PALLIATIVE CARE NURSES' PERCEPTIONS OF SUFFERING

IN PALLIATIVE CARE PATIENTS

by

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ABSTRACT

Suffering has been part of the human condition since time began, and people have long sought answers to the questions it raises from religion, philosophy, medicine, and the arts. People living with progressive, life threatening illness can suffer greatly from physical symptoms and a variety of personal issues. Palliative care offers these patients quality of life through symptom management and a unique approach of competent, compassionate care in which nurses play a major role. Many health professionals and others in society believe that assisted suicide and voluntary euthanasia should be options for people who are suffering despite the best efforts of palliative care.

Throughout the health literature on suffering, there is a wealth of philosophical perspectives and research using both quantitative and qualitative methods. Although many papers focus on suffering in palliative care, none were done from the perspective of palliative care nurses. Using a qualitative method based on grounded theory, this study explored the perceptions of eight palliative care nurses about the suffering of their patients. Specifically, findings describe how the nurses recognize suffering, their strategies for helping patients who are suffering, the conditions which help or hinder the alleviation of suffering, and the personal impact on the nurses of caring for patients who suffer.

Findings suggested that patients suffer in three realms: bodily discomfort, interpersonal discord, and personal distress. Strategies that patients and nurses used to alleviate suffering were specific to each realm. Their goals were to achieve bodily comfort, create interpersonal harmony, and find inner peace. The work pattern of patients and nurses was unique; as suffering became progressively less tangible through the bodily, interpersonal, and personal realms, the work of patients increased, and the work of nurses

decreased. Physical suffering was more amenable to direct nursing interventions; suffering at the interpersonal and personal levels was essentially something only patients could resolve, and the nursing role became more supportive.

Caring for patients who suffer affected the nurses positively and negatively. The nurses derived great satisfaction from being able to help alleviate suffering. Unfortunately, the nurses, too, suffered when they could not prevent or relieve suffering in their patients. They coped with these difficulties by setting realistic expectations of themselves, being able to learn from their experience, and feeling supported by their colleagues and by management in specific ways. From the results of this study, nursing implications for practice, education, administration, and research were identified.

TABLE OF CONTENTS

LIST OF TABLES

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My thesis is dedicated to the memory of

my niece,

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1974 - 1979

one of my first inspirations for working in palliative care

and my mother,

Muriel Helen Stone Flinn

1926 - 1999

whose life and death will continue to inspire my work.

CHAPTER 1

AN OVERVIEW OF THE RESEARCH PROBLEM

Background to the Problem

Introduction

Suffering has been part of the human condition since time immemorial, and people have long sought answers to why people suffer, and what can be done about it. Philosophers, playwrights, and theologians saw humanity as needing guidance to make their experiences of suffering "sufferable" (Fitcher, 1981, p. 81). They attempted to provide this insight through their writing and their work. Much of life's suffering is manifested in illness, death, grief, and therefore, nurses are witness to great suffering (Daly, 1995 b; Kahn & Steeves, 1986, 1994; Pollock & Sands, 1997; Rodgers & Cowles, 1997; Travelbee, 1971; Wright, 1997).

Suffering and Palliative Care

Progressive, life-threatening diseases can be a major source of suffering. People in the advanced stages of diseases such as cancer, acquired immunedeficiency syndrome (AIDS), congestive heart failure, and amyotropic lateral sclerosis (ALS), can suffer greatly from the physical devastation and the potentially overwhelming personal challenges these conditions present. Since the late 1960s, palliative care has been advocated as the preferred approach to caring for people for whom cure is no longer possible (Byock, 1994a; Mount & Hamilton, 1994; Van Eys, 1991). To palliate means to relieve without curing (Van Eys). Palliate comes from the Latin *pallium*, to cloak, which has its roots in the word for a particular kind of cloak shepherds wore to protect themselves from stormy weather (Leone, 1997). As Leone explains, "Palliative care is not therefore what one can

do when 'nothing else can be done' but rather, what 'there is to do' under those circumstances" (p. 54). Providers of palliative care strive to help patients achieve a quality of life that enables them to live as fully as possible in the time they have remaining. The staff attempt to ease suffering by addressing the person's "total pain" (Saunders, 1978, p. 194): the physical pain and symptoms, and the psychological, social, and spiritual/existential pain with which they may be struggling (Cherny, Coyle, & Foley, 1994a; Gregory, 1994). In many palliative care programs, cancer is the most common diagnosis, as over one-quarter of the more than 200,000 deaths in Canada each year are due to cancer (Statistics Canada, 1998). Other progressive diseases are also seen in smaller numbers (Jarvis, Burge, & Scott, 1996; Munn & Worobec, 1997; Tong, Porterfield, & Mills, 1993; Yeomans, Spring, & Porterfield, 1995). Some palliative care programs specialize in caring for people with AIDS (Foley, Flannery, Graydon, Flintoft, & Cook, 1995), or have significant representation from this population (Kuhl, 1995).

<div align="center">Responses to Suffering</div>

Nursing and Compassionate Care

Palliative care nurses are in a special position to help alleviate suffering. They have skills and expertise to relieve many physical symptoms and the psychosocial or spiritual/existential distress that can constitute suffering (Barkwell, 1991; Chapman & Gavrin, 1993; Cherny, Coyle, & Foley, 1994 a; Coyle, 1992; Davies & Oberle, 1990; Elsdon, 1995; Gurfolino, 1994; Prior & Poulton, 1996; Salt, 1997). Nurses may do this on their own because of the intimate nature of their work and their prolonged contact with the people for whom they care, or in conjunction with other members of the interdisciplinary palliative care team (Ferris & Cummings, 1995; Saunders, 1990). Many

authors write that competent, compassionate care must be offered to people to help them through their suffering (Byock, 1994 a; Cassell, 1982, 1991; Ersek & Ferrell, 1994; Gregory, 1994; Lindholm & Eriksson, 1993; Steeves & Kahn, 1987; Travelbee, 1971; Vaillot, 1966; Younger, 1995). They believe that suffering can be transcended by finding meaning in it and renewing one's sense of self-integrity. The word compassion means "suffering with" (Byock, 1994 a; Gregory; Lentz, 1985) which is from the Latin *passiones* (Gould, 1990). This is not to say that nurses are able to understand fully the suffering patients experience, or are able to bear the suffering for them, but they can offer to share it and accompany them in their suffering. People need not feel alone or abandoned.

<u>Assisted Suicide and Voluntary Euthanasia</u>

There are also many people who believe that physician-assisted suicide and voluntary euthanasia should be legitimate options for terminally ill people who are suffering because palliative care is not available everywhere, and because it cannot relieve all suffering. The arguments for and against physician-assisted suicide and voluntary euthanasia (sometimes referred to together as assisted death or aid-in-dying) are presented throughout health care literature and other sources (Baume, 1996; Bernat, 1996; Brody, 1996; Foley, 1997; Klagsbrun, 1991; Kowalski, 1996; Lowy, Sawyer, & Williams, 1993; Special Senate Committee on Euthanasia and Assisted Suicide, 1995; Sumodi, 1995). Nurses have been part of and will continue to contribute to the public debate on these issues, whether in the form of position statements (Canadian Nurses Association, 1994), scholarly papers (Coyle, 1992; Kowalski, 1996; Sumodi); or on ethics committees and in community discussions (Tilden, Tolle, Lee, & Nelson, 1996). Because unresolved

suffering is central to the debate on assisted death, it was hoped that the results of the present study would provide another important nursing perspective through an expanded understanding of suffering and its alleviation in palliative care patients.

Statement of the Problem and Purpose

There is a great deal of theoretical literature about what it means to suffer and what the goals of care should be, much of it from the literature on oncology and palliative care. Despite the fact that nurses represent the largest number of health care providers, and in palliative care, work so closely with people who are suffering, there is relatively little written about the experiences of these nurses, or from the perspective of nurses. The following research questions were raised as a result of the literature review:

(1) How do palliative care nurses define suffering?

(2) How do palliative care nurses know when someone is suffering?

(3) How do palliative care nurses respond to patients who are suffering?

(4) What is the personal impact of caring for patients who are suffering?

The purpose of doing this research was to explore and describe the experience of palliative care nurses who care for patients who are suffering. By eliciting the experiences of the nurses themselves, the researcher expected to obtain a comprehensive and valid account of nurses' responses to the suffering of patients that would provide a useful basis for identifying supportive nursing interventions. Specific objectives were to:

(1) describe palliative care nurses' perceptions of suffering in their patients who are suffering;

(2) describe how these nurses identify suffering in palliative care patients;

(3) describe how palliative care nurses respond to patients who are suffering;

(4) describe the personal impact on nurses of caring for patients who are suffering;

(5) develop a beginning theory of the process by which palliative care nurses respond to patients who are suffering.

Definition of Terms

Terms used in the research questions were defined as follows:

Palliative Care: A program of care which is consistent with the philosophy and principles of the Canadian Palliative Care Association as described in *Palliative care: Towards a consensus in standardized principles of practice* (Ferris & Cummings, 1995).

Palliative Care Nurse: A registered nurse who has worked in a palliative care inpatient program for at least one full year, or who has worked in the role of primary nurse for palliative patients on a home care service for at least one full year.

Patient: A person with a progressive, life-threatening disease who is registered with and receiving care from a palliative care program as an inpatient or at home.

Progressive, Life-threatening Disease: A disease for which cure is no longer possible and which significantly limits life expectancy.

Significance of the Study

Enhanced Palliative Care Nursing

Many people with progressive, life-threatening disease are referred to palliative care programs in the last months of their lives so they may have the best quality of life possible in the time remaining. This quality of life often depends on how well their suffering can be addressed by the palliative care providers, the majority of whom are nurses. An exploration of the experiences of a sample of these nurses was expected to increase understanding of the suffering of people with progressive, life-threatening illness,

and of nurses' responses to that suffering. New knowledge could broaden the range of interventions that can help people who are suffering. New information gained about how the suffering of their patients affects palliative care nurses and what best helps the nurses to deal with those effects, would have the potential to improve the work life of palliative care nurses, better enabling them to provide good patient care.

Contribution to the Debate on Assisted Death

Assisted suicide and voluntary euthanasia are issues of current interest for people in health care and society in general because they are being proposed as options for people to choose to end their suffering when palliative care cannot relieve it. The problem of unrelieved suffering is at the heart of the debate, and because of their experience, it was thought that nurses who work in palliative care could contribute to the quest for knowledge that would improve care for people who are suffering from terminal illness. The more effectively suffering can be alleviated, the less perceived need there would be for such measures as assisted death. As well, increased understanding of suffering would result in better informed arguments on both sides of the issues of assisted suicide and voluntary euthanasia. The study provided an opportunity for palliative care nurses to share their experiences of caring for people who suffer during terminal illness, and thus to advance current knowledge and practice around suffering.

Assumptions

The study was based on the following assumptions:

- Registered nurses who work in palliative care have knowledge and experience in relieving suffering.

- Registered nurses who work in palliative care are able to articulate their experiences of caring for people who are suffering.

Summary

Suffering has been part of the human condition since time began, and people have long sought answers to the questions it raises from religion, philosophy, medicine, and the arts. People living with advanced disease may suffer greatly with physical pain and other symptoms, psychosocial concerns, and spiritual/existential issues, which can arise from a number of progressive, life-threatening illnesses, and a variety of personal circumstances. Contemporary Canadian health care offers palliative care to people with terminal illness in hopes of giving them good quality of life by alleviating their suffering through its unique approach of competent, compassionate care in which nurses play a major role. Unfortunately, palliative care is not accessible to everyone, and when it is, it cannot always relieve all suffering. Many health care providers and others in society believe that physician-assisted suicide and voluntary euthanasia should be options for people who are suffering despite the best efforts of palliative care.

