as they face death due to illness, several subjects examined the role of the patient within their family. As one subject noted, "with an older person, its just adult children or no children available or there's not much family involved." Another subject observed, "An older person they may have a spouse but . . . I guess they're not needed as much it seems to me by their families."

In comparison, subjects identified the younger patient as having a much different role in and structure to their family. This was repeatedly viewed as a key factor in the difference between the way in which younger and older patients face illness and death. For example, one subject observed that younger

patients are likely to be "leaving behind an active spouse and maybe there's financial concerns, children, and I find that they can't let go." Another subject said:

Its the prime of your life . . . you get your education, you get married, you start your family, you buy a home, you do all this stuff and then when something like cancer strikes, . . . it just throws everything off . . . when you're 28 you're going hold it here, I've hardly lived.

Subjects described how establishing a family and career leaves younger patients fighting hard to beat their disease rather than accept it. Subjects also described the effect that the younger patients' families have on them and their nursing care. One subject said:

I think that's the biggest difference between the older people and the younger people, that I become much more involved with the families than with older people but perhaps that's because they are present, they are much more present . . . so it's a real fight not just for the patient but for the families and the nurse as well.

Several subjects compared the needs of younger with older patients and their respective nursing care demands. One subject noted that the younger patients generally have more questions about their disease and treatment than older patients. As a result she felt that she needed to "be more up on [her] clinical knowledge." A second subject agreed, "I tend to think they have a lot more questions about things . . . when

you're 85 you're not questioning it so much."

Similarly, another subject said:

I think they can be a little intimidating if they're young professional kind of people that are still in the work force and often they're quite well read about their condition and the treatment and all that and I think in the beginning they can be quite intimidating and you have to get past that to develop a rapport.

One subject highlighted the issue of balancing therapeutic with social relationships in developing a rapport with the younger patient group.

Finally, the subjects compared how they are affected by nursing these patients. One subject said, "The younger group, it's harder . . . harder for both nurse and patient." Another subject echoed that "emotionally it's the hardest." A third subject described that she found the death of a younger patient much harder to get over than the death of an older patient. She noted, "I can recall the faces of every one of these young people that have died." Thus, subjects identified several differences between younger and older patient groups, both in terms of the way in which the patients approached illness and death, and the way in which the subjects approached providing their nursing care.

Family As A Stressor

In discussing the difficulties and stresses experienced in nursing the young-middle aged dying patients, a variety of factors were identified around the patients' families. As discussed in the previous section comparing the younger and older patient groups, subjects found the families of younger patients to be both more complex in structure and more involved in the care of the patient. This was discussed at some length when subjects were questioned about the stress they experienced when nursing this patient group.

The structure of the younger patient's family was often distinguished simply by the number of family members involved. As one subject observed, "You usually have more family members to deal with." A second subject agreed, "You end up nursing a lot more people when you have a younger patient." And a third subject described "families [as] one of the most difficult things because it is a complicated situation with a younger person."

The family was also described in terms of the ages and roles of its members. The younger patient's family frequently includes dependent children, spouses, and parents. In addition, several subjects described having to address the needs of these family members as

well as the needs of the patient. As one subject stated:

You go into a room thinking OK, we need to find out about this patient's family. Do they have kids? Do they have a partner? How is everybody in the family? There's a lot of psycho-social needs, a lot of listening, a lot of sitting and listening.

Another subject observed:

It means a spouse, sometimes very young children then its very emotional from their point of view and that makes it difficult from a nursing point of view too -- the families. You're not dealing with the dying person, you're dealing with the family on top of it.

Meeting the needs of the family was viewed as difficult. One subject described the fine balance between providing the family with privacy and knowing when to step in and offer help. Another subject brought up the issue of not knowing the family history:

You have to wade your way through all those protective people to get to the patient and you're often not nursing just the patient you're nursing the entire family and if nothing else, timewise that's very consuming and emotionally too. You're dividing yourself up in that many more pieces. And everyone brings in a whole bag full of emotional family histories. You know, the supportive brother who's sitting there holding her hand may be someone that she hasn't seen for years and they've had a major disagreement and they haven't spoken and yet you don't know that. You don't know the history.

Responding to the needs and reactions of the patients' families was seen as being difficult. In particular, subjects discussed these difficulties in terms of dealing with the patients' children.

Dependent children were viewed as a source of stress by the subjects. One subject identified dependent children as a great source of stress for the patient, the nurses, and the medical staff. Another subject remembered a situation which she felt was made more stressful because of the children involved. Some of this stress she linked to not knowing what to say to the children. A third subject stated:

I guess the hardest part is there is no real information out there about when to involve the kids. The family doesn't know when to involve the children. How do you tell the children?

The patients' parents were also viewed as a source of stress by the subjects. The pain and helplessness of these parents was felt keenly. One subject said, "I often think it must be the most devastating thing in the world to see your child die, even if your child is an adult." A second subject agreed, "Parents losing a child, a young adult child, there seems to be some general awful pain that's involved in that's just beyond." While a third subject lamented, "I have a hard time looking at parents who are losing a child. I can't begin to empathize with them. What can you do for them? Not much really."

In describing the stress experienced when dealing with the families of younger patients, the subjects talked about both the terrible pain that the parents feel as well as the nature of the involvement of

parents in the care of the patient. Subjects described role changes where patients were seen to relinquish control, while their parents assumed greater control over their care. As one subject expressed, "They're like us before they get sick and then after they get sick they seem to regress and the sicker they are the younger they become and the more their parents take a role." Another subject noted, "I haven't ever seen parents try to promote the independence and control again. They take over to make it easier."

This role reversal was seen as creating some of the difficulties the subjects experienced both in supporting the younger patients and in supporting their parents. One subject described the following situation:

We had a young man recently where I wanted to go in when he was alone and give him a chance to talk but he had a very domineering kind of mother who didn't leave him alone very often and had a lot of anger and bitterness.

Similarly, another subject remembered a patient who was able to talk to the nurses about death and dying but when the family came in "he wasn't able to talk about it anymore." The subjects' frustration with not being able to openly communicate with the patients was compounded by the protective and sometimes adversarial responses of the families. As one subject stated:

Logically, in the back of your mind you understand that's just the way she is, and especially being a

parent you understand how she must feel and at the same time its difficult to listen to these curses.

In acknowledging the difficulties experienced in nursing young-middle aged dying patients, subjects agreed that many of these difficulties arose from the involvement of the patients' families. As one subject stated, "I find its very stressful on the nursing staff. You have to deal with it differently, its a different approach." And, as cautioned another subject, "It's something that you have to learn how to deal with. If you don't, you burn out."

Other Stressors

System stress.

While subjects discussed at length their difficulties in dealing with the families of young-middle aged dying patients, they also identified several other stressors. Stressors were identified around general nursing and facility issues. These are discussed in the following category -- 'system stress.'

Approximately half of the subjects described time management difficulties when asked about the stressors they experienced in nursing this patient group. As one subject lamented, "It's the same old thing in nursing, there's no time." Another subject revealed, "I find myself becoming very scattered and I find myself becoming very angry with myself because I'm not able to spend the time that I want to." An additional

consequence of this time management issue was identified by another subject. She talked about the difficulty she has in prioritizing her time between the patient's technical needs and 'other' needs.

"Unfortunately," she said, "the technical thing ends up being the priority . . . you don't have a choice."

This focus on technical nursing was central to the frustration several subjects described with respect to caring for the patients who required palliative rather than curative care. At the time that the interviews for this study were conducted the lack of a treatment mandate with respect to providing palliative care was identified as a fundamental factor in this dilemma:

Well, there is really no policy or straightforward guidelines because this is a treatment centre. When a patient becomes palliative, where should they go? What happens?

Another subject identified a lack of physician support for the provision of palliative care at the agency. She noted that "sometimes the physicians here just don't understand, they don't understand our feelings."

In addition to the perceived lack of agency and physician support for palliative care, another subject identified the lack of a knowledge base to guide nurses "dealing with these patients who are dying." She noted:

We don't have the education behind treating palliative patients . . . and if it is something we are going to be going into we need the training

as well. [We need] to know how to deal with the patients properly and to know how to deal with our own feelings as a group and as individuals.

Another subject voiced frustration with not feeling confident in her ability to talk to the children of dying patients. She suggested, "Maybe it's because I don't have children and I feel that I don't have enough credibility and I'm not qualified . . . to talk to a child." Regardless, she identified that she felt ill-equipped to deal with this part of her patient care. She revealed that this stress is heightened on weekends and night shifts when she needs to "hold off until [she can] get the expert because it's such a fragile situation."

Finally, in discussing system stressors, one subject described her frustration with the lack of patient/family follow up. She identified a strong desire to "find out how that family is coping. What happened to the kids, are they OK?" She said she felt things are "left open" and finds this lack of closure to be very frustrating.