This chapter outlined the rationale for a study of palliative care nurses' perceptions of suffering in palliative patients for whom they have cared. It was expected the findings could expand understanding of the phenomenon of suffering in palliative care patients from the perspectives of nurses, and of nurses' responses to that suffering. Such advances in knowledge could have fourfold benefits. First, a better understanding of suffering from the perspective of palliative care nurses could result in nursing care that is more effective in relieving suffering. Second, any improvement in alleviation of suffering could help make occasions when assisted death is seen as a solution to suffering, less frequent. Third,

increased understanding of suffering could only serve to better inform both sides of the

debate on the issues of physician-assisted suicide and voluntary euthanasia. Fourth,

articulation of the personal impact of patients' suffering on nurses themselves, could make

it possible to begin to identify how nurses deal with their own experiences, and what kind

of support best helps them to do that well.

As well, the research questions were formulated, terms used in the study were

defined, and assumptions were outlined. A further review of the literature in Chapter 2

will elaborate on the background of the problem and the context from which the research

questions arose.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

The literature review places the study in the context of the current literature

available on the topic of suffering and further develops the rationale for the study. This

review is done under two headings: the general literature and the nursing literature. The

general literature provides definitions, and describes characteristics of and responses to

suffering. Much of this is written from the perspectives of disciplines other than nursing.

The second part explores the nursing literature from research and theoretical perspectives

that include studies of nurses' perceptions of suffering; the nature of suffering and nursing

responses to suffering; and a series of studies dealing with the concepts of suffering and

enduring.

General Literature

<u>Definitions of Suffering</u>

Numerous authors have attempted to define suffering. Travelbee (1971) is one of

the first nursing authors to write about suffering. She defines suffering as "an experience

which varies in intensity, duration, and depth...a feeling of displeasure which ranges from

simple transitory mental, physical, or spiritual discomfort to extreme anguish and to those

places beyond anguish, namely the malignant phase of despairful 'not caring' and the

terminal phase of apathetic indifference" (p. 62). Copp (1974) writes that suffering is "the

state of anguish of one who bears pain, injury, or loss" (p. 491). Benedict (1989)

describes suffering as "...a negative affective state resulting from an event or situation that

is perceived to be physically painful, uncomfortable, or psychologically distressing." (p.

34). Cassell (1991), who has written extensively about suffering, states that suffering is

"... the distress brought about by the actual or perceived impending threat to the integrity

or continued existence of the whole person." (p. 24). Cherny, Coyle, and Foley (1994 a)

define suffering as "...an aversive emotional experience characterized by the perception of

personal distress that is generated by adverse factors undermining the quality of life." (p.

57). Though their words differ, all these authors capture the intensely negative meaning

and poor quality of life implied in the experience of suffering. Travelbee is the only one

who claims that the concept of suffering can also include "simple transitory...discomfort",

which some authors, such as Campbell (1987), Chapman and Gavrin (1993), Kupperman

(1994), and Rodgers and Cowles (1997) would suggest is indiscriminate use of the word

'suffering'.

<u>Characteristics of Suffering</u>

As authors have theorized about the concept of suffering, they have identified a

number of characteristics which serve to differentiate suffering from less distressing

circumstances. Lack of meaning or purpose is the characteristic referred to most

consistently in the literature on suffering (Benedict, 1989; Byock, 1994 a; Cassel, 1991;

Cherny, Coyle, & Foley, 1994 a; Ersek & Ferrell, 1994; Loewy, 1991; Starck &

McGovern, 1992; Stavros, 1994; Steeves & Kahn, 1987; Travelbee, 1971; Wallace,

1995; Wright, 1997; Younger, 1995). Lack of meaning refers to the inadequate

explanation or the injustice of the various conditions or characteristics, be they physical,

psychosocial, or spiritual/existential, that may be present in a particular experience of

suffering. Many of these authors ground their views in the writings of Frankl (1984), a

survivor of Nazi concentration camps, who believed "In some way, suffering ceases to be

suffering the moment it finds a meaning..." (p. 135). Frankl makes a point of claiming that one does not have to suffer to find meaning. The threat to personal integrity mentioned in Cassell's (1991) definition of suffering is frequently cited by others as being central to the experience of suffering (Chapman & Gavrin, 1993; Copp, 1990b; Gregory, 1994; Kahn & Steeves, 1986, 1994; Roy, 1993; Starck & McGovern; Younger).

There are a number of other characteristics which are not essential to the experience of suffering, but may be present. These include: feelings of vulnerability or loss of control (Copp, 1990 b; Kleinman, 1988; Kupperman, 1994; Steeves, Kahn, & Benoliel, 1990; Younger, 1995); a sense of despair or hopelessness (Cassell, 1982; Cherney, Coyle, & Foley, 1994a; DuPont & McGovern, 1992; Flaming, 1995; Kupperman); alienation or loneliness (DuPont & McGovern; Younger); fear in anticipation of symptoms, of an unknown future, or of death (Cassell, 1982; Chapman & Gavrin, 1993; Cherney et al.; Georgesen & Dungan, 1996); and guilt (Aden, 1984; Bregman, 1987; Cherney et al.; Rodgers & Cowles, 1997). Cassell (1982, 1991) maintains it is the whole person who suffers, and that what is suffering for one individual may not be for another. Cherney et al., Copp (1990 b), Kahn and Steeves, (1994), Salt, (1997), Starck and McGovern (1992), Wright (1997), and Younger (1995) are in agreement with this claim.

Physical Pain as Suffering

Pain can be a major source of physical suffering. Barkwell (1991), Coyle, Adelhardt, Foley and Portenoy, (1990), and Twycross (1978) suggest that 40 to 90% of people with advanced cancer experience severe pain. Other symptoms, such as dyspnea, nausea/vomiting, and diarrhea, common to cancer and other illnesses, can also be very

distressing (Baines 1978; Cherny, Coyle, & Foley 1994 a; Copp, 1974; Doyle 1984).

Many authors believe that although some people equate pain with suffering, pain in and of

itself does not constitute suffering (Chapman & Gavrin, 1993; Cherny et al.; Gregory,

1994; Frankl, 1984; Hill, 1992; Kahn & Steeves, 1986; Kupperman, 1994; Loewy,

1991; Younger, 1995). They explain that the meaning and the threat of the situation to

the one experiencing the pain is crucial in determining whether the person is suffering.

Psychological, social, and spiritual/existential concerns can also create suffering, either on

their own, or in combination with physical symptoms.

<div align="center">Responses to Suffering</div>

Spiritual Responses to Suffering

Spirituality and religion provide a context that will influence the experience of

suffering for almost every individual, and therefore they are significant considerations for

nurses who deal with suffering. People may be spiritual or religious, both, or neither, and

it is important to differentiate between spirituality and religion (Elsdon, 1995; Grey, 1994;

Smyth & Bellamare, 1988). Spirituality has more to do with what it means to be human,

the meaning of life. It is broader than religion and may be more philosophical. Religions

are institutions for spirituality that teach specific beliefs and offer rituals and other forms

of religious practice. Cherny, Coyle, and Foley (1994a), and Heitman (1992) claim that

those who are non-religious often "ask deeply spiritual questions" (Heitman, p. 84) when

they encounter suffering. Spiritual suffering in terminal illness may be experienced in a

quest for meaning, a need for forgiveness, or while clinging to hope. World religions such

as Judaism, Christianity, Islam, Buddhism, and Hinduism, have tried to bring meaning to

human suffering, and the guidance offered to followers addresses widely ranging questions

from human and divine causes of suffering, to the purposes of suffering (Bowker, 1970).

Those who are religious will be affected by the degree to which they hold to what their

religion teaches. Suffering may reinforce people's spiritual and religious beliefs, cause

them to question their beliefs, or even to reject their beliefs. Heitman suggests that

traditional explanations almost consistently relate suffering to human behaviour, see

suffering as an opportunity for growth, and concede that faith is needed "...to transcend

suffering and to live with its mystery." (p. 84).

<u>Philosophical Responses to Suffering</u>

A common theme in the literature from various disciplines is that suffering is part

of life (Daly, 1995a; Lindholm & Eriksson, 1993; Mount, 1993; Starck & McGovern,

1992; Vaillot, 1966). The idea that suffering is an opportunity for personal growth is

found in philosophy, psychology, medicine, and nursing, and in everyday wisdom (Ersek

& Ferrell, 1994; Hinds, 1992; Salt, 1997). Starck and McGovern (1992) suggest that

people should be helped to see that suffering is a "teacher", not an "enemy" (p. 26). Lentz

(1985) maintains that when one faces suffering, three things must be done: see it and

express it, weep over it, and transform it. She stresses the importance of avoiding apathy,

which comes from the Greek *apatheia* - "non-suffering", because it is so tempting for

people to try to avoid the pain in life, a thought also put forth by Byock (1993),

Somerville (1996), and Younger (1995). Vaillot (1966) writes that in existentialism,

commitment is a "willingness to live fully one's own life, to make that life meaningful

through acceptance of, rather than detachment from, all that it may hold of both joy and

sorrow" (p. 500). Younger relates Vaillot's idea to wisdom, in particular as a quality that

will incline nurses to committed compassion and care. Kupperman (1994) states that

without suffering, one cannot feel joy. All of these thoughts are worthy of aspiration, but may be of little comfort to people who are actually suffering. Authors such as those cited in this paragraph do not mean to glorify suffering, or to say that suffering should not be relieved. Rather, their ideas to point to the need for competence and compassion, and accompanying patients as they journey through their suffering. Nurses can play a major role in providing care characterized in these ways.

Assisted Death as a Response to Suffering

In Canada, debate about whether assisted death and voluntary euthanasia should be legalized has been taking place for a number of years, and the solution will ultimately be decided in Parliament. Such a solution should reflect a consensus of thought in Canadian society and will need to be in keeping with the *Canadian Charter of Rights and Freedoms*. Several official inquiries have addressed the issues of assisted suicide and voluntary euthanasia to varying degrees, including the British Columbia Royal Commission on Health Care and Costs (1991), the Law Reform Commission of Canada (1983), the Special Advisory Committee on Ethical Issues in Health Care (1994), and the Special Senate Committee on Euthanasia and Assisted Suicide (1995), hereafter referred to as the Senate Committee. The Senate Committee conducted a comprehensive review of many related issues: use of life-sustaining treatment; pain control; sedation; advance directives; palliative care; assisted suicide; and euthanasia. The importance of palliative care was recognized for the role it can play in relieving the suffering of people who are terminally ill, and the Senate Committee concluded that palliative care could be considered an alternative to assisted suicide and euthanasia. As a result, five of the Senate

Committee's 28 recommendations dealt with the need to make palliative care a priority in Canadian health care and accessible to more people.