Identification.

All of the subjects discussed identification when asked about the stressors they encountered in nursing young-middle aged dying patients. This was true for subjects who were in the young-middle aged group and for subjects who were in older age groups. Identifying

with these patients was frequently described as a factor which makes their nursing care difficult. In addition, many subjects revealed that this identification affects how they viewed their own lives and families, as well as how they interact with the patients.

A strong sense of identification with the patient was a factor in the difficulties subjects experienced when nursing this patient group. For example, one subject described a situation where she identified very strongly with the patient. As a result, she felt that she "wasn't able to be very helpful from a professional level simply because it did affect [her] so much because [she] was looking at [her] own life." A second subject described being so profoundly affected by identifying with certain patients that she could not nurse them:

When I was a new mum with a new baby it was very difficult. I found it terribly tragic every time I heard about a mother who was breast feeding her child and found a lump in her breast and then there they are with us. It was just more than I could stand sometimes and so I would choose to stay away from those patients for a while.

Another subject described being particularly affected by identifying with "the significant other who's being left behind." She described feeling "an incredible amount of pain" and being "very, very concerned about them." Finally, a third subject summarized, "I always

find it really hard, that age group, especially hard because I identify so much because of . . . what's going on in [their] lives."

While most of the subjects (ie. 85%) were in the same age group as the targeted patient population, some of the subjects interviewed (ie. 15%) were in older age groups. These subjects described identifying with the patients' parents. As one subject noted:

I think again being a parent helps. I can more easily think in terms of how they might feel than how this kid might feel, who I usually think of as a child.

This subject identified the young-middle aged male patients with her/his son. The experience of nursing these patients had a significant impact on this subject:

There but for the grace of God can lie my son . . . it's almost like a physical punch somewhere in your body that you have to get over to sort of relate to them on a patient-nurse basis.

In identifying with their patients, the subjects described how they put themselves in the patients' places and projected how they and their families would be affected. For example, one subject said:

This could be me, this could be my husband, I could be facing, you know trying to prepare my children to be without me. And I think that has a fairly powerful tug.

Another subject asked, "How would I be coping if that was me?"

Another aspect of identifying with this patient group was the anxiety and fear described by most of the subjects. One subject stated:

It's too close to home, you know a 32 year old woman with two little kids and when you identify terribly and if it's something that I'm particularly terrified of getting myself then . .

Another subject described the paranoia she shared with her peers as a result of patient identification:

I tend to think it's made us all really really paranoid. I mean we all go around thinking what's this ache, what's this pain, because we've seen it, we see it all up here.

Thus, identification with the young-middle aged dying patients affected the way in which subjects viewed their patients and themselves and was described as a factor in the difficulties they experienced in nursing these patients.

Helplessness, sadness, grief.

In discussing the stress they experience in nursing the young-middle aged dying patients, all of the subjects described feelings of helplessness and grief related to the sadness of the patients' situations. Subjects recalled these situations and their feelings vividly. As one subject observed, "With older people I can put the memories out of my mind but these stay. Even thinking about it I can recall the emotions." Another subject asked, "How do you deal with [it] and go home . . . and forget about it?"

Feelings of helplessness were central to the subjects' discussions of this nursing experience. One subject stated, "You want things to be different for them and you can't make the difference that you want to make." Similarly, another subject observed:

Sometimes I just get the sense that they're looking at me and they want something that I do not have, and there's no way, and these eyes are looking at me for something and I look back and the message is I can't do anything else.

These feelings of helplessness affected how the subjects approach the care of these patients. As one subject recalled:

It makes coming onto the ward very difficult and basically dreading having to look after him because there was nothing you could say or do or supports that you could provide him with that would help his behaviour and help him to accept his death and help him deal with it right to the end. Very helpless.

In addition, this subject identified limitations within the system. Another subject referred to these limitations when describing her feelings of helplessness:

It was very frustrating, there was clinical nurse specialists that came, there was the chaplain, there was every resource that we could think of and nothing made a difference.

The subjects told stories of incredible sadness when describing their feelings of helplessness. In fact, one subject described working at the cancer clinic as like "being in the sad movies that they used to make . . . you know, young people dying of cancer."

They recalled these sad situations in great detail.

For example, one subject recalled:

And he looked at me like that was the first time he'd actually thought of his wife dying, and it was the saddest thing I'd ever seen and I just cried for five hours after. It was just horrible, the whole thing was just so horrible and he just totally collapsed and sort of sobbed and sobbed and that was it.

Similarly, another subject recalled:

I remember this husband came over and said, "There's something wrong with my wife." I knew that she had died, we were expecting her to die. And her little two year old daughter was lying on the bed saying, "mummy wake up, wake up" and they had a baby as well and she was holding the baby and they were visiting from Toronto and didn't even have their family here.

Another subject described how there were times when "literally one tragic, tragic unbelievably tragic story would end and somebody would die and all those feelings would linger and then there would be someone else who would be even more tragic."

The subjects were profoundly affected by the sadness and tragedy they experienced when nursing these dying patients and their families. They described a variety of responses. One subject stated, "All I have left when I think about it is the grief and the bitterness and the anger." Another subject described "drifting in [a] misery that just never seemed to end." A third subject talked about her feelings of guilt because she wasn't sick, she was "lucky enough to go home."

Two of the subjects described crying uncontrollably at sad movies. One subject rationalized, "Probably what it is, is that I'm crying for all those patients that I never allowed myself to cry for." Similarly, another subject described:

When I go to a sad movie and I'm crying, I'm not really crying about what's going on in the movie I'm just crying, but it's OK to cry and to get it out.

Other subjects described having to hide their emotions and postpone their grieving while they are at work. For example, one subject said:

Right now I have to do this, and when I get home I'll have some time to be sad and do some of my own grieving.

She observed that "at the time, no it's not a good time to be grieving." Another subject agreed:

It's a constant check. I'm always having to keep myself aware of where I am with these patients because if you lose it and you go over the edge sometimes it's too late to get it back and then you end up just, well we've all been through it, the grieving . . . you know I sometimes think oncology nurses are constant grieverers if you don't know how to deal with it.

Subjects identified several areas of stress associated with nursing the young-middle aged patients and their families. They discussed stressors within the system such as issues around time management. Identification with the patient or family was also discussed as a source of stress. Finally, subjects

talked at length about the stress of feeling helpless in these unbelievably sad and tragic situations.

Coping With the Stress

As discussed above, the subjects described a variety of stressors which make the nursing care of the young-middle aged dying patient difficult. All of the subjects talked at length about the difficulties that they have experienced. They identified the stressors and the coping strategies that they implement to deal with these stressors.

System support.

The system itself was recognized as a source of stress, however, all of the subjects identified ways in which the system was involved in providing much needed support. For example, one subject noted that "how you deal with someone who's dying has a lot to do with how comfortable and how supported you feel in the system." Another subject agreed, "The more safe and the more support you get in the environment when you're dealing with these kind of people the less that you kind of take it home in some other way."

Specific factors related to the system were identified as supportive. The role of management was viewed as very important. One subject noted:

Just having it recognized, having the powers that be say, "yeah it must be really really hard to do

that," that was helpful. Having it recognized that we were doing a good job in the middle of a difficult situation.

Another subject described the management as very supportive:

They give you space to feel and they try to give you support so that you can feel, which in a certain sense can make it harder. But, it's better in the long run.

A third subject described how her manager supported the nurses having time to talk to each other during the difficult times.

Another important factor identified for coping with stress was a team approach. One subject praised the agency for promoting team work and providing the range of professionals necessary to provide high quality patient care. The success of the team approach was identified at the ward level as well:

We coped more as a ward and tried to cope as a ward rather than individually because it was exhausting. We could just take very short shifts with him.

Another subject stated, "I've learned that too over the years that you can't do it alone, which is a big part of what we're all about, is a team."

Subjects acknowledged the importance of their patient assignments both in terms of choosing their own assignments and in terms of the size of their assignments. One subject felt that being able to choose her own assignment helped her to cope with the

stress of caring for difficult patients. She described a situation where she deliberately choose not to nurse a patient in order to cope with the stress she was experiencing. Another subject stated that it was easier to cope with the difficult patients when she could "balance" her patient assignment:

It seems easiest to cope if there is one person and your assignment is balanced or something like that with a young person and older people or dying people and not-dying people, and if the ward in general doesn't have a lot of sad situations where everyone is feeling the pull and there isn't anyone else to sort of take over if you can't.

In addition, the size of the patient assignment was viewed as an important factor in coping with the stress. One subject observed that it "makes a world of difference and that it is a credit to this facility" that the nurse-patient ratio is such that she felt able to provide quality nursing care.

Scheduled support meetings and debriefing meetings were also identified as interventions within the system which helped the subjects to cope with their stress.