Many proponents of palliative care believe that there are too few cases of unrelieved suffering in palliative care for there to be a real need for legalization of assisted death, and some go so far as to say that palliative care can control all suffering, even if it has to be through sedation (Brescia, 1991; Byock, 1993; Cherny, Coyle, & Foley, 1994a, 1994b; Harvey & Pellegrino, 1994; Moulin, Latimer, MacDonald, Scott, Scott, Deachman, & Mount, 1994). A number of authors (Angell, 1997; Gregory, 1994; Ogden, 1994; Tilden, Tolle, Lee, & Nelson, 1996) observe that few palliative care supporters acknowledge that for some people who are suffering, palliative care cannot offer what they need, and sedation is not an acceptable alternative to death. As well, there is the fact that palliative care is not yet available to all people (Foley, 1991; Harvey & Pellegrino; Senate Committee, 1995). Some palliative care supporters fear erosion of palliative care services if assisted suicide and voluntary euthanasia are allowed (Brody, 1996; Coyle, 1992; Senate Committee). However, even the most ardent advocates of assisted suicide and voluntary euthanasia agree that palliative care is always preferable to assisted death, and that regulations for assisted death would have to include a stipulation that palliative care has been offered to the person who is suffering (Angell; Brody; Miller, Quill, Brody, Fletcher, Gostin, & Merier, 1994). These authors believe, and others agree, that if excellent palliative care is made available to all who need it, there would be significantly fewer requests for assisted death (Coyle; Fins & Bachetta, 1995; Foley, 1991, 1997; Sachs, Abronheim, Rhymes, Volicer, & Lynn, 1995).

Nursing Literature

General

Nursing contributions to the literature about suffering are a small part of the vast amount that has been written. Copp (1974) suggests that as human beings, nurses are reluctant to venture into discussion about suffering because of their general discomfort with dying and death, and because suffering makes them recognize their own vulnerability to similar life experiences. As well, because the medical model has traditionally been so prevalent in health care (and nursing) its view of the ill person as a body may have discouraged attention to the person actually suffering (Cassell, 1982). The literature regarding suffering has grown in fields of emotional and mental health (Justice, 1992; Knight, 1992; Lazare, 1992; Lindholm & Eriksson, 1993); chronic and acute illness (Benedict, 1989; Kleinman, 1988; Morse & Johnson, 1991; Pollock & Sands, 1997), and especially in the area of palliative care, as the references throughout this paper indicate.

Research and Theoretical Perspectives from Nursing

Nurses' Perceptions of Suffering

Davitz and colleagues looked at nurses' perceptions of suffering in relation to a number of factors. Davitz and Pendleton (1969) conducted four studies to determine nurses' perceptions of suffering relative to (1) the nurse's cultural group; (2) the nurse's clinical specialty; (3) patient diagnosis; and (4) patient characteristics. Puerto Rican nurses (one of four groups studied) inferred the highest amount of suffering in the patient scenarios they were given. Clinical specialty and patient gender made no difference, but

patient diagnosis (burns, depression, and leukemia - in that order - over diabetes), and low socioeconomic status were accorded more suffering.

Baer, Davitz, and Lieb (1970) and Lenburg, Glass, and Davitz (1970) studied nurses' perceptions of suffering in comparison to the perceptions of other occupational groups. In the first study, social workers assigned the highest level of physical and psychological suffering to verbal and non-verbal communication, significantly more than nurses. Physicians had the lowest scores. The second study looked at perceptions of physical and psychological suffering related to the stage of illness among nurses, physicians, nuns, and teachers. Scores on all counts were highest for nuns, then teachers, nurses, and physicians in that order.

Davitz and Davitz (1975) conducted a study over several years with 700 nurses in which the nurses were asked to rate pain and suffering (loosely defined) in sets of scenarios in which patients had the same diagnosis but very different personal circumstances. Results showed that the nurses' personal belief systems influenced their perceptions in terms of the patients' age, gender, socioeconomic class, and ethnic group. Mason (1981) surveyed 161 nurses using a Likert-style questionnaire with 60 patient situations for which the nurses rated physical pain and psychological distress. Characteristics of the nurses were analyzed as well (gender, race, age, education, years of nursing experience, full or part-time job status, type of position, area of clinical practice, and hospital of employment). The only statistically significant relationship was that nurses with the least amount of clinical experience perceived the greatest level of physical suffering.

Battenfield (1984) reviewed the literature available at the time and developed two related schemata to assist nurses in determining where a person was in his or her suffering - information which would then help the nurse to better guide the person toward the ideal position on the scales. The first scale is a numerical continuum, rating turmoil to contentment from one to five. The second is five "qualitative responses observable in situations of suffering" (p. 38), each with a number of indicators to allow the nurse to choose the stage most applicable to the person at the time. The five stages are: initial impact; turmoil without resolution; and three recovery responses: coping; accepting/understanding; finding meaning. Battenfield includes excerpts from interviews done with nine patients, and explains how analysis of the interviews using the schemata indicates that features of suffering were "detected" (p. 41).

A taxonomy can be a useful tool for looking at any concept, and Flaming (1995) describes a taxonomy developed through an ethnoscientific study of nurses' descriptions of their perceptions of patients' suffering. The taxonomy ascribes four domains to suffering: to bear it; to stay in control; to protect; and to strengthen, and within each of those are two more increasingly specific levels. The categories of physical, psychosocial, and spiritual/existential suffering are common in writing on suffering, but Flaming's work brings in new ideas, such as manipulation as a means of patient control, that patients may try to protect and strengthen both self and others, and that some patients do not want their suffering relieved. Along with currently recognized "types" of suffering, there are also "new labels" identified, such as martyr-like, flaunted, self-absorbed, and peaceful, some of which are an interesting contrast to the commonly mentioned characteristics that are more likely to evoke compassion.

Kahn and Steeves (1986) review the literature around the physical and psychological aspects of suffering, meaning in suffering, and the concept of self. From this discussion, they theorize about how nurses infer suffering, suggesting that nurses do so from an interaction of the text, the context, and the reader. The text is comprised of the physical, psychological, and sociocultural features of the patient's experience, and the interpretation by the nurse (as reader) of that experience. As the reader, the nurse is influenced by professional and personal experience, and his or her own values and beliefs. The patient can also be a reader. The context is the physical environment and historical background of the situation, and the quality of communication between nurse and patient. Kahn and Steeves go on to recommend that research around suffering should be directed to understanding the phenomenon rather than prediction of it, and argue that qualitative methods are the preferred means of learning about the lived experience of suffering. Steeves, Kahn, and Benoliel (1990) describe the findings of their study *Nurses' Interpretation of the Suffering of Their Patients*, done through interviews with graduate nursing students about their experiences with suffering in a variety of practice settings. The authors identify five themes: (1) suffering as a patient condition (causes, medical symptoms, effects); (2) first transition; (3) suffering as an experience (characteristics); (4) second transition; (5) suffering personalized by nurses (their own reactions, their own contributions to suffering). The first transition in nurses' interpretations occurs when the nurses begin to describe suffering in terms of an individual person's response to a disease or condition, rather than the problem itself. The second transition comes with the realization that although it is another person - the patient - who is suffering, that they

themselves are very much a part of the experience. The five themes are not exclusive of each other; they may all be present within the nurse consciously or subconsciously.

In the studies by Mason (1981), and Davitz and her colleagues (Davitz & Pendleton, 1969; Baer, Davitz, & Lieb, 1970; Lenburg, Glass, & Davitz, 1970), the authors speculate about reasons that might explain why nurses would seem to be less sensitive to patient suffering than was perhaps expected. However, it is more important to note that the situations the nurses were given to assess were hypothetical, and did not involve any interpersonal exchange between nurses and patients. As such, the findings offer limited information about the real experiences of nurses working with people who are suffering. Battenfield's quantitative study (1984) and Flaming's use of the qualitative ethnoscience method (1995) are more useful than the studies of Mason, and Davitz and colleagues, because they draw on suffering from real life situations. Flaming's taxonomy is quite descriptive and adds thought-provoking ideas for nurses to consider when caring for people who are suffering. Battenfield's schemata could be helpful for nurses who are learning about suffering and how to recognize it. However, qualitative understanding of suffering and an awareness of the many influences on interpretation of suffering, as suggested by Kahn and Steeves (1986), could enhance the perceptions of nurses who use Battenfield's tools. The qualitative work by Steeves, Kahn, and Benoliel (1990) offers valuable insight into the experience of nurses who work with people who are suffering, and will be compared with the findings from the present study.

The Nature of Suffering and Nursing Responses

Steeves and Kahn (1987) theorize about the experience of meaning in suffering by drawing on personal anecdotes and writings from various authors on aesthetics, health and

meaning, and phenomenology. They find many themes - courage in the face of adversity; seeing the whole of reality rather than the parts; coming to know something greater than oneself; a sense of coherence or well-being within and external to oneself; and the idea that one does not understand being - rather, being is understanding. The thoughts of Steeves and Kahn allude to the ideas of other authors, such as Byock (1993), Daly (1995 a, b), Frankl, (1984), Lentz (1985), Mount (1993), Salt (1997), Starck & McGovern (1992), Somerville (1996), Stavros (1994), Vaillot (1966), and Younger (1995), who write about the human capacity to transcend suffering, and that people who do so experience new learning, personal growth, and creation of meaning. These perspectives encourage further exploration of suffering through qualitative methods.

Kahn and Steeves (1994) describe stories of patient suffering from the perspectives of nurses. The authors advocate for the role nurses could play as witnesses to suffering and visionaries for a future where nobody's suffering is ignored. Qualitative research with palliative care nurses would provide information that comes from their experiences as witnesses to suffering, which could add to the current body of knowledge from which nurses draw to help people who are suffering.

Kahn and Steeves (1995) bring together their many years of experience, theorizing, and research with suffering with eight aphorisms of suffering. They relate the aphorisms specifically to another narrative from Steeves' (1992) work with people undergoing bone marrow transplantation. These principles reflect and expand on much of what has been written by individuals in other disciplines about suffering.

Copp (1990a, 1990b) contributes to the literature with two editorials on suffering. In them she explores the nature of suffering, outlines a number of characteristics of

suffering such as vulnerability and threatened self-concept, and suggests possible interventions in response to suffering. She does this to inform nurses about what constitutes suffering, and to better enable them to prevent suffering in patients, or at least to be able to prevent its exacerbation. Unfortunately, Copp's suggestions lack depth; they give the impression that prevention and relief of suffering are relatively straightforward.

Daly's (1995 a & b) analysis of suffering within Parse's Theory of Human Becoming (1992) suggests that suffering is a "chosen" (p. 50) way of being, in that people choose the way they will respond to suffering. Daly's assumption that human beings choose freely and are fully responsible for their decisions must be questioned. Though human beings may have the potential to be free, factors such as education or family and social circumstances can influence, and perhaps limit, their choices in life or during illness. Daly, like Cassell (1982), Kahn and Steeves (1994), and others, writes that the experience of suffering is unique to each person, and only that person can express the meaning found in his or her suffering. Parse's Human Becoming Theory reflects the common theme in the literature on suffering that one should ideally strive for transcendence of suffering, and is very much rooted in caring and the idea that it is the whole person who suffers. Parse's approach to nursing care, and her qualitative research methodology, which Daly uses, provide insight into the experience of the one who suffers. However, the esoteric quality of the theory and its complex language may discourage nurses from reading the model, which would limit potential benefits to practice.

Most of the nursing literature described above (Daly, 1995; Kahn & Steeves, 1994, 1995; Steeves & Kahn, 1987; Steeves, 1992) affirms the nature of suffering, the

importance of meaning in the experience of suffering, and appropriate responses to suffering, through ideas similar to those written from the perspectives of other disciplines. The two editorials by Copps (1990a, 1990b) do so as well, but the points she makes are not quite as convincing. The qualitative nature of all these papers, along with the work of Flaming (1995), Kahn & Steeves (1986); and Steeves, Kahn, & Benoliel (1990), demonstrates an approach more suitable to questions about the nature of suffering, and the perceptions of suffering by nurses, than is possible by quantitative methods used in such studies as Daviz & Pendleton (1969); Baer, Davitz, & Lieb (1970); Lenburg, Glass, & Davitz (1970); Davitz & Davitz (1975); Mason (1981); and Battenfield (1984). This observation supports the idea that a qualitative methodology, such as grounded theory, was an appropriate choice for the research questions in the study that explored the experience of palliative care nurses who care for patients who suffer.

<u>The Concepts of Suffering and Endurance</u>

Dewar and Morse (1995), and Morse and Carter (1995, 1996) examine suffering and endurance as related, but quite separate concepts. Dewar and Morse use qualitative methods to learn about the experience of twenty people who dealt with a "catastrophic health event related to illness or injury". They identify numerous intrapersonal and interpersonal characteristics that are fairly consistent with other literature about the nature of suffering. These features are considered to be "unbearable" by the participants, who also develop ways to learn to bear and manage those characteristics. Dewar and Morse discuss means by which nurses can help the person to better cope and bear the experience, and how nurses can avoid contributing to the failure to endure.

Morse and Carter (1995) report a case study of a woman whose three children all die in the same fire that inflicted extensive burns on herself, and whose husband tells her of his plans for divorce before she is finished rehabilitation. Morse and Carter take the endurance/suffering analysis further by differentiating more clearly between the two concepts. They define enduring as "the capacity to last, to get through, to survive an experience or an intolerable situation" (p. 39), and say that suffering is "the emotional response to the loss" (p. 39), which "requires reflection, a looking back, and evaluation of the immensity of the loss" (p. 40). They write that suffering can only occur after endurance and that in endurance there is an absence of suffering. Morse and Carter describe four "comforting strategies" the survivor used to endure. The first two strategies are enduring to survive (physiological needs) and enduring to live (psychological needs). The third is suffering which occurs when "one has endured enough and feels strong enough to suffer" (p. 40), and the fourth phase is reformulation of self.

Morse and Carter (1996) continue their analysis of the concepts of endurance and suffering. They expand their definition of suffering to "an emotional response to that which was endured, to the changed present, or to anticipating the altered future" (p. 43). They still differentiate between endurance and suffering: "individuals will move from enduring to suffering when they are able to acknowledge that which is being endured, and when they are emotionally strong enough" (p. 43). When suffering becomes too much, they may retreat to the enduring stage, and continue to move back and forth. The purpose of the research was to further develop the concepts of both endurance and suffering, though it is not clear in the paper that the definitions above came out of this research. The study is an analysis of qualitative interviews from a data bank, which had originally been

conducted on the concept of comfort. Morse and Carter (1996) found evidence of the comforting strategies described by Morse and Carter (1995), and a third type of enduring - enduring to die. Enduring to die involves efforts towards matters such as organizing financial affairs, making funeral arrangements, and keeping alert and oriented. Morse and Carter maintain that while one is living in any of the three phases of enduring, one is not suffering, and that suffering only happens when one is strong enough to handle it.

The work of Dewar and Morse (1995), and Morse and Carter (1995, 1996) raises a number of questions. People may try to get through a difficult or potentially devastating experience by focusing on other thoughts or activities, but because one is trying to be optimistic or courageous, or is not being emotionally expressive, does not mean one is not suffering. It is difficult to understand how one could begin to suffer only after being through the crucial physical and psychological challenges of "enduring to survive" and "enduring to live". The word endure is used throughout the literature on suffering as a verb to indicate the act of getting through the suffering (Battenfield, 1984; Byock, 1994b; Huang & Emanuel, 1995; Kahn & Steeves, 1986; Kupperman, 1994; Younger, 1995). Copp (1974), Flaming (1995), and Rodgers and Cowles (1997) use the verb "to bear" instead of "to endure". Several authors write that when suffering becomes truly unendurable, the patient may become dysfunctional, mentally ill, have thoughts of suicide, request euthanasia, or may actually commit suicide (Burgess, 1993; Cherny, Coyle, & Foley, 1994 a, b; Gregory, 1994; Lindholm & Eriksson, 1993; Rawlinson, 1986).

Morse and Carter's (1995) work is inconsistent with other literature on suffering, and with the researcher's nursing experience with people with chronic and terminal illness. Initially one could attribute this lack of consistency to semantics, but perhaps it is more

than that. Perhaps it is because the work is based on the case of one who suffered greatly, but who had the possibility of a long-term future, something that people with progressive life-threatening illness, especially in the terminal phase, do not have. The assertion that suffering is absent in all three stages of what is called enduring (Morse & Carter, 1996) is questionable too. However, the assertion seems to be especially incompatible with the stage of enduring to die. It is acknowledged that the activities Morse and Carter associate with "enduring to die" are often a part of the terminal stage of an illness, but the person can be doing these activities while suffering.

The researcher questioned the value of differentiating between the concepts of enduring and suffering to the extent that Dewar and Morse (1995), and Morse and Carter (1995, 1996) do. Their research may confuse nurses who care for people who suffer. In regard to the present study, it was felt that their research did little to contribute to the body of knowledge pertaining specifically to the suffering of people with progressive, life-threatening illness, or to the way in which nurses, in particular palliative care nurses, choose to respond to such suffering.

Summary

The literature review in Chapter 2 provided a current picture of suffering from a variety of disciplines. Many of the authors described the nature of suffering: definitions, characteristics, and how health care providers can respond to suffering. Nursing research has been limited, but has been increasing over the past 20 years. Studies by nurses have been done from the perspectives of patients, and of nurses. Nurses' perceptions of and responses to suffering have been studied hypothetically, and to a lesser degree from real experience. These nursing studies were done in a variety of practice areas, but not in

palliative care where there is a significant amount of suffering, suffering that is perhaps

quite different from the suffering of acute illness or injury. Qualitative research around the

experience of palliative care nurses would be valuable for an expanded perspective of

suffering in terminal illness, improved nursing interventions with people who are suffering

in palliative care, and in helping to reduce the occasions where people's suffering compels

them to ask for hastened death. In Chapter 3, the method used for the study will be

described.

CHAPTER 3

RESEARCH METHOD

Introduction

The design selected for a study should be determined by the nature of the research question (Strauss & Corbin, 1990). Qualitative research methodology is employed to gain knowledge and develop theory about phenomena from an inductive approach (Morse & Field, 1995; Strauss & Corbin). Qualitative methods are suited to research questions which seek to explore the real world of persons through the insights and meanings they find in their own experiences, rather than through statistical analysis.

The method initially selected for the research was grounded theory. Grounded theory (Glaser & Strauss, 1967) is a qualitative method which attempts to discover what transpires in a given context and the processes persons use to respond to these situations (Burns & Grove, 1993; Morse & Field, 1995). Grounded theory was appropriate for the research questions because it was reasonable to assume that psychosocial processes were inherent in the ways palliative care nurses met the challenges of caring for people who were suffering. Data analysis did not result in a clear description of integrated psychological or social processes. Therefore, because the results did not meet the definition of a grounded theory, it is more accurate to say that the a qualitative method, based on grounded theory, was used for the research. Grounded theory is particularly useful when little is known about the phenomenon being studied or to gain new understanding into a well researched area (Morse & Field). Most studies on nurses' perceptions of suffering have been inadequate in their approach, and there are only two studies (Flaming, 1995; and Steeves, Kahn, & Benoliel, 1990) that have looked at this

using qualitative methods. No studies have specifically addressed the perceptions of palliative care nurses about the suffering of their patients. As well, although the nature of suffering has been well documented, it was hoped new knowledge would come out of this study about suffering in palliative care.

<div align="center">Selection of Participants</div>

<div align="center">Sample Selection</div>

Grounded theory research uses theoretical sampling which Strauss and Corbin (1990) define as "sampling on the basis of concepts that have proven theoretical relevance to the evolving theory" (p. 176). Participants were selected for their ability to give beginning information about the phenomenon being studied. The data from these interviews were analyzed for emerging concepts, and additional data were sought to develop them in more detail through the increasingly abstract levels of categories. The scope of this study did not allow for further theoretical sampling so that data collection and analysis could continue through to category saturation and conceptualization. Such information would be gained by choosing more deliberately the subsequent participants for their ability to fill gaps in the theory that is forthcoming from the data. Theoretical sampling would continue until all categories became saturated, that is, when no new information was being gained, the categories were well-developed or dense, and relationships between categories were well established.

In qualitative research, the number of participants is small relative to sampling for quantitative research and may appear to be unrepresentative of the population being studied. However, the objectives of grounded theory are for concepts to be representative of the phenomenon in question and to be as widely applicable as possible. This was

achieved by having a data collection large enough for multiple examples of the concepts of the phenomenon being studied to occur. The findings are not generalized to a larger population; rather, the conditions under which they exist are specified.

<u>Selection Criteria</u>

The sample of eight participants for this study was an adequate number to achieve a degree of representativeness of concepts and applicability of findings, acceptable for the level of a masters thesis. Participants were chosen who met the following criteria:

- Were registered nurses.

Rationale: Registered nurses have completed education programs whose requirements are such that their graduates can be expected to have an adequate level of nursing knowledge, an ability to think reflectively about their experiences, and an ability to articulate those experiences in a way that would benefit the research. As well, registered nurses constitute the greatest number of staff in palliative care programs and often have 24 hour contact with patients.

- Had worked on the palliative care inpatient unit of a large teaching hospital for at least one full year, or had worked in the role of primary nurse for palliative patients in the home care service of a regional health board for at least one full year.

Rationale: This minimum amount of experience would allow for adequate time to have been able to put into practice their palliative care education and to have cared for patients who were suffering. Having participants from both institutional and home care settings would make the findings of the study more widely applicable.

The researcher attempted to select participants who reflected a variety of characteristics, such as age and length of palliative care nursing experience, which would make the findings more widely applicable. Demographic data that were tabulated included: age; gender; cultural identity; religious, spiritual, or philosophical affiliation; level of nursing education; years of general nursing experience; years of palliative care nursing experience; place of employment (the hospital or the home care service); and palliative care experience in another setting. (Please see Table 1, page 32.)

Selection Procedures

The hospital and the home care service were chosen as research sites because they were recognized as providing specialized palliative care services. The researcher first met with the Nurse Manager of the hospital palliative care unit to explain the study, selection criteria of nurses, and recruitment strategies. Recruitment strategies included posting notices directed to the staff nurses outlining the study and selection criteria. This was followed by a meeting with interested staff to present the study in more detail and answer their questions. The researcher left phone numbers for herself and her thesis committee chairperson on the posted notices, and with the Nurse Manager and staff to encourage them to call the researcher or her committee chairperson with questions. The staff let the researcher know of their interest in participating through the Nurse Manager, with whom the researcher maintained contact. With the agreement of the Nurse Manager, simultaneous application for approval of the research was made to the hospital's Research Advisory Committee and the Behavioural Research Ethics Board of the university where the researcher was enrolled in the graduate nursing program.