One subject stated:

Caring for a patient with cancer that's in your own peer group is just so incredibly personally taxing, if you didn't have some kind of help . . . we're pretty fortunate here having support group meetings and things like that. If you didn't have people caring about you in that respect, and if that isn't in place in nursing, I don't think I'll last forever, I couldn't do it.

Another subject agreed that the support group meetings helped her to cope with her stress. In particular, she

acknowledged the role of the clinical nurse specialists at these meetings. She observed that "it's really helpful to talk to a fellow nurse and somebody who's maybe not as involved." A third subject recalled having biweekly "stress debriefing meetings" led by the clinical nurse specialist during a period of intense stress. She remembered:

It did help. We primarily talked about our young patients between that 20 and 40 year old age group. That's what comes up all the time. That's the consistent thing that people are finding the most stressful and needing to talk about, and needing to say "this is what's happening."

While most of the subjects described the support meetings as an important coping strategy, one subject cautioned that these meetings aren't always effective. She noted that the nurses who are there for the difficult deaths may be on days off when the debriefing meetings take place.

Stepping back.

In addition to feeling supported by the system, subjects also described their own strategies for coping with the stress of nursing the young-middle aged dying patients. The importance of both physically and emotionally distancing themselves from these difficult nursing situations was echoed by all of the subjects.

Subjects described distancing themselves in a variety of ways. Several subjects highlighted the

importance of taking breaks during their shifts. One subject stated:

You need a break. I find that some of the newer nurses here don't do that and I warn them and I say look you've got to realize your limitations or you're going to burn out real quickly.

Another subject described the positive benefits of her breaks:

The way it's set up here there's no fresh air. I need to get out at least once a day, if possible go out for lunch or whatever. It is just to get away from the building when I'm feeling particularly scattered.

A third subject stated she felt rejuvenated after her days off. She observed, "Sometimes I need a break, you know give me a break for a few days and I'll be OK."

Thus, taking time away from the stressful situations was seen as helpful. This was made particularly evident by the number of subjects who described having gone to part-time hours in an effort to cope with the stress of nursing young-middle aged dying patients. As one subject observed:

Part of my solution was to cut back to half time and I was feeling quite burnt out and maybe if I continued to work full-time when maybe I wouldn't feel so healthy.

A second subject agreed:

Going part-time is one thing. It's made it easier to be here, that was really important for me because I love what I do, but doing it full-time wasn't working for me anymore . . . I find I don't take my work home with me anymore which is really important for me, I keep it here.

Another subject noted that "working half time allows you to pull back because you can't develop a really intense relationship." Further, another subject noted that by working part-time she comes back to her difficult patients with a fresh approach.

In addition to distancing themselves from stressful situations by taking breaks and working part-time, subjects also emphasized the importance of choosing their patients, in particular, choosing not to nurse certain patients, as another way of distancing themselves. One subject observed the need "to recognize [your] own limitations, and to say it's good, it's not only OK to say I don't think I can work with this person today." Another subject stated:

I'll take them for three days . . . but as to coming back to them the next week, if they're still living I'd totally remove myself from that situation. I just sort of let it be in the background of my head.

A third subject agreed:

I wouldn't choose the same person over a long time because I know that it would get me down eventually but I'd be happy to work or spell off with other people.

Subjects not only protected themselves by choosing not to nurse certain patients, they also tried to protect each other from these stressful situations.

For example, one subject recalled:

I was working with T and he had looked after this person the previous shift and didn't want to look after her because he felt very stressed out about

her because she's doing poorly. I was really happy to look after her because I know at the same time that I want to do that for T because that's how we do it. We look after each other.

Another subject observed:

My co-workers are so in tune they recognize it in each other . . . and say "I think you need a break from that person today." I think if someone's telling me that, they're telling me that for a reason. They're seeing something that I'm not.

Maintaining an emotional as well as physical distance from stressful patient situations was also seen as an important coping strategy. Subjects described the difficulty of balancing the nurse-patient relationship, and the need to constantly evaluate their roles as they become increasingly involved in stressful situations. One subject described that in these situations she begins to "care for [the patient] too much." Subjects described both consciously and subconsciously limiting their emotional involvement with these stressful patients. For example, one subject described:

Subconsciously I must prevent myself from becoming too absorbed in that person dying that I don't consider myself cold at all. I'm right there for them but part of me must remove myself from it and I do.

In contrast, another subject described consciously limiting her involvement:

Sometimes you get to a point where I've felt that I'm kind of overly involved here and I'm becoming more than a health professional and I quite consciously pull back.

The need to limit involvement was recognized by several subjects. As one subject stated, "I just try and be a nurse and not be a friend." Another subject cautioned:

You've got to be able to pull away too . . . every patient you deal with it's not your experience, you're facilitating it. It's not you so you have to to be able to pull away too . . . I've never gotten involved to the point where I'm going to see the patient on days off or whatever.

Finally, two subjects described drawing "lines" that helped them to limit their involvement with the patients and families and maintain a professional distance. One subject stated, "The line is if I take it home with me, and if I find myself being really ineffective and too subjective in taking care of them."

The other subject observed:

I always maintain that there's this line that oncology nurses have to walk along and you have to remain professional and skilful . . . and yet you have to be compassionate and you have to be caring. But, if one out balances the other there's something wrong.

Talking about it.

In addition to "stepping back," subjects identified "talking about it" as the most helpful coping strategy in dealing with the stresses of nursing the young-middle aged dying patient. One subject stated simply, "Talking about it, that's probably the best I find." Subjects described talking about these

stressful situations with other nurses and with non-nurses.

Only one subject felt that there was an advantage in talking things out with someone other than another nurse. She rationalized:

Talking to nurses can be good too, but sometimes it helps to talk to other people about how you're feeling because then you don't get that just kind of nursing perspective.

In contrast, the other subjects all described choosing to talk to other nurses for support. These subjects indicated that non-nurses would not be able to truly understand the nature of the stress that they experience. As one subject noted, "I've stopped expecting people to understand because they can't. Why should they?" A second subject highlighted the lack of insight of non-nurses into the nature of her work:

With outside friends and family there's a genuine misunderstanding. They say why don't you quit or why are you doing this then. You know, peers know why you're here and all that sort of stuff.

Thus, the majority of subjects emphasized the importance of being able to talk to other nurses as a way of coping with their stress. One nurse noted that when you share with your peers "you're sharing a common situation and they can relate to what you're saying." Another subject agreed, "I find that it's best too talk to someone who knows exactly what you mean."

Other subjects agreed that it was useful to talk about things with their peers at the Cancer Agency. However, several subjects also indicated that they were able to talk through their stress with nurses who worked in other areas. For example, one subject observed:

I talk about it. We talk about it amongst ourselves at work. I have nursing friends who work in all different fields and we can share our stories and talk about it that way.

Another subject agreed:

I don't think anybody can understand unless you work in this area or you're like my nursing friends who work in other hard areas.

It is interesting to note that two of the subjects were married to nurses. They both described getting a lot of support from their spouses which they attributed, at least in part, to their being nurses. As one subject noted, "She cries her eyes out while she's listening to me but she's a nurse too so she understands." The other subject attributed his spouse's ability to be empathetic to the fact that she had experienced similar situations.

In describing the support they receive from their peers, two subjects noted that they specifically looked to the clinical nurse specialists for support. As one nurse described:

Especially I saw the CNS as a great resource, I don't know she just had an easy rapport and she's a nurse and she's also a nurse who specialized for

the patients. But I've just found that telling her what's happening and having her hear me out and then giving me advice, that's been really beneficial.

A second subject agreed, noting that she sought out the CNSs "just because they know, they know what's going on around here."

Outside activities.

In discussing their coping strategies, the subjects focused on the work environment. However, all of the subjects identified activities in their personal lives which they attributed to helping them deal with the stress of nursing young-middle aged dying patients. These activities appeared to fall within two distinct groups. Subjects identified activities which helped them to relax and activities which required a high level of energy.

Several subjects discussed coping with a highly stressful situation at work by coming home and "relaxing." For example, one subject described:

After a really stressful day come home, have a bath. If I'm lucky, he's made me dinner. I'll maybe have a glass of wine to relax me. It's pretty nice.

Similarly, another subject prescribed:

I can't be dragging work home with me all the time. It's not going to help. Go home and have a bath instead. Go home and do something else to relax you.

In contrast, other subjects described going home from stressful work situations and trying to cope by

increasing their activity level. For example, one subject stated, "I guess I just get myself so busy that I don't allow myself to sit there and have it soak in, I just don't." A second subject agreed, "When you come home you have to be able to sort of get away from it . . . just being busy and having other things in your life is the best sort of remedy."