Table 1. Demographic Characteristics of Study Participants

Characteristic	N
Gender	
Female	7
Male	1
Range of Age in Years	30-63
Ethnic/Cultural Identity	
Canadian	3
Caucasian/Canadian	3
Anglo-Saxon/Canadian	1
Irish	1
Religious/Spiritual/Philosophical Affiliation	
Evolving/Christian background	1
Protestant	1
Baptist	1
Roman Catholic	3
None	2
Level of Nursing Education	
Diploma	2
Baccalaureate	4
Masters	2
Current Place of Employment	
Hospital Inpatient Unit	4
Home Care Service	4
Range in Years of Nursing Experience	7-32
Range in Years of Palliative Care Nursing Experience	4-16
Types of Palliative Care Experience	
Inpatient Specialized Unit	5
Community (generalist model)	4
Independent Hospice	1
Shift Care (24-hour in-home nursing)	4
Other: Long-term Care	1
Oncology	1

Note: N = 8

The process for accessing nurses in home care was similar to that described above. The research application process of the regional health board specified that the research proposal be submitted and reviewed by the Research Officer, who then presented it to the appropriate nursing personnel for their approval. The researcher and her committee chairperson were available by telephone or to meet with any of those people to further explain the study and answer their questions. After approval was granted, the researcher discussed recruitment strategies with nursing management, and used ones similar to those outlined for the hospital palliative care nursing staff. Simultaneous application for approval of the research was made to the Behavioural Research Ethics Board of the researcher's university.

<div align="center">Data Collection and Analysis</div>

Research conducted with the grounded theory method is not based on frameworks from previous research; instead the framework comes from the data, and can later be compared to other works if appropriate. Grounded theory development can involve both inductive and deductive processes because the concepts, constructs, and hypotheses all arise from (that is, they are grounded in) the data, after which the hypotheses can be tested (Burns & Grove, 1993; Field & Morse, 1995; Strauss & Corbin, 1990).

The procedures for data collection for grounded theory can include observations, interviews, and review of records and documents (Burns & Grove, 193; Field & Morse, 1995; Hutchinson, 1993; Strauss & Corbin, 1990). In this qualitative study, personal face-to-face interviews were used because that was the best way for the participants to share their experiences as palliative care nurses caring for patients who were suffering. The interviews were held in comfortable, quiet areas at the participants' workplace.

Comfort with the audiotaping equipment was facilitated with an introduction during which the researcher began to establish rapport with the participants by expressing appreciation for the participants' willingness to share their experience, and with a friendly exchange of information about each other's backgrounds.

The researcher conducted a 1 to 1-1/2 hour interview with each of eight participants, and a second interview with three of the participants. The researcher had prepared a number of open-ended questions based on the literature and her experience to guide the interview, but her use of these questions was limited. Because the study was based on grounded theory, the researcher tried to be open and sensitive to what the participants were conveying in the interviews, and to respond with thoughtful questions that would encourage participants to share more of their perspectives. The interviews were audiotaped and transcribed by the researcher, who did an initial analysis of each transcript as soon as possible after the interview, before conducting another interview. Confidentiality of the taped interviews and transcripts was assured by using code numbers rather than the names of the participants, by limiting access to the documents, tapes, disks, and transcripts to the researcher and her committee chairperson, and by keeping all items locked in a safe place when not in use. Data on computer hard drive was accessible only by password.

Analysis of the data involved three kinds of coding procedures which corresponded to theoretical sampling, introduced earlier in this chapter, of which there are also three types. Open sampling was the first stage of theoretical sampling, and data collected through this process was analyzed by open coding. At this point, the researcher looked for features that were repeatedly present or notably absent, which were questioned

and compared, and grouped into categories according to their theoretical relevance. Relational or variational sampling, which was more directed than open sampling, was guided by the theoretically relevant information that was forthcoming. Participants were interviewed with the purpose of developing the categories at a deeper level and to make connections between them through axial coding of the data - to make the categories more dense. This process continued until the researcher realized the need to fill in some gaps in the categories and to verify relationships between categories. Discriminate sampling is done to deliberately choose participants who are able to contribute to the objectives of closing the gaps and verifying relationships. In this study, participants who did second interviews, enacted this role. Data analysis continued with selective coding. Theoretical sampling and analysis normally continue until the categories are saturated and their integration into a framework can be completed.

<div align="center">Issues of Rigor</div>

It is recognized that while qualitative and quantitative research both use legitimate scientific methods, the differences in approach necessitate that they be evaluated by criteria appropriate to the method (Burns & Grove, 1993; Guba & Lincoln, 1994; Leininger, 1994; Sandelowski, 1986; Strauss & Corbin, 1990). Burns and Grove write that the first step in ensuring rigor is that the researcher carefully adheres to the philosophy of the qualitative method being used - in the case of the present study, the researcher followed the grounded theory method as espoused by Strauss and Corbin. In addition, the researcher considered all the data collected, endeavoured to let go of her own established views, and was open to new ideas coming through from the data. Sandelowski explains four criteria by which to further judge qualitative research:

credibility rather than internal validity; auditability versus reliability; fittingness instead of external validity; and confirmability over objectivity. Leininger also provides guidelines that complement those of Sandelowski.

One can be confident of a study's *credibility* (Sandelowski, 1986), or believability (Leininger, 1994), when people recognize their own experience of the same thing in the findings, or when other researchers or readers recognize the experience only from what they have read in the study. The results of this study were read by six seasoned palliative care nurses from hospital and home settings of services other than those of the participants, and confirmed the similarity to their own practice. Researchers who do qualitative work increase the value of the findings by carefully documenting their own experience while carrying out the research in which they can become personally involved with the participants or the subject matter. The background of the researcher is significant to grounded theory, and must be acknowledged and "bracketed" (Hutchinson, p. 187). In this study, the researcher had knowledge and experience as a nurse in palliative care which could have influenced the study. To avoid a potential bias, the researcher kept a reflective journal throughout the research process, maintained an audit trail (see below), and received the guidance of an experienced committee. More positively, the researcher's knowledge and experience in palliative care enhanced her own sensitivity to the data, and the increased the comfort of both researcher and participants during the interviews.

Auditability is evidenced through consistent documentation of the "decision trail" - the researcher's detailed notes of all steps taken from initial interest in the topic to theoretical conceptualization (Sandelowski, 1986). It is a process which, if followed by a second person, would show that the researcher's conclusions are logical. This

researcher's audit trail was comprised of the journal; field notes (which included observations and impressions from the interviews, written as soon as possible after each interview); and memos to record ideas arising from the data analysis.

Fittingness or applicability is demonstrated through theoretical sampling, when participants and data are representative of the particular group being studied (anyone with the experience is considered representative). As well, the findings should fit the data from which they came and real life contexts outside of the study (Sandelowski, 1986). Fittingness has features of what Leininger (1994) calls meaning-in-context and transferability. In this study, the participants were representative of the group being studied, and the results compared favourably to the literature, and to the experience of other palliative care nurses.

Confirmability replaces the quantitative criterion of objectivity (Sandelowski, 1986). The nature of looking at human life experiences precludes qualitative research from being neutral. It is the neutrality of the findings themselves that is confirmed. The researcher does become involved with the participants and the subjective data gained from them, and as Leininger (1994) suggests, the researcher went back to the participants (three of them) to confirm that the findings and interpretation of the data were accurate. Leininger also lists recurrent patterning and saturation as criteria (described earlier in this chapter), and in this study, there was ample evidence of recurrent patterning.

Limitations

The nature of the subject of suffering in palliative care led to discussion during the interviews of the sensitive and controversial topics of sedation, assisted suicide, and voluntary euthanasia. The participants discussed these matters briefly, but did not

elaborate. They may not have felt comfortable talking about their thoughts in more detail, and as the focus of the study was their experience in caring for people who are suffering, the researcher did not pursue these issues. The researcher wanted to ensure that the nurses did not feel compelled in any way to give information that they did not want to give. The researcher was aware that the absence of information about these sensitive matters could result in a less complete picture of the nurses' experiences with the suffering of palliative care patients, but the researcher was committed to the priority of upholding the rights of the participants in the study.

There have been many cutbacks in the provincial health care system, and one result is that nurses have more work to do and less time to do it. Therefore the time the nurses had to participate in this study was somewhat limited. Although the researcher had offered to be available at times which might have been less busy or otherwise more convenient for the nurses, such as weekends, or evening and night shifts, the nurses chose to meet during daytime shifts. They did not choose the option of meeting when they were not on duty.

The study was the researcher's first experience with qualitative research. Her skills for data collection and analysis were limited, and therefore the quality of the findings is at a beginner's level.

The timeframe for the research was another limitation because the project was conducted within the confines of a graduate program. At the time of the second interviews, members of the provincial nurses' union were involved in various job actions, which prevented the researcher from doing further interviews. In addition, the researcher

was required to move from the province unexpectedly, and did not have the opportunity to resume second interviews with the participants.

Ethical Considerations

It was not anticipated that taking part in the study would harm the participants in any way. Nevertheless the participants were sharing personal and confidential information with the researcher, so they received assurances that what they revealed would be kept private and their rights as human research subjects would be protected. To ensure this the researcher adhered to the following protocol:

1. Ethical approval for the study was obtained from the university's Behavioural Research Ethics Board, from the Research Advisory Committee of the hospital, and from the Research Officer and appropriate persons of the regional health board.

2. The researcher had telephone conversations as necessary, and meetings with the persons responsible for research in the agencies and the staff nurses to explain the purpose of the study, what would be expected of participants, and how confidentiality would be ensured. The voluntary nature of participation was emphasized.

3. The written consent for participation explained the purpose of the study, what would be expected of participants, and how confidentiality would be ensured. The voluntary nature of participation was emphasized.

4. Documents, tapes, disks, and transcriptions were coded to remove any identifying characteristics. Tapes were erased as soon as they were transcribed. Access to the tapes, disks, and transcriptions was limited to the researcher and her thesis committee chairperson. Documents, tapes, disks, and transcripts were locked in a secure place when not in use and data stored on computer hard drive was accessible only by password.

Summary

In Chapter 3, the method of grounded theory was described and the rationale for using it to study the research questions was clarified. A qualitative method based on grounded theory was used to explore the real world of palliative care nurses: the processes they use to help people who are suffering; the insights and meanings they have gained from that experience; and their own professional and personal responses to patients' suffering, in order to better understand the suffering of palliative care patients. Sampling, participant selection, procedures for data collection and analysis, criteria for evaluation of qualitative research, limitations to the research, and ethical considerations were also explained in relation to the study. Copies of the letters of information and the informed consent can be found in Appendixes A to C. A copy of the interview guidelines is in Appendix D. In Chapter 4, the results of the study will be presented.

CHAPTER 4

RESULTS

Introduction

The purpose of this study was to explore the perceptions palliative care nurses held

about their patients' suffering. The nurses described situations of suffering, how they

knew patients were suffering, how they responded to patients who were suffering, and

how patients themselves responded to their own suffering. The nurses also discussed the

personal impact of caring for patients who were suffering.

In this chapter, the data will be presented under the following headings: suffering

in the context of palliative care; recognition of suffering; the three realms of suffering:

bodily discomfort, interpersonal discord, and personal distress; strategies that patients and

nurses use to respond to suffering; conditions that influence alleviation of suffering;

outcomes of attempts to alleviate suffering; and the personal impact of caring for patients

who suffer. It should be noted that only plural and feminine pronouns will be used in

reference to the nurses, in order to protect the identity of the male participant.

Suffering in the Context of Palliative Care

The nurses in this study described patient suffering within the context of palliative

care. Palliative care is offered to people with a limited life expectancy, according to a

philosophy that emphasizes quality of life and peaceful death, and can be provided at home

or in hospital. Quality of life is maximized through symptom management and an open,

supportive approach to personal issues that contribute to suffering. Death is an expected

outcome and is addressed in a realistic and sensitive manner to help patients come to terms

with their dying, and to be able to let go and die in peace. All of these features

differentiated palliative care from other approaches to care that focus on cure and on the future. As one nurse summarized, "...just about everything else is about hanging on."

Nurses in this study, working in both hospital and community palliative care, thought that palliative care nurses may be more attuned to patient suffering than other nurses because of their knowledge of palliative care philosophy and principles, and their personal interest and commitment to palliative care. Nurses who provide inpatient or home care within structures that do not embrace a palliative care philosophy, may not have the knowledge, skills, time, or inclination to care well for patients who are suffering. The nurses stressed personal suitability:

> I think that not everybody can do this job that we're doing. Not every physician could do it. Not every nurse could do it...besides the physical symptoms...some nurses and doctors don't want to talk about these things; it's uncomfortable to talk about suffering...so there are some people who are just less suited to it...So I think staff selection is important and you should have very insightful people who are more self-aware. And this allows nurses to reach out to someone in a greater way.

Central to the context of palliative care are the factors of progressive, life-threatening illness and expected death. Palliative care is provided specifically to patients whose illnesses are usually no longer curable, and who have agreed to palliative management of their physical symptoms and support for dealing with the personal issues resulting from their disease. All human beings will die eventually, and most people are aware of this, at least theoretically. For palliative patients, the inevitability of one's death is sharpened and felt more deeply because of the reality of their prognoses, and may be part of their suffering. As one nurse expressed, "Death becomes real for them in a way that it isn't for us. They *know* their candle is going to eventually go out. But we sort of think our candle might burn forever."

Palliative patients come to the realization of their impending death in different ways. Some patients become aware of this gradually, beginning at the time of their diagnosis, or at some other point during their active treatment. They may experience times of hope for remission, and times of what may appear to be denial of their prognosis. Moments of recognition may be filled with fear, which they sometimes choose to 'set aside' for awhile until they can face the fear again, or because they want to protect loved ones from the reality. Other patients may be suddenly jolted into reality, even if they thought they had faced their prognosis 'matter-of-factly'. One nurse described a situation in which the patient had agreed to a do-not-resuscitate (DNR) order for her being placed in her home. Several weeks later, when she was able to get out of bed and wheel herself around the house, she came face to face with the written DNR instructions, which had been put on the fridge in full view for the nurses and other caregivers. Seeing the order unexpectedly, abruptly brought back to her the fact that she knew death was imminent, an idea that had been so painful to her that she tried to focus instead on day-to-day pleasures and quality of life. She was upset for three days, and with the support of the nurse was able to come to accept her situation once again. When patients finally acknowledged their imminent death, the nurses often found the patients felt freer, and that they were better able to express themselves. Other patients became angry or despondent.

The magnitude of the difficulties palliative care patients face is heightened by the urgency to resolve problems before their time runs out, as illustrated by this situation:

> She was fighting against time to try and rebuild that (relationship). So there was a lot of stuff going on with her and I could see her trying to race against time. I don't think she felt there would ever be enough time and I think that's part of where that suffering came from.

Recognizing Suffering

The nurses described situations in which they believed patients were suffering; however, they had difficulty succinctly defining suffering, or articulating exactly how they knew patients were actually suffering. Patients did not always use the word "suffering", and older patients were more inclined to use the word 'suffering' than younger patients, possibly because they had more life experiences that they considered to be suffering. The nurses seldom used the word 'suffering' in describing suffering, and they said they did not usually ask patients if they were suffering. The nurses thought that it was not necessary to be so explicit because it was most important was that needs were identified, confirmed by patients, and addressed. The nurses intuitively "knew" when patients were suffering because of their work experience: "How do I know? Sometimes I think you can almost feel it, you can just feel it."

Three Realms of Suffering

The nurses explained that patients who were suffering struggled with three types of suffering: bodily discomfort from a wide range of symptoms, interpersonal discord with loved ones, and their own personal distress. Individual patients responded differently to apparently similar situations, indicating that patients' perceptions of what was happening were key to identifying problems as suffering.

<u>Bodily Discomfort</u>

Suffering as bodily discomfort arose from many physical symptoms associated with progressive, life-threatening illness, and reactions to those symptoms. The nurses most often mentioned pain, but also included other symptoms such as nausea and dyspnea. The nurses recognized physical suffering through evidence such as moaning or screaming,

body language that showed tension or restlessness, facial expression, and verbal communication. Less intense symptoms did not necessarily produce suffering, but did lead to suffering when they began to interfere with patients' daily life or cause emotional distress. Symptoms gave rise to feelings which were directly related to that bodily discomfort, and were distinct from other emotional issues patients may have been dealing with. One nurse explained:

> I think maybe the emotional pain is what makes you, you. The response back and forth. And what does the pain mean to you? Does it mean the cancer is spreading? Does it mean your life is out of control? Does the pain mean you can't go out to dinner tonight or that you can't go out to dinner ever again? I think everybody has their own interpretation of pain. And I should say that should be symptoms, not just pain. It could be shortness of breath. If you're so out of breath you feel it's out of control, and you get panicked, part of that fear is emotional for sure. I don't think that it's just the respiratory response, I think it's the emotional response as well to whatever the symptom is. It's scary and things are out of control and it escalates and you don't know what to do about it...everything else can be great. I mean no issues anywhere else.

Although the nurses described discomfort on a physical level, they believed the body was more than just tissue and bone. The body was intimately connected to the person, the sense of self. Deteriorating abilities and appearance threatened that sense of self when patients felt despair about their bodies. One nurse spoke of a young woman with cancer who had been a teenage model: "She looked at herself in the mirror the other day and said, 'Look at me. I look like an old lady.'" Another nurse, who had been describing a young woman whose spirit she had found to be particularly inspiring, explained how the patient felt when she became confined to bed and dependent on care from others: "It was about two or three days before her death. She said, 'I have no sense of myself anymore.' And she looked down at her body and said, 'This isn't me. I don't want this anymore.'"

Interpersonal Discord

The nurses thought that interpersonal discord in patients' emotional and social relationships created great suffering. Common examples were patients' relationships with family members or friends involving recent or long-standing conflict such as rejection or unforgiveness. Interpersonal discord was also caused by patients who chose not to attempt reconciliation, or who maintained they did not care about the relationship. In these instances, the nurses perceived that the patients still suffered, and caused suffering for others as well. The nurses believed it was usually important for patients to resolve differences before they died, especially if they felt responsible for the problem. Resolution did not always happen, as with this young man:

> He also had a really horrible background - he was a thirty-ish year old patient, and he said, 'I can count up 53 foster homes I've been in.' He reunited with his real mom sometime around the time of his diagnosis, but things didn't go very well. So he needed that family love and he didn't have that. He certainly had a wonderful partner, and a couple of other good friends. But he was really aching for that family love as well. So he had to deal with his past life. I don't think he ever did, as hard as we tried with him, with a life story and that, to resolve that component. I really don't think he did.

In addition to situations of conflict, the nurses thought that interpersonal relationships that were loving and positive also created interpersonal discord leading to suffering. In such situations, nurses saw patients suffer because of the close relationship and the thought of leaving loved ones behind. Changes in family members' roles and relationships, necessitated by patients' illness could be problematic as well. Relationships could be a source of concern for patients for other reasons; the nurses believed that patients suffered because of their worry about the well-being or financial circumstances of family members after they died, as in this situation:

But a big part of her suffering was the fact that, her husband was older and he had a drinking problem. She was the major caregiver of this fellow and a big concern was who was going to look after him when she died. She also had a son who was a drug addict and he kept wanting to visit her and she let him visit in the beginning. But she was afraid he was just coming in because she had drugs and he was trying to get access to her drugs. So she was worried about that...So that increased her suffering in her dying process. She did not want to die until she was sure the family was okay, that the situations were taken care of...

Personal Distress

The nurses discussed the suffering of personal distress that occurred on a spiritual/philosophical level - struggles of an intimate, personal nature, and issues specific to patients' own characteristics, beliefs, and choices. For example, some patients were afraid of dying; others were unhappy with some aspect of their life and were trying to come to terms with that. In the following situation, the nurse identified age as a factor that influenced suffering; the patient felt it was unfair that she had to die so young:

And she suffered till the day she died. I think there were some things resolved in her life with her mother, but I definitely feel that age has a large component to do with suffering. And for her being in her early 30s there was so much loss there, so much that was incomplete in her life that she felt she could have, should have, would have done...But it was the whole realm of simply her dying too young. Now, what is too young? That's all very subjective and for her that was what was happening with her at the time, she felt she was dying too young herself.

Personal distress could result from issues of a more traditional religious nature. Some patients felt guilty about having left the faith in which they were raised. Patients who did not belong to a formal church sometimes felt they would have had more comfort and support if they had. Others wondered about their own role and their God's role in causing their illness:

And talking about their relationship with God and their religion, sure they do, sure they do. Wanting, I think, a lot of reassurance about the fact that now, it wasn't because I was bad that God's punishing me. Wanting someone else to say, 'You know I don't think God works that way.'

The nurses believed that a lack of meaning caused some patients great personal distress. Some patients were concerned about their own contribution to society, or had questions about the meaning of life in general. Some had been on a quest for meaning all their lives, while to others a deep sense of meaning was not important at all. For many palliative patients, a life-threatening diagnosis gave rise to the need to look for meaning in their illness or in their lives, as they adjusted to the changes their disease brought to their lives, or as they prepared to die.

The Interplay of the Bodily, Interpersonal, and Personal Realms

The nurses offered examples where physical symptoms alone resulted in suffering. They spoke of numerous situations of suffering that had emotional or spiritual issues at the centre, unrelated to physical symptoms. However, the nurses also described situations where physical, emotional, and spiritual suffering were all related; they referred to this as "total pain". One nurse thought of suffering as a spiral, which showed the importance of trying to resolve each aspect of suffering simultaneously:

I use the word spiral. The pain's escalating, or it could be just sort of a whirlpool. Everything falls in and it just really escalates. And that, when it's the emotional that's so painful, it makes that physical pain worse. It all ties in. And then the physical pain makes your coping with the emotional component worse too. So, it definitely ties in.

Strategies for Alleviating Patient Suffering

The nurses described approaches, or strategies, that patients used to help themselves in their struggle to deal with the suffering of bodily discomfort, interpersonal

discord, and personal distress, and thus achieve bodily comfort, create interpersonal harmony, and find inner peace. The nurses frequently used the word "struggle" in their descriptions; for example, "Sometimes we see them come to their peace, but there's a lot of struggle prior to this time." "Struggle" indicated the great difficulty patients had in trying to overcome suffering. The nurses spoke of the patients' deliberate effort, hard work, hope, and progress as they strove to alleviate their suffering. Alleviation of suffering required work on the part of patients and often, receptivity to the participation of others, such as nurses, in that work. One nurse portrayed the dual roles in this way:

> I'm trying to imagine people that I haven't discussed suffering with...Some people are ready, some people have done so much work it just astounds me...working through all kinds of things. Working through a life review, or relationships - some people have really done a lot...I think it is the human condition, I think there will always be suffering. And I don't think you can take it away from someone unless they want to give it away. If they can give it away, or let it go, then perhaps. But I think it's the individual's work to do. You can support them to do it, but you can't do it for them.

Patient strategies were complemented by what nurses and others did for and with patients. (This study focused only on patient and nurse strategies.) The nurses emphasized that most of the work required to alleviate suffering had to be done by patients themselves. Patient and nursing strategies often enabled patients to overcome their suffering, though in the nurses' experience, suffering was sometimes only reduced, not eliminated. As well, causal conditions for suffering could recur, making relief from some suffering only temporary. Both patients and nurses also used strategies to try to prevent suffering. The nurses did not believe that all palliative patients necessarily suffered.