Still, other subjects identified that they coped with their stress through distraction. Two subjects described watching movies when they found work becoming stressful. One of them noted, "I want to watch a movie, a funny movie. I don't want to watch something sad. I don't want to watch a thriller." Another subject with a new baby described the importance of home life in coping with stress:

Home life, it's just so much fun just going home seeing the new baby. That's almost an instant stress reliever. Some days can be so bad here, barely dragging yourself out of the door here at 7:30 and you get home and there's your baby, and I have all the energy in the world to play with her.

Thus, subjects identified a variety of coping strategies to deal with the stresses of nursing the difficult young-middle aged dying patients. These strategies included support from within the work environment, being able to step back and take breaks from these patients, talking about their experience, and employing activities in their personal lives.

Positive Benefits

After discussing the stressors and the coping strategies that they implement when nursing young-middle aged dying patients, the subjects were asked to discuss why they continue to nurse these difficult patients. All of the subjects were easily able to identify positive benefits of this area of their practice. Subjects described gaining insight about themselves and about others. As one subject stated, "The kind of work that I do really has an effect on how I see the world and my relationships with other people." Another subject observed, "I often think we learn a lot more from them than they do from us."

Several subjects talked about gaining a new perspective on what is important in life through working with these patients. As one subject observed, "We take life for granted a lot and that's something I'm learning not to do." Another subject identified the need to "just appreciate the value of life [because] we're healthy, no problems, doing the simple things in life, the things we take for granted." A third subject described gaining a new perspective through nursing these difficult patients:

It gives me a kind of bigger perspective . . . you can't kind of minimize what's happening in other people's lives or in your own. But sometimes it makes it easier to deal with the smaller things, like in the scope of things this isn't much of a big deal.

In discussing their new perspectives, several subjects talked about having a heightened awareness of their own mortality. One subject stated, "I just can't live my life with this open-ended indefinite life expectancy ahead of me because that's not how life works." A second subject observed, "You think 'I hope I'm here next year too,' and you know that it's not a given anymore and I must admit I think about that more than I used to." A third subject cautioned: "Life isn't long, life is short."

This new perspective on life also affected how subjects live their lives. For example, one subject noted that she is less likely to wait for things to happen, stating:

It makes you think don't wait, don't wait for things if you really want something bad enough . . . don't wait until you're 65 because there are no guarantees.

Another subject noted, "It makes you very thankful for what you do have right now." She added, "When something bugs me that I might have used to get worked up about, I won't bother now." A third subject described how her interactions with her family have changed through nursing these patients:

I think that there's a lot of positive stuff that it's done for my relationship with my husband and my family. It's made me appreciate my family much more because I see what these families go through. I remember a few times just phoning my mum and dad up to tell them that I love them because it was,

you know, you are so affected by it. It'll either make or break a family, and I've seen it do both.

Subjects identified their relationships with their patients and as very positive learning experiences.

For example, one subject observed, " I am just always so amazed at the strength that these people have . . . that's the kind of insight I get out of it, the kind of strength and courage the people have." Similarly, another subject described being inspired by the grace and dignity of these patients. She said, "It gives you hope." Again a third subject stated:

It certainly amazes me every time, the huge power of family and of love and support and more often than not we see families coming together with enormous strength that they never knew they had . . . there is always something good that can come out of it.

A fourth subject said simply, " You get to meet very special people. There's something different. I don't know what it is but there is something different about oncology patients."

Some of the subjects identified the positive benefits that this nursing experience has had on their spirituality. One subject observed:

I'm challenged to think about my own beliefs, philosophies, life and death. And turn that over to my life, my living, my relationship with my family. I'm more appreciative.

Another subject stated: "It's done a lot for the spiritual side of me as well . . . in my own faith it's

made me feel even more grounded than I ever have." A third subject stated:

It's made me think a lot more about spiritual matters, which makes my life fuller as a consequence and I mean the whole concept of the individual deaths are often awful but the whole concept of death is less frightening to me.

Finally, subjects discussed the positive benefits of this nursing experience in terms of the challenges of caring for this patient group. As one subject stated, "If I think I really have been helpful, yeah I feel great. It's that much harder [than nursing other patients] so it's that much more of a thrill." Another subject identified enjoying the high level of intensity she experienced with these patients. A third subject summarized, "I seem to get a renewed energy. I feel better with my skills and everything going into it. It's challenging and rewarding looking after them."

Making Sense of It

While subjects were easily able to identify the positive benefits of this often difficult nursing experience, most of them struggled when asked to explain how they "make sense of it." The magnitude of the suffering and sadness surrounding the dying of these young-middle aged patients proved to be very difficult for most of the subjects to come to terms

with. However, one subject was able to apply her own Christian belief system to these nursing experiences:

I'm a Christian. I have a belief system. I believe that this isn't the end. I believe that there is certainly something better. In that way I'm able to accept it on that level . . . you have to make sense of it somehow, how could you think otherwise.

Other subjects identified that they feel more comfortable with the situation when they know that the patient has a belief system. For example, one subject stated, "I do find it easier if the person themselves does have some sort of belief system or values or whatever and is ready to accept it for whatever reason themselves." Similarly, another subject observed:

I tell myself that even if I can't make sense of it that there is some sense somewhere and that if anybody knows what sense is made out of it, it's the person, the patient themselves, and that they are OK [even] if the ones left behind aren't.

However, the majority of the subjects clearly had great difficulty making sense of the patient's experience. As one subject said, "I just don't think it makes any sense. I don't have a way of coming to terms with that. I think it's just very sad that this kind of thing happens to people." Another subject agreed, "I do think about it in terms of why does this have to happen. But I have never been able to make any sense out of it."

Subjects struggled not having answers to their patients' questions. As one subject stated:

When people ask that question "why me?" "Why am I dying?" the best answer for me is I don't know. And I don't know. I haven't really figured that one out. You know it's an honest answer.

Subjects struggled not having answers to their own questions. One subject recalled:

It made me face a lot of things about my own faith. It made me face a lot of questions that we ask that don't have answers. There was a lot of misunderstanding on my part. I felt angry a lot, just at the super-natural forces or God if you want to put it that way, as to why it was happening. Why this person, why not me?

Similarly, another subject struggled with his own questions:

How can this be allowed if there is a loving God who personally care for each of us. I just, how can this be allowed. For me, everybody, this was a vicious horrible evil thing to put us through, pointless, senseless.

Further, he described the effect that this struggle has had on his spirituality:

The only thing that really it has done for me, it has made a very serious dent in my relationship with the Divine, because I think that maybe oncology nursing in general sort of adds to that because I find it very difficult if not impossible to say there is a loving God who allows such suffering to pass. I can't come to terms with that.

While most of the subjects struggled with the large philosophical questions of life and death, some subjects took fatalistic approaches to dealing with the difficult patient situations. One subject stated simply, "There's no rhyme or reason, it could be any of us." Another subject observed:

It's going to happen. Sometimes it happens through cancer, sometimes through car accidents . . . as long as they've been well informed, the nursing care has been great, the support's been good then they can start getting on with the other things . . . death is just part of our being here for everybody.

This approach provided the subjects with a way of making sense of the tragedies they witnessed.

Thus, subjects identified a variety ways to approach the experience of nursing the young-middle aged patients in an effort to "make sense of it." Some of the subjects stated that they were unable to make any sense of these tragic situations. However, other subjects felt able to deal with the tragedy by applying their own belief system or through believing that the patients had strong belief systems. Still other subjects took a fatalistic approach to these difficult patient situations.

Summary

This chapter presents the data obtained from interviews with 14 nurses employed at the B. C. Cancer Agency. The interviews were based on the conceptual framework developed in Chapter One, and thus, the data presented reflects these themes. The data were categorized to reflect the relative importance of these themes as discussed during the interviews. These data categories examine the nurse's experience when caring

for the young-middle aged dying cancer patient.

Subjects compared the issues involved in nursing this patient group with the issues involved in nursing older patients. They discussed at length the stressors inherent in this nursing experience, with an emphasis on "the family" as a source of stress. In addition, strategies for coping with these stressors were identified. Subjects described the positive benefits that they gained through nursing these difficult patients. Finally, they described their struggles with trying to "make sense" of their experience.

Chapter Five - Analysis of Findings

This chapter presents an analysis of findings from the subjects' accounts of their experiences in caring for young-middle aged patients dying from cancer. A variety of issues emerged from these accounts. However, three themes appeared to warrant further exploration and analysis. The first relates to the finding that subjects experienced considerable distress by virtue of identifying with dying patients of an age similar to their own. The second relates to the stress experienced by the subjects as they address the care needs of the families of these patients. In particular, subjects found interactions with the patients' parents and dependent children to be very stressful. Finally, issues around providing palliative care in a curative setting are examined. Because each of these themes was powerfully represented in the subjects' descriptions, and because each represents an unique component of the experience of caring for young-middle aged dying patients, this chapter will consider these three themes in detail.

Issues in Identifying with Patients

All of the subjects discussed the difficulties they experienced when nursing patients in the young-middle aged group. Subjects described identifying

closely with patients who were in their age group. In fact, when asked why they found the young-middle aged patient group to be so stressful and difficult to nurse, subjects' initial responses were frequently something to the effect that "this could be me."

Of the fourteen subjects interviewed, twelve (ie. 85% of the sample) were, in fact, within the age range (ie. 20-45 years of age) of the patient population targeted in this study. For the two subjects who were not in the age range of the target patient population, identification was also an issue. They identified with the patients' parents, imagining the terrible tragedy they would experience should their child, like the patient, be dying of cancer.

The link between stress experienced by the nurse, and patient identification has been described in the literature (Vachon, 1987). In keeping with the findings of this study, Alexander (1990) found that palliative care nurses experience greater stress when nursing patients under the age of 40. He noted that the principal reason for this was that nurses identify with these patients.

The nature of the identification.

In examining the nature of patient identification as discussed by the subjects in this study, sharing similar ages and life situations appear to be central

factors. However, other factors may also be significant. For example, the subjects also stressed that these patients and their families required a high level of nursing involvement, both in terms of time and intensity.

The following factors demanded a high level of emotional and time commitment on the part of the nurse. The young-middle aged dying patients were seen as angrier and more emotionally intense than other patients. Subjects found that they asked more questions, and required more information about their disease and treatments. In addition, these patients were found to have difficulty accepting their disease and death; they had difficulty "letting go." Patients and families were observed to fight hard against the eventuality of death. It might be hypothesized that subjects identified so strongly because of these patients' desire and fight for life.

Thus, level of involvement appears to be a critical factor in patient identification. This is also in keeping with the finding that the subjects outside of the age range of the target patient population identified closely with the parents of these patients. Ultimately, patient/family identification may not be a significant stressor until a critical level of involvement is reached. Interestingly,

subjects did not reflect on their level of involvement with patients with whom they did not identify. Further insights as to why subjects identified strongly with certain patients and not others could help to clarify the relationship between patient identification and patient involvement.

Patient identification was always discussed in terms of painful and stressful patient/family relationships. Subjects recalled these relationships with great emotion. They described feeling guilty for not being sick, and being frightened of experiencing the same fate as the patient. As the subjects recalled their relationships with these young-middle aged dying patients, their memories were highlighted with feelings of anger, fear, helplessness and guilt.

In contrast to these negative aspects of patient identification, it is interesting to note that Davies' and Oberle's "Supportive Care Model" (1990) encourages the nurse to "enter" the patient's experience. According to this model, nurses must establish a rapport and find the common bond which will allow them to make the connection which is seen as a necessary part of their supportive role. A variety of strategies are involved in making and sustaining this connection, including being available to the patient and family, and giving of self.

Coping mechanisms.

The subjects recognized that both their work and home lives were affected by the experience of nursing these patients. They identified a variety of coping mechanisms for dealing with their stress including support within the work environment (eg. support meetings, team approach), talking with peers, and their involvement with activities outside of work. These strategies and others have been identified in the literature (Munley, 1985; Zelewsky & Birchfield, 1992). However, the creation and maintenance of a "distance" between themselves and their young-middle aged patients appeared to be the primary coping mechanism utilized by subjects.

A variety of strategies were identified by subjects enabling them to maintain some distance between themselves and these patients. For example, the "distances" ranged from ensuring that they took their breaks to working only part-time. Again, similar strategies are identified in the literature (Munley, 1985). However, while distancing strategies may be effective in decreasing stress, they may also be a sign of burnout (Munley, 1985). Thus, the intent and ultimate consequences of these strategies should be considered in more depth.

The costs of distancing behaviours.

In discussing distancing as a method of coping with their stress, subjects frequently referred to their fears around the issues of over-involvement and over-investment. They emphasized the need to maintain a professional balance in their nursing relationships with young-middle aged patients, and feared shifting from a professional, therapeutic focus to one where their emotional over-involvement clouded their judgement and rendered them ineffective as caregivers. Similarly, Zelewsky and Birchfield (1992) recognized the "emotional danger" in nurses becoming so attached and involved in the suffering of their patients that they were overwhelmed personally and ineffective professionally.

Thus, distancing was viewed by the subjects as an effective method for preventing over-involvement and over-investment, and reducing their stress when nursing the young-middle aged dying patients with whom they tend to identify so strongly. At the same time, these patients were also recognized as having greater care needs than other patients. Subjects agreed that these patients and their families required a greater intensity of involvement and greater time commitment than did other patients. Distancing behaviours on the

part of the nurse appear to contrast with the magnitude of the needs of these patients.

In light of this contrast, there may be costs associated with distancing from such needy patients. While there may be benefits to the nurse, one might question how the patient benefits when distancing is employed. How are the multiple and complex needs of these patients and their families met if the nurse is focused on limiting her/his involvement in order to maintain a professional relationship? How do intimate nurse/patient relationships develop when nurses choose not to keep the same patient assignment as a way of distancing? Finally, can the nurse meet the criteria for the supportive care role (Davies & Oberle, 1992) in these situations?

Subjects vividly remembered situations in which they had become over-involved and over-invested in their relationships with certain patients. These experiences appear to have profoundly affected the subjects, leaving them frightened of becoming so deeply involved again. Perhaps the pain associated with these relationships relates to the subject's strong identification with the patient. Thus, they also experience the desperate desire for life and the loss of hope. It might be hypothesized that these fears provide the driving force for the emphasis on

monitoring and preventing over-involvement which was apparent in this study's findings. In fact, subjects not only monitored their own level of patient involvement, but also monitored the involvement of their peers, particularly their more inexperienced peers.

The literature also documents situations where nurses should step back to put some distance and perspective between themselves and their patients. While making a connection is central to providing supportive care to these patients (Davies & Oberle, 1992), Larson (1992) warns that this connection can be jeopardized if the nurse's focus turns to her/his own painful, emotional reaction to the patient's situation. Further, the literature directs nurses to examine the nature of their involvement with their patients and assess whose needs are being met in an effort to ensure a healthy level of involvement (Larson, 1992; Munley, 1985; Zelewsky & Birchfield, 1992). Davies and Oberle (1992) describe this as preservation of integrity and view it as integral to the nurse's effective functioning.

Recognizing that real issues and concerns are associated with the nurse becoming over-involved with these patients, there are also issues and concerns associated with minimizing involvement. The emphasis

subjects placed on distancing from these most needy patients suggests that past experience with over-involvement may lead them to minimize their patient involvement thereby jeopardizing their ability to provide supportive care (Davies & Oberle, 1992).

Subjects determined the extent to which they became involved with their patients based on what they described as a "professional line" or "professional balance." The degree to which these nurses were able to meet the supportive care needs of their patients must be understood in terms of this line. Subjects described determining this line for their less experienced peers. Thus, it would appear that nurses with the least experience have the least control over where the line is drawn and that the level of patient involvement considered appropriate is determined primarily by the more experienced staff. Therefore, it might be hypothesized that the fear of re-experiencing a very intense and painful patient relationship is a fundamental factor in determining the position of this line.

While subjects emphasized their need to employ distancing behaviours with the target patient group, they also acknowledged that they felt "drawn" to care for these patients. Thus, a powerful dichotomy exists for nurses caring for young-middle aged dying patients.

Although unable to make sense of the great tragedy of these situations, subjects maintained that they benefited greatly by nursing these patients. At the same time, they found these situations so upsetting and stressful that they felt forced to distance themselves from caring these patients. What compels nurses to care for these difficult patients when they constantly feel the need to monitor and limit their patient involvement and investment? It might be hypothesized that the strength of patient identification is a central factor in this conflict.

In summary, patient identification plays a central role in the subjects' experience of caring for young-middle aged dying patients. Subjects in the target age group identified strongly with the patients while older subjects identified with the patients' parents. The magnitude and complexity of the needs of these patients and families, combined with strong identification on the part of the subjects, produced highly emotional and intense relationships. Experiencing these emotionally exhausting relationships lead subjects to focus on carefully limiting their involvement through distancing behaviours designed to maintain a professional balance. Ideally this balance enabled the subjects to function effectively as professionals and escape the difficulties associated with patient over-involvement

and over-investment. However, there may be significant costs associated with distancing. For example, distancing may prevent the nurse from establishing the intimate patient connection necessary to provide supportive care.

Issues in Caring for Families

In discussing the stressors they experienced while nursing the young-middle aged dying patients, subjects frequently referred to patients' families. These families were seen as being larger and more complex in both structure and needs than the families of older patients. Family plays an important role in the patient's response to diagnosis, treatment, and prognosis. In fact, the palliative care literature identifies the family, including the patient, as the unit of care (Rovinski, 1979). Thus, it is important that issues around the family be addressed and understood in order to facilitate the nurse's ability to support the patient.