Patient and nurse strategies were sometimes specific to one of the three realms - physical, interpersonal, and personal suffering, but a similar approach might also be used in another realm for a different reason. The nurses used a variety of strategies to help

patients surmount their suffering. It was necessary for all nursing strategies to be embued with one most important quality, which the nurses identified as compassion. They saw compassion as "...putting yourself in their place and thinking how you would feel if you were in that position" and "...if you had to put it (compassion) all into one word it would be to listen. Just to listen. Listen to what they need and what they feel." Many nurses characterized compassion using the same words they used to describe the nursing care they gave: being gentle, giving choice, exploring what is important to the patient, and personalizing care.

Nursing strategies figured more prominently than patient strategies in overcoming suffering related to bodily discomfort. During interpersonal discord and personal distress, patient strategies became more dominant and nurse strategies decreased. For such suffering, nurses acted primarily as facilitators, because they believed the work to alleviate suffering that was less tangible could only be done by patients. (Please see Table 2, page 51, for an overview of the strategies used by patients and nurses to alleviate suffering.)

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Strategies for Achieving Bodily Comfort

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Overcoming the suffering of bodily discomfort by achieving comfort required different contributions from patients and nurses. The nurses explained that patients participated by making decisions about investigations and treatments.

Strategy Used by Patients for Achieving Bodily Comfort

Making decisions. The nurses indicated that it was important to many patients to make decisions in the management of their illness. As well as being a means to achieve bodily comfort, having this autonomy served to ease some of patients' personal suffering because it helped preserve a sense of self and a sense of control in overwhelming

Table 2. Strategies Used by Patients and Nurses to Alleviate Patient Suffering

Strategies for Achieving Bodily Comfort

Strategy Used by Patients	Strategies Used by Nurses
Making decisions.	*Communicating information.* *Supporting choice.* *Doing for.* *Advocating.*

Strategies for Creating Interpersonal Harmony

Strategies Used by Patients	Strategies Used by Nurses
Optimizing relationships. *Organizing affairs.* *Leaving memories.*	*Facilitating communication.* *Facilitating coping.* *Coordinating resources.*

Strategies for Finding Inner Peace

Strategies Used by Patients	Strategy Used by Nurses
Having a positive attitude. *Maintaining hope.* *Achieving goals.* *Resolving spiritual questions.* *Finding meaning.*	*Facilitating self-awareness.*

circumstances. Decisions about treatment options were made wholly or in part by patients, and were informed by information provided by nurses and physicians. Many patients preferred family members to be involved in care and decision-making as well. Nurses respected, and sometimes needed to encourage, such involvement. It was also important for patients to retain control over more ordinary, day-to-day decisions that

affected their physical comfort, with nurses integrating those patient preferences into care, as this nurse did:

> And another way I try to minimize her suffering is giving her a lot of control - 'When would you like to be washed?' and try to fit it in with other patients I have...One thing that she said to me is that, 'You know when I ask you for something you listen and give me choice.'

The nurses remarked that some patients were too unwell or had little interest in making decisions beyond agreeing with the suggestions that nurses or physicians thought were best. Other patients found it difficult to make decisions and lacked confidence in the choices they made about their care. One nurse spoke about a patient who chose to stop taking protease inhibitors (drugs used in treatment of HIV/AIDS) because of the side effects. When his viral load increased, he agonized over whether he had done the right thing, and had great difficulty deciding if he should try a new combination of medications.

The nurses related examples of patients who tried alternative or complementary therapies, or travelled great distances for unproven treatment, hoping for either a miracle cure or more time. Hope brought some meaning to patients' lives, but the nurses were not always comfortable with such choices because they saw patients spending large amounts of money they could not really afford. As well, some nurses believed that patients focused too much on fastidious treatment routines rather than spending quality time with their families. However, the nurses tried to be as supportive as possible.

The nurses discussed how patients made treatment decisions in response to changes in their physical condition in order to enable themselves to continue to do what they wanted to do, which lessened their suffering. One patient, who had accepted that she was palliative, continued to take what some care providers considered to be acute-care

treatments: platelet and blood transfusions. While this patient had chosen not to aggressively treat her disease, the interventions enabled her to live long enough, and with enough strength and energy to do what she wanted to do before she died.

Strategies Used by Nurses for Achieving Bodily Comfort

Four nursing strategies: communicating information, supporting choice, doing for, and advocating, enhanced patient decision making, and helped ease the questions, concerns, and suffering of bodily discomfort.

Communicating information. The nurses believed that accurate and relevant information was crucial for patients to be knowledgeable and involved in management of their illness. As explained above, making decisions about treatment to alleviate suffering and retaining some control was important for patients who were suffering from bodily discomfort. Clear communication was essential to the exchange of such information between patients and care providers, and nurses facilitated that process. The nurses provided key facts and explanations about treatment. Equally important were the nurses' responses to patients' questions and their feelings about what was happening with them. For example, based on past experience, some patients anticipated problems with their medications. They often had misconceptions and fears about addiction when using drugs such as morphine. The nurses tried to clarify and correct misunderstandings with accurate information. The nurses felt it was imperative to listen to patients' descriptions of their pains or symptoms because each patient's experience was unique. Some patients were willing to compromise on their pain control if they felt it would keep them more alert and energetic. Patients often interpreted their pain in relation to their disease trajectory; for example, they believed that the worse their pain was, the closer they were to death.

Nurses considered such patient perceptions when making recommendations about treatment. At the very least, understanding the patients' point of view helped nurses' understanding of patient decisions they did not agree with, as shown in this example:

> Pain is such a complicated issue. You can get it under control but you have to work with the client. We had one man who would only accept - I work on a scale of zero to five in the degree of pain that people have - and he would never let the pain be less than a two, because he felt that if he accepted full pain control then he would die. And if he was still a plus two he knew he was still alive and he would not accept more than enough medication to get him to a plus two...You have to work with that client and allow him to die the way he wants to die...

The nurses emphasized the importance of patient education in management of terminal illness and alleviating suffering. The nurses explored patients' knowledge and understanding of problems that needed attention, and then provided the necessary teaching and possible solutions for patients to consider. The nurses did this gradually, getting to know patients and their families, and presenting the information with attention to timing and pacing of information. The nurses also considered patients' understanding of their advancing disease and what their priorities were for the time they had left. The nurses sometimes acted as guides, indicating to patients and families what they could expect as the illness progressed and making suggestions for care. One nurse commented:

> I can remember another client who died and the wife said to me, 'You were always kind of one step ahead.' And I said, 'Well it's not really that I was one step ahead. It's just that I'm familiar with this part of the journey and so I have an idea about what might be coming up down the road. But if you haven't been down this road before, you just don't know where you're going to have a left-hand and a right-hand turn.' So, there are some things I can predict, but there's a lot that I can't because each one's different. So I think that I'm just a guide. I've been on the road before with other people so I think that's how I'm helpful to people.

Supporting choice. The nurses supported informed choice for patients by ensuring patients' knowledge was as complete as possible so they could choose the best options to

achieve bodily comfort and reduce their suffering. Despite having informed choice,

patients often made decisions that did not resolve problems in the way the nurses wanted.

However, to be truly supportive of the idea of patient choice, the nurses continued to be

as helpful as possible, despite their different perspectives:

> And some people will go out being in pain when they really don't have to be. Again, as a home care nurse, I'm going to offer them options. I mean discuss, educate them to the best of my knowledge, and then allow them to make the decisions...So it's a process that doesn't always work out - some people suffer needlessly because of their choices. But if you've educated them to the amount of what you can do, and what medication can do for them, then you have to accept that they're just going to suffer and be there with them.

The nurses sometimes talked over treatment options with patients in advance, in

case the patients later became incapable of making decisions. These discussions resulted

when patients expressed fears of physical suffering, such as being in extreme pain or

respiratory distress, closer to the end of life. The knowledge that their symptoms would

be managed according to their wishes brought great relief, as was the case with a patient

with ALS:

> And she was asking for this (euthanasia) and we (the nurse and physician) spent a lot of time with her. And found out that really what she wanted was assurance that she wouldn't choke to death. And when she was given that assurance, that if the time came that they would sedate her, she was a different person...And we did in fact sedate her. And she died very peacefully.

Some nurses discussed sedation, a treatment used to ease suffering in situations of

extreme physical or emotional distress, restlessness, or to render patients unaware of death

from suffocation or a major vessel bleed. The nurses believed careful consideration of the

decision on the part of patients and families, nurses, physicians, and other team members,

was essential because large amounts of drugs were required, patients were unable to eat or

drink, and patients would no longer be able to interact with others. Decisions about sedation were ideally made when patients were fully conscious and able to contemplate deterioration in their condition - a time when sedation would be beneficial. Not all the nurses were familiar with the practice of sedation, and several nurses expressed discomfort with the practice because they did not feel they knew enough about why it was used or how it was done. Other nurses were knowledgable about sedation and felt it was an important treatment option in palliative care.

The nurses explained how they generally tried to foster independence in patients, and encouraged families to do the same for as long as was appropriate. Sometimes though, patients enjoyed being lovingly doted on, such as women who had always done everything for their families, and were receiving care for the first time in their lives. Other patients resisted such efforts, feeling they were being smothered. The nurses watched what was happening on an ongoing basis, encouraged a good balance, and intervened with suggestions and support when necessary.

<u>Doing for.</u> The nurses described how good management of the suffering of bodily discomfort is dependent on the nurse's knowledge and practical skills. Management began with accurate assessment and confirmation of physical symptoms, emotional, social, and spiritual issues. Assessment had to be ongoing throughout home care contact and during any admissions to inpatient palliative care. Nurses in both settings felt that because they spend more time with patients in comparison to other team members, that they were able to observe more, read notes from previous staff, and listen to what patients said. The nurses were also attuned to other indicators of physical suffering when patients could not consciously communicate, such as moaning with repositioning.

The nurses deemed it crucial to have a broad knowledge base and practical skills to be able to achieve and maintain a high degree of patient comfort. Knowledge and skills ranged from titrating opioids to therapeutic touch to good mouth care in the last days of life. This learning started when the nurses were new to palliative care, and continued for some time until the knowledge became "second nature":

> Well, I think, probably in the beginning when you start palliative care you're very focused on symptom management. That is just a critical part of palliative care and I think that if you really have good knowledge of symptom management that you can alleviate some of the suffering...For the first few years I really learned about symptom management. I mean I really know about...different types of pain and terminal restlessness or dyspnea or all those kinds of things. In the beginning, certainly peripherally I was kind and supportive to families, and interested in all the other things. But, I really focused on a lot on those physical tasks, I think of them as the technical part, and an important, critical part for sure.

The nurses believed that they and their colleagues should be committed to ongoing learning through reading journals, attending seminars, and learning from colleagues, which occurred to varying degrees with nurses in the study.

In addition to practical skills, the nurses stressed the importance of being aware of and arranging supports that complemented direct nursing care, such as homemakers, physical aids such as commodes, and interdisciplinary consultation such as occupational therapy. For some patients and families, just knowing these services would be available when they needed them eased their worry. Other patients and families did not always see the value of such support, and in hindsight expressed the wish that the nurses had been able to better convince them to use the services. This went beyond informing and allowing choice, to "persuading". Some nurses were comfortable with 'persuading, while others did not perceive it to be part of their role.