The dependent children.

Patients with dependent children were found to be particularly stressful to nurse. Subjects identified that they felt ill-equipped to talk to these children about the illnesses and impending deaths of their parents. However, they felt that the clinical nurse

specialist did possess the knowledge base to communicate effectively and successfully with these children. Subjects appear to have a sense that there is a specific knowledge base determining the "right" and "wrong" things to say in these situations. Further, the fear of saying the "wrong thing" appeared to be a factor in the stress subjects experienced when nursing patients with young children.

One might question whether there are, in fact, specific things which should or should not be said to these children. Further, in examining this issue it would be interesting to determine whether nurses who have children are better able to cope with and communicate with patients' children. One subject did question her "credibility" and "qualifications" to talk to children in light of the fact that she was childless.

Subjects discussing this issue identified their feelings of inadequacy with respect to communicating with the children. However, their descriptions suggest that there may be significant unidentified factors which also contribute to their stress. For example, subjects are very aware of what the patient's outcome will be, while at the same time the children may be blind to the tragedy which will forever change their lives. In identifying with these patients, subjects

may be projecting what the future of their own children would be in a similar situation. Further, there may be a difference between subjects who have children and those who don't, in terms of the effect that patient identification has on their ability to cope with issues around the patient's children.

The parents.

Subjects identified that coping with parents was also a factor in the stress they experienced when nursing young-middle aged dying patients. It is interesting to note that subjects did not describe similar feelings of frustration with respect to the role of, and their interactions with the spouses of these patients. With 85% of the subjects being in the same age range as patient and spouse, perhaps they identified more strongly with, and thus, empathized more closely with the spouse as opposed to the parents. In particular, subjects described their difficulties in dealing with the patients' mothers. They viewed patients relinquishing control to their parents in a very negative light. Why were these role changes seen to be so upsetting?

It appears that the subjects value the ability and desire of patients to maintain some control and independence as their disease progresses. In contrast they were upset by what they saw as the parents' role

in facilitating patients' dependence. However, the literature suggests that these role changes are a natural consequence of the patient/family's progression through illness and dying to death. For example, the research of Davies, Reimer, and Martens (1990), with respect to the experience of families when one of the members receives palliative care, reveals that the redefinition of roles is a central task in enabling the family to cope with the change in the patient's status. The patient redefines herself/himself as a reflection of the person they has become through their illness. At the same time, family members redefine the patients and assume extra responsibilities and roles in response to the patient's increased dependence.

Subjects voiced frustration noting that, as parents became increasingly involved in the patient's care, they were no longer able to communicate as openly and honestly with the patient as they had before. In addition, some parents were observed to take on an adversarial role in their attempts to protect their child. Thus, the nature of the nurse/patient relationship was significantly changed in light of increased parental involvement.

In examining the frustration of subjects with respect to the role changes of patients and their parents, one must consider the subsequent changes in

the role of the nurse. With changes in roles comes changes in the balance of power. Perhaps, subjects felt in some way that their role was diminished, as highlighted by the new limits they experienced when communicating with their patients. One might question whether a struggle for control between nurse and parent, as primary caregivers, was a factor in the adversarial approach subjects attributed to parents and the distress they felt with patients' increased dependence.

One might consider whether patient care is in any way compromised in light of these role changes. For example, if the patient no longer communicates openly and honestly about dying and death with her/his nurse, are these needs being met through communication with her/his parents? If not, are the patient's needs being met in some other way by the parents? Is it not appropriate that in dying and death, the patient does become increasingly dependent upon the parent, particularly the mother? It would seem very natural to revisit the original child/parent dynamic in the face of impending death.

Perhaps, the stress that subjects attributed to dealing with the parents needs to be understood in terms of adjusting to their own role changes. While the intimate role with the patient may appear to be

compromised by an increased parental presence, it must be remembered that the nurse plays a crucial role for both patient and family throughout the dying and death. As noted by Rovinski (1979), each patient and family must be seen as a unique group, and the nurse must appreciate the situation from the family perspective in order to facilitate their family crisis coping mechanisms. Therefore, the patient can not be considered apart from the family, especially when families are as closely involved with the patient as were the families described by subjects in this study.

In summary, the subjects frequently found it difficult to cope with the families of the young-middle aged dying patients. As discussed above, dependent children and highly involved parents were both particularly difficult to deal with. Subjects felt ill-equipped to communicate with dependent children. Further, they felt that their patient communication was severely limited as patients became increasingly dependent on their parents. Coping successfully with these family stressors is critical in providing supportive care for both patient and family.

Issues in Shifting From a Curative to a Palliative

Focus

Subject interviews were punctuated by expressions of the great sadness and grief they experienced when nursing young-middle aged dying patients. Feelings of helplessness and hopelessness were discussed in relation to the difficulty they had making sense of the tragedy of these situations. Their professional and personal lives were profoundly affected by nursing this patient group, leading subjects to choose to work only part-time or employ other distancing behaviours.

The literature has explored the stress associated with the nursing care of dying patients. Studies have compared the stress experienced by palliative nurses with that of nurses working in other settings (Bram & Katz, 1989; Thompson, 1985). The results indicate that palliative nurses experience less stress and greater rewards in their care of the dying than do nurses in settings with a curative focus.

Examining these comparisons in terms of the findings of this study, it must be remembered that this study focuses specifically on the stress associated with nursing patients in the young-middle aged group. Subjects indicated that this stress was much greater than that experienced when nursing older patients. Further study might help to determine the extent to

which the stress identified by subjects when nursing the target population is a function of the issues discussed in this chapter, and to what extent it relates to the unique nature of the target patient group. The literature does recognize significant difficulties inherent in providing palliative care in curative settings (Garossino, 1991; Mount, 1976; Thompson, 1985), however issues unique to nursing young-middle aged dying patients are not addressed in these studies.

Mount (1976) observes that curative skills and goals are not appropriate for meeting the palliative needs of patient and family. This observation is supported by the findings of this study. Several subjects associated their stress with a lack of support for palliative care that they perceived on the part of some physicians, and the agency as a whole. It is important to note that at the time that these interviews were conducted, the agency did not have an integrated palliative care mandate. However, at the time of this writing, this is no longer true. There is now a joint committee of nurses and physicians examining palliative issues within the agency.

Nonetheless, at the time the interviews were conducted the lack of a specific mandate for palliative care was of concern to subjects. They expressed

concern about where patients would receive their care after moving from a curative to a palliative diagnosis. While there appeared to be a strong desire to provide palliative care for these patients, subjects questioned whether they had the necessary knowledge and expertise to provide this palliative care as well as cope with their own responses to these situations. Subjects also questioned whether they had the administrative support necessary to provide palliative care.

Subjects did, in fact, experience significant stress when providing palliative care to the target population. And, the primary coping mechanism they employed involved some degree of distancing. It is interesting to note that in a comparative study of palliative and oncology nurses (Bram & Katz, 1989), the authors concluded that patient contact was not inherently stressful for the palliative nurse, but instead, was what they valued most in their work. This contrasts with the findings of this study, where subjects associated their stress with a high level of contact and involvement with the target patient group.

The results of Bram and Katz (1989) also suggest that the hospice environment is a less stressful environment in which to care for dying patients than is a hospital oncology unit. Hospice nurses perceived greater support for discussing work-related feelings

and problems in the workplace than did the oncology nurses. Findings also suggest that hospice nurses experience less dissonance between their ideal and real work situations. In light of these findings, one might question whether greater support of palliative care within the Cancer Agency would create a work environment such that the subjects would feel more comfortable and competent in providing quality supportive care.

The work environment is an important factor in determining the "philosophy" of a nursing unit which, in turn, encourages a particular response to dying and death (Thompson, 1985). Experience has also been found to be a positive factor in determining nurses' attitudes with respect to the dying (Garossino, 1991; Thompson, 1985). However, Thompson (1985) concludes that nurses in curative settings are not able to completely adopt a palliative orientation in the face of the daily task structures and the aura of failure that dying carries within curative settings. He predicts that caring for the dying in curative settings will have greater psychological costs and fewer rewards.

Perhaps, the stress identified by subjects in this study was related to their difficulty in achieving the philosophical reorientation necessary to provide

palliative care in a curative setting. Degner, Gow, and Thompson (1991) observed that an important behaviour for nurses working in curative settings was to facilitate the transition from curative to palliative care. The experiences of subjects in this study indicates that the nurses themselves must make the transition from curative to palliative care, and that this transition may be a difficult one.

Some of the difficulty in achieving this transition may be related to lack of support in the work environment (Thompson, 1985). Perhaps another important factor to consider is the patient's progression along the disease trajectory. Palliative nurses know their patients only as palliative patients; however, the subjects in this study formed relationships with patients who were desperately hoping and fighting for cure. These relationships may have begun at diagnosis when the ravages of disease and treatment had not yet begun to affect the patient and family. Once cure is no longer the goal, a significant emotional and mental shift is required on the part of the nurse, the patient, and the family. Concepts such as hope and quality of life must be reevaluated to fit with a new palliative focus.

Perhaps the difficulty and pain associated with this transition is expressed in the difficulty subjects

had making sense of these tragic situations.

Palliative nurses were observed to enter into, and come away from relationships with dying patients with comparative ease (Thompson, 1985). This contrasts with the dread subjects in this study felt in anticipation of caring for a patient in the target population, and the feelings of anger, bitterness and sadness they felt after the patient's death -- their inability to make sense of it.

It is assumed that the subjects had developed personal philosophies with respect to their work in oncology which facilitated their ability to participate in the complex treatment regimens and cope with the resultant complex physical and emotional costs to the patient. However, the findings from this study suggest that subjects had not developed a similar philosophy with respect to palliative care. One might predict that such a philosophy would significantly decrease the stress that subjects experience when nursing the young-middle aged dying patients and help them to "make sense of it."

In summary, in understanding the difficulties subjects experienced when nursing young-middle aged patients one must consider issues involved in shifting from a curative to a palliative focus. For example, to what extent did the lack of support in their work

environment and their lack of a palliative expertise and philosophy affect their stress? Further, what role did facilitating the patients' transition from curative to palliative care, as well as making their own transition, play in creating their stress? Finally, the stress of the subjects in relation to the above factors must be considered specifically in terms of the unique nature of the target population.

Summary

In analyzing the subjects' descriptions of their experiences nursing young-middle aged dying patients, an overwhelming sense of their difficulties and stress emerged. All fourteen subjects discussed identification as a factor in the stress they experienced. Subjects within the target age group identified with the patients, while older subjects identified with the patients' parents. They recognized the intense involvement, both in terms of time and emotion, which these patients and families required. They also recognized the dangers of becoming over-involved and employed distancing behaviours in order to limit involvement and maintain a professional balance in their patient relationships. However, distancing is not without its costs, whether current or potential, to

the patient and family. Significantly, there was no discussion of these costs by subjects.

Patients' families were also identified as important factors in creating stress for the subjects. Several subjects stated that they felt ill-equipped to talk to the dependent children of their patients. They voiced concerns with respect to saying the "wrong things." Subjects also identified their concerns and frustration when the patients appeared to be relinquishing control to highly involved parents. This frustration may be linked with changes in the nurses' role and the balance of power in the patient relationship as the parental involvement increases. It might also be hypothesized that the stress and frustration subjects described may also relate to viewing the needs of patient and family separately. This contrasts with the belief documented in the palliative care literature that the family must be considered as the unit of care (Mount, 1985).

A third area of stress emerged as subjects indicated that they felt a lack of support within their work environment and a lack of expertise with respect to providing palliative care. The literature suggests that support within the work environment and an appropriate philosophical orientation enables palliative nurses to cope with the stresses inherent in

caring for the dying. In examining the stresses described by subjects in this study with the documented experiences of palliative nurses, it must be noted that the literature has not explored the experiences of palliative nurses in terms of the target patient population. Thus, the extent to which providing palliative care in a curative setting, patient identification, and family stressors created the stress described in this study can not be determined without further research which also takes into account the unique nature of young-middle age dying patients.

Chapter Six - Summary, Conclusions, Implications

This concluding chapter begins with a summary of preceeding chapters, providing an overview of the study's purpose and conceptual framework, review of related literature, methodology, and presentation and analysis of findings. The following section outlines conclusions based on study findings. The final section in this chapter explores implications of the study findings and conclusions in terms of nursing practice and education, administration, and research.

Summary

Research has addressed issues facing nurses who care for patients dying of cancer. The vast majority of these patients are over the age of 45 years old. Thus, with the exceptions of pediatric oncology patients and patients with HIV, the literature has focused primarily on the older patient group. Consequently, nursing issues with respect to the 20-45 year old patient group have not been examined. This study intends to address this gap in the literature by describing the experience of oncology nurses caring for young-middle aged (ie. 20-45 years old) patients dying of cancer.

The conceptual framework driving this study recognizes that the target population presents unique

challenges for the nurse. The families of these patients frequently include dependent children and parents, all requiring an intense involvement on the part of the nurse. Further, nurses in a similar age range, may experience a strong identification with the patient. It is believed that insights into these issues may help to prevent some of the symptoms of stress and burnout which these nurses experience.

A review of related literature recognizes stressors affecting the nurse in the following areas: the work environment, the patient and family, and personal inner experience. Stressors within the work environment were viewed as being particularly significant. In the area of patient and family stressors, young-middle aged oncology patients were identified as being particularly stressful. A variety of strategies for addressing such stressors and thus, preventing burnout have been identified. These strategies include support within the work environment, for example, adequate staffing, good orientation and on-going education, regular support meetings, and multidisciplinary team meetings. The need for nurses to develop personal philosophies with respect to dying and death, and to develop satisfying personal lives is also emphasized. While the patient group targeted in this study is documented as being stressful to nurse,

the literature does not specifically examine the difficulties, or related coping strategies with respect to nursing these patients.

In light of the gap in the literature with respect to nursing the target patient population, a descriptive study design was chosen. Convenience sampling was used, and fourteen subjects were interviewed for approximately one hour each. All subjects were registered nurses working in oncology who had cared for a young-middle aged dying cancer patient within the past two years. Data analysis was concurrent with data collection, confirming the categories derived from the conceptual framework. The data was sorted into these categories, which were then reworked through subdividing and combining categories to accurately reflect the data. Study limitations include limited generalizability with the sample representing only one institution. In addition, the precision and sensitivity of the categories was limited by the fact that theoretical sampling was not used.

The interviews yielded rich and illuminating data which was sorted into the following categories: general responses to the experience; comparisons with older patients; the family as a source of stress; other stressors; coping with the stress; positive benefits; and making sense of it. Although valuable insights

could be drawn from all of these categories, three areas were selected for indepth analysis. The areas selected for analysis included: issues in identifying with patients, issues in caring for families, and issues in shifting from a curative to a palliative focus. It was felt that analysis of these issues was important in describing the oncology nurse's experience in caring for young-middle aged patients dying of cancer as outlined in the study's purpose.

Conclusions

The following description of the experience of oncology nurses caring for young-middle aged patients dying of cancer was based on this study's findings and analysis.

Oncology nurses find nursing young-middle aged patients dying of cancer particularly difficult and stressful. The relationships that they form with these patients are highly emotional, with the nurses experiencing feelings of guilt, helplessness, hopelessness, anger, and bitterness. Nurses in the same age range strongly identify with the patients, while older nurses identify with the patients' parents.

Although the nurses are able to recognize the multiple and complex needs of these patients, they feel that they lack the necessary expertise to successfully

meet these needs. For example, they feel ill-equipped to communicate and cope with the dependent children of their patients. They also experience stress and frustration in their interactions with protective and involved parents who appear to promote dependent behaviour on the part of the patient. Further, the nurses feel that they lack expertise in palliative care, in general; and, they believe that there is a lack of support in their work environment for the provision of this care. (Again, since the time that these interviews were conducted, the B.C. Cancer Agency has developed a mandate to address palliative care issues.) These factors all contribute to the difficulties oncology nurses experience when caring for young-middle aged patients dying of cancer.

Oncology nurses find the intensity of their grief and sadness, in combination with the stress that they experience when nursing these patients, overwhelming. As a result, they strive to maintain highly professional relationships by closely monitoring the level of their involvement and investment, and that of their peers, with these difficult patients. They fear becoming overly involved in the tragedy that is the dying and death of these patients. Thus, they employ distancing strategies such as changing patient assignments and working only part-time.

However, despite the fears, difficulties and stressors, and despite their inability to make sense of these tragic situations, oncology nurses feel that they benefit positively from nursing the young-middle aged dying cancer patients. In fact, although they may face these patients with some dread, they feel drawn to nurse them, thankful for the insights and enrichment that these patients bring to their lives.

Implications

The findings from this study have implications for nursing practice and education, administration, and research as discussed in the following sections.

Nursing practice and education.

When considering the findings from this study, one is struck by an overwhelming sense of how difficult and stressful it is to nurse the young-middle aged patient dying of cancer. And thus, in determining the implications these findings hold for nursing practice and education, recognition of the difficulties and stressors inherent in this nursing care provides an appropriate starting point.

Nurses whose practice includes the patient group targeted in this study should be aware of the difficulties and stressors they may encounter when nursing these patients. In particular, an awareness of

issues around patient identification, and recognition of the stressors related to the complexity of the family unit's needs and structure could help prepare the nurse to cope in these difficult situations.

Nurses may feel the need to employ distancing behaviours when nursing this patient group, especially if they have previously nursed patients who required a high level of emotional involvement and time commitment. However, they should be aware of the potential costs of such distancing. Before any distancing occurs, nurses should assess and continue to reassess whose needs are being met in order to ensure that they maintain a level of patient involvement necessary to provide supportive care.

Finally, when faced with nursing a young-middle aged patient dying of cancer, nurses must understand and be able to apply the philosophy of palliative care in their work. Thus, nurses should recognize the "family" as the unit of care. As a result, difficulties and stressors they may experience with family interactions need to be acknowledged and addressed as a part of the care they are providing for the patient.

Nursing education has a responsibility in ensuring that nurses develop an awareness and understanding of the issues involved in caring for this patient group,

and are thus able to prepare for, and cope with the difficulties they may encounter. Basic nursing education must address the needs of the dying, and in doing so should examine the salient concepts of palliative care. Further, ongoing education with respect to palliative care should be provided for oncology nurses, acknowledging that they do nurse palliative patients. Such ongoing education must also acknowledge that oncology nurses face unique issues in their provision of palliative care which relate to providing this care in a curative setting. In particular, the tremendous impact that the transition from a curative to palliative diagnosis has on the patient, family, and nurse must be explored.

Nursing administration.

The findings from this study also have implications for nursing administrators, in particular those in oncology settings. Firstly, there should be an awareness and understanding on the part of administration of the impact, and potential impact, of this patient group on the nurses who care for them. The stresses and difficulties these nurses experience leave them vulnerable to burnout. Thus, strategies for successfully coping with the stresses and preventing burnout are essential. A variety of such strategies

have been identified both in the literature and in the findings of this study.

In demonstrating an awareness and understanding of the issues involved in caring for young-middle aged patients dying of cancer, and support for the nurses providing this care, the administration should have a clear mandate regarding palliative care issues. Recognition of the fact that the nurses do provide palliative care, and that this care involves issues other than curative care issues, must be addressed in the mission statement of the institute. Such a statement would acknowledge commitment on the part of the administration to provide palliative care within a curative setting.

Administration should provide direction and support to address palliative care issues at all levels within the institute. In particular, the work setting itself should be conducive to providing palliative care. The research of Bram and Katz (1989) found that there was a need for congruence between professional ideals and the philosophy of the healthcare setting. Several strategies could help to achieve this congruence. For example, the philosophy and support of the administration towards palliative care should be emphasized in personnel hiring practices. In addition, staffing practices with respect to the number and type

of patients assigned should reflect support for and an understanding of palliative care issues.

In developing a work environment which is supportive to the nurse providing palliative care, a variety of strategies can be implemented. First, there should be a team approach to palliative care. As noted by Mount (1976), a multidisciplinary team is necessary to meet the multidimensional needs of the patient and family. This team should include the physician, nurse, clinical nurse specialist, nutritionist, occupational and/or physiotherapist, chaplain, and social worker. Regular team meetings would facilitate a team approach towards care, reinforce the family as the unit of care, and ensure successful information sharing. Support for a team approach must be demonstrated by the administration.

The development of a philosophical orientation incorporating palliative care in a curative setting is a major task for oncology nurses (Thompson, 1985). Systematic inservices covering the following topics would be fundamental to the development of such a philosophy: grief, loss, and bereavement; family dynamics and coping mechanisms; coping mechanisms of children and adolescents; religious rituals regarding dying and death; ethical issues regarding dying and death; symptom management; and palliative care. Such

inservices need to be supported by administration both in terms of providing the necessary time and obtaining the appropriate expert speakers.

Despite a supportive work environment and an appropriate philosophical orientation there will be situations where the nurse is devastated by the tragedy she has shared. As the findings from this study indicate, this appears to be particularly true with the young-middle aged patient group. There must be support for the nurse experiencing this grief within the work environment. For example, nurses should be encouraged to share their feelings with peers and others in an ad hoc manner. In addition, there should be support meetings organized to respond to these difficult situations. The services of a chaplain, clinical nurse specialist, or similar appropriate professional should also be made available to address individual needs.

Thus, administration can play a vital role in supporting oncology nurses in their provision of palliative care. These nurses require the support of a multidisciplinary palliative care team, the support of ongoing education, and a supportive work environment. A clear mandate from the administration to provide direction and address palliative care issues forms the cornerstone of this support.

Nursing research.

Finally, the findings from this study have implications for nursing research. For example, an underlying premise of the present study was that oncology nurses experience stresses and difficulties which are unique to caring for the target patient group. Studies comparing oncology nurses and palliative care nurses reveal that palliative care nurses experience greater rewards and less stress in caring for dying patients than do oncology nurses. However, these studies have not targeted the young-middle aged patient group. Thus, research into the experience of palliative care nurses caring for this patient group may help to determine the extent to which the difficulties described by oncology nurses in the present study can be attributed to issues specific to the target patient group.

The issues involved in nursing this patient group appeared to center around the strong patient identification that the nurses experienced. Several hypotheses emerged from the analysis of patient identification issues. For example, it was hypothesized that identification with members of this patient group was linked to the desperate desire for, and fight for life which defined these patients. Thus, perhaps the identification was in some way born of the

nurses' desperate hope for, and fight for the lives of these patients.

Insight into this phenomenon could also be achieved through examining why nurses identify so strongly with certain patients and not others. For although subjects' discussions centered around those patients with whom they identified, it must not be assumed that they identified with every patient within the target age range. An understanding of what factors lead to this identification would provide insight into the phenomenon. Research around the above questions could provide insights into "why" and "when" identification becomes an issue for the nurse.

Insight into "how" identification impacts practice involves different questions. Analysis of this study's findings also led to hypotheses regarding the role of identification in determining the nurse's level of patient involvement. Analysis suggested an equation where strong patient identification leads to a high level of patient involvement (perhaps over-involvement) and ultimately results in the nurse experiencing the patient's tragedy at a very deep and personal level creating intensely painful memories. It appears that subsequent identification is tempered by these memories resulting in distancing (perhaps under-involvement). At the same time nurses feel forced to protect and

distance themselves from a high level of patient involvement, they feel drawn to nurse these patients. Again, it is hypothesized that the strength of the patient identification is fundamental to this dichotomy. Thus, while patient identification was undoubtedly a central issue in the nurse's experience as determined by the present study, many questions remain to be answered in understanding this phenomenon and its impact on nursing practice.

Finally, a variety of issues were identified around providing palliative care in a curative setting. The literature has recognized and addressed some of these issues. However, issues around the transition that the nurse experiences as the patient moves from a curative to a palliative diagnosis have not been examined. This transition is of great significance to patient, family, and nurse. It is also unique to the curative setting, thus research into the nature of this transition could further illuminate the experience of the oncology nurse as compared to the palliative care nurse. Understanding the role that this transition plays in the stress that nurses experience would be important in successfully coping with this stress and preventing burnout.

The findings from this study illuminate a variety of issues which appear to be central to understanding

the oncology nurse's experience in nursing the young-middle aged patient dying of cancer. Further research of these issues would add to this understanding. It is hoped that this understanding would ultimately improve nursing practice through decreased stress and burnout.

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Appendix: C
Demographic Data

Subject Code: _____

1. Age: 20-30 _____ 31-40 _____ 41-50 _____ 51+ _____

2. Education:

a. Nursing Education:

Diploma _____

Bachelor's Degree _____

Graduate Degree _____

b. Other Diploma/Degree _____

c. Specialty Courses: (eg. palliative care)

please specify _____

3. Nursing Experience:

a. Total number of years worked in nursing _____

b. Total number of years worked in oncology _____

Appendix: D**Interview Guide****1. Introduction.**

- a) How much experience have you had nursing dying patients aged 20-45 years old?
- b) What has that experience been like for you?

2. Sources of stress.

- a) What do you find uniquely stressful in nursing dying patients aged 20-45 years old?
- b) How is this different from nursing older dying patients?

3. Coping with the stress.

- a) How do you deal with these stressors?
- b) Do you use these coping mechanisms when nursing older patients?
- c) Have you ever been unsuccessful in coping with the stress?
What was the outcome?
- d) Does the stress of nursing these patients affect your private life?
In what way/s?

4. Positive aspects of nursing these patients.

- a) Would you choose to nurse a dying patient in this age group again?
What motivates your decision?
- b) Have you come to any new realizations as a result of providing this kind of nursing care?
Describe them.
- c) Have there been any positive benefits as a result of providing this kind of nursing care?
Describe them.

5. Making sense of the experience.

- a) What do you see as your most important role in nursing these patients?
- b) How does the experience of caring for these patients affect you personally?
- c) How do you make sense of the experience of death in this age group?