Advocating. The nurses in both the home and hospital settings saw themselves as advocates for suffering patients. Advocacy was needed most often in circumstances requiring intervention in treatment decisions for physical symptoms. Advocacy was also required in emotional or social situations. One nurse described her frustration with a situation in which the patient's physician was not adjusting the medications for the patient's physical pain and confusion, despite seeing her on a daily basis:

> And I just can't see anybody wanting to be like that. The dignity was gone. There was no respect for who she was. Allowing another living creature to go through this was just - ohhh (shudders)...I did a one-on-one with this physician and explained my concerns about this woman...

The nurses described scenarios that required decisions about bodily comfort that ranged from when to start low dose opioids, to the need for sedation for patients screaming in pain. In the situations presented, there was either a reluctance on the part of physicians (who were general practitioners) to increase dosing or change inappropriate medication, or the treatment plan was modified far too slowly. The nurses attempted to influence such medical decisions by sharing assessments and knowledge of treatment protocols, and through reasoned discussion. When these efforts were ineffective, the nurses approached other levels of authority such as nursing management, medical directors, or palliative care specialist physicians. The nurses felt particularly drawn to advocating for vulnerable patients, who were inarticulate, uneducated, or otherwise intimidated, and especially for those patients who did not have family or friends to advocate for them. Occasionally the nurses advocated on behalf of patients no longer able to communicate, such as when family members requested treatment or non-treatment contrary to the wishes patients had previously expressed.

<u>Strategies for Creating Interpersonal Harmony</u>

Nurses observed patients using three strategies to help alleviate suffering from interpersonal discord by creating harmony with others: optimizing relationships, organizing affairs, and leaving memories.

<u>Strategies Used by Patients for Creating Interpersonal Harmony</u>

<u>Optimizing relationships.</u> The nurses believed that most palliative care patients had relationships with family and friends that were very important to them. Patients enjoyed their solid relationships, which helped prevent suffering. Relationships that were not so good contributed to suffering, and while they could, patients wanted to improve mediocre ones, and attempt to mend broken connections. Reminiscing was an enjoyable way for patients and families to strengthen their relationships and provide pleasant memories of this time for the family after death. The nurses believed that patients themselves were likely to know the most effective way to approach relationship problems that needed to be addressed. They reasoned that patients knew their relatives and friends best, their characteristics, and ways of responding in given situations. One patient gradually dealt with his parents' negative feelings about his homosexuality and diagnosis of AIDS, and in the end, was able to be cared for and die in their home. Patients might set milestones for themselves to achieve reconciliation, for example, "Well I could really have peace of mind if I could speak to him. I haven't spoken to him in ten years since we had this silly fight." It was sometimes beyond the control of patients to do anything about such circumstances, but thinking about situations put patients in a good frame of mind, and at minimum gave them something to live for.

The nurses commented that the illness trajectory and expected death of patients changed individuals and relationships in families. Roles and responsibilities sometimes had to be relinquished and new ones taken on. The adjustment could be difficult and cause suffering for all involved. Strong emotions were often expressed. Patients and family members were often angry about the expected death. Families sometimes blamed patients and patients blamed themselves for their perceived role in causing their illness, such as smoking. Patients and family members often wanted to protect each other from bad news or their own feelings of sadness. They usually recognized the importance of talking with and listening to each other about their thoughts and feelings, but this did not always happen if individuals were unable or unwilling to do so.

In some situations, interpersonal harmony was not restored, but the nurses found that attitude helped patients deal with the resultant suffering. The 'right' attitude was not something specific, but was whatever worked for a given individual; the nurses' role was to help patients work through their feelings. Patients went to great lengths to try to mend relationships but sometimes did not succeed. Such results left some patients very depressed. Others, although they were tremendously disappointed, took a more realistic view and tried to get on with other things in life. For example, one patient had been estranged from her daughter for 20 years. When the woman learned she was dying, she went to great expense to find the daughter, even engaging a private detective. The nurse went on to explain, "And then she became resolved to the fact that it wasn't meant to be. And she didn't spend any more time belabouring the fact; she had put out all the feelers that she could."

The nurses described changes in established relationships that happened for better or for worse, and were beyond the control of patients. For example, as illness progressed, patients often became more isolated from friends, while at the same time, becoming closer to others who were more involved in their care. Again, attitude influenced how patients responded. Faced with a poor prognosis, many patients appreciated life more, focusing on the positive instead of the negative, and were grateful for what they did have rather than wishing for what they did not. This kind of thinking enabled these patients to better accept the changes that came with their illness, thereby creating interpersonal harmony, and also contributing to inner peace.

Organizing affairs. The nurses explained the importance that many patients put on organizing their affairs for family and others they were leaving behind. This included matters such as finalizing wills, closing businesses, and making funeral arrangements. The worry of leaving things undone for families added to patients' suffering, but completion of those tasks eased or even prevented suffering. Patients also did things that made a difference for their families while they were still living. One young patient had complicated symptoms and knew she would probably be dying within three months. Yet, she remained positive and tried to live life as fully as possible. She was supportive of her family and played a major role in planning her own care because they were too upset and disorganized to do it well. In that way, she was able to ease their suffering, enhance their relationships with her, and thereby easing her own suffering over the fact that they were suffering too.

Leaving memories. The nurses reported that many patients wondered and worried if loved ones would remember them after they died. To be remembered was of

considerable concern to many patients, who often did things to ensure they would be

thought of in a special way after they died:

> They're doing things as well, things like saying good-bye to her friends. There are
> completion things that are big, very significant to her, like tapes for her friends. So she
> would write down what she wanted to say and her husband would set up the
> equipment to tape. She's done quite a few, I don't know how many she's done. She's
> doing it for her special friends to say good-bye.

The nurses described patients who were parents with young children, to whom it

was important to leave remembrances like videos and letters for special occasions in their

children's lives. Others chose to trust that family members would ensure their children

remembered them because they were not comfortable with the idea of "reappearing" in the

future. Often, terminally ill parents struggled to decide what to tell their children about

their illness. One nurse related a story of a couple who did not tell their children how sick

their mother was, intending to tell them later. When the mother became worse,

unexpectedly, the children had to be told quickly, and they had little quality time together

before she died. Withholding information, keeping secrets, protecting children, protecting

loved ones, were all part of trying to keep those relationships as they were, or "normal"

for as long as possible, an attempt to create positive memories of the time of illness. The

nurses deemed that such an approach was not always realistic, and in the long term was

not always the best choice. The nurses tried to enable patients and families to consider all

benefits and drawbacks, and then allowed patients and families to decide their own course

of action.

Strategies Used by Nurses for Creating Interpersonal Harmony

The nurses explained how they enhanced the work of patients to create interpersonal harmony in these ways: facilitating communication, facilitating coping, and coordinating resources.

Facilitating communication. The nurses believed they had an important role in assisting patients and families in their relationships and in facilitating open communication regarding the illness situation:

> You're kind of the neutral third party and you can make it quite a safe environment for people to talk about feelings. Like, maybe somebody doesn't want to say it to somebody else because they're worried about how the other one's feeling. And sometimes if you bring it out into the light of day, you can really help people not find it so frightening.

The nurses used communication skills they learned in school and in their work to relate to patients who were suffering. As well, they stressed the value of considering the uniqueness of each patient and family, and the need to adapt their approach to individual circumstances:

> Sometimes I think you're kind of a chameleon because you're going in there trying to fit into their environment, kind of scout it out, find out what it is in their world is significant, and what can you do to help.

The nurses perceived that nurses new to palliative care were at times reluctant to communicate on the intimate level often required with patients who were suffering. With a good orientation to palliative care, and as they gained experience, these nurses became more comfortable raising and discussing sensitive issues. The nurses also explained the importance of the character of palliative care nurses: for patients and families to "allow" nurses into their lives, they had to sense that the nurses were credible, personally

committed to patients and families, and it had to be clear to them that the nurses respected them. The nurses believed that patients and families could tell when nurses were just "doing a job for the pay cheque", and were not really sincere about what they said, although it might be "the right thing to say". The nurses emphasized the importance of bearing in mind that patients respond better to some nurses than others. It was essential for the nurses to continue to do for patients what they felt was right, even when they felt ignored or unappreciated.

The nurses explained that, unfortunately, they were not always successful in helping families work through difficult situations. The nurses emphasized that they tried their best and learned that that was all they could expect of themselves and that was enough. They reminded themselves that the responsibility and most of the work to alleviate the suffering of interpersonal discord belonged to the patient, who sometimes chose not to allow resolution. In one situation of family estrangement, a patient would not allow her daughter, whom she had disowned 15 years previously, to come to see her, despite the pleading of her husband and numerous discussions with the nurse. The nurses acknowledged that in some situations of interpersonal discord, they could only do so much and that there were times when problems were too complex for their skills. Nurses recognized when this was the case, and when they needed to engage other resources who had the appropriate expertise, such as social workers or clergy.

Another kind of discord in relationships occurred when patients or family members chose not to share or inquire about information regarding treatment or prognosis, or chose not to talk about their thoughts and feelings in relation to these and other issues arising from the illness and expected death. The nurses cited many reasons for these responses,

such as fear of acknowledging bad news or fear of causing suffering for others. One

patient did not want his son to be told that he (the patient) was dying of AIDS because he

was ashamed, but the nurse accidentally revealed this information. Fortunately, the son

had already suspected the diagnosis, and did not let on to his father that he knew. The

father eventually told the son, and it was a big relief for both of them. The nurses

maintained that it was possible, and worthwhile, to try to facilitate communication in these

situations and other relationship problems. The nurses dealt with the issues in a number of

ways: by talking to both parties separately and together; ensuring knowledge and

understanding were correct; defusing anger; raising points for them to think about that

they may not have considered before; gently reminding people that time was short and

death would be final; and most of all, listening and being there to support patients and

family members in need. The nurses also recognized indirect signals that indicated when

people needed to talk, and when they wanted to be left alone.

In the occasional cases where patients had no family or friends, the nurses often

became like family - talking, spending time, and being there at the time of death. Other

members of the interdisciplinary team, or volunteers, also became surrogate family.

Facilitating coping. Throughout life, patients and families had learned to deal with

various experiences of suffering that came their way; some did this well, others did not.

The nurses observed that when these patients dealt with their present illness, they usually

used the strategies and coping mechanisms, effective or not, that they had previously

learned. The nurses found that it was unlikely that patients and families would learn new

ways of coping or strategizing when confronted with the suffering of life-threatening

illness.

The nurses made the best of what patients and families had to offer by identifying and encouraging strong coping skills and beneficial practices and by helping to defuse stressful factors or situations. Some patients and families were not able or willing to change lifelong habits. Reflection was sometimes helpful, depending on how it was used in the past or was being used in the present. For example, brooding about issues without taking positive action was unproductive; making good decisions and acting on them was helpful. Some patients and families were pragmatic; they knew what needed to be done and did it. The nurses attempted to teach new coping behaviours, but found they did not have a lot of success. Some patients and families were helped by hearing about other patient situations from nurses which could validate what they were going through and help them to feel they were not alone in their experience.

Coordinating resources. Families needed the services of palliative care nurses because a member was palliative, would have increasing care requirements, and would die sooner than later. Patients and families suffered when they worried about down times and crises that could be expected in the forthcoming months as patients got weaker and would need more care. The nurses needed to know how the referral and resource system worked and the limits of those resources. It was helpful to have patients and families involved in planning care, and sometimes all that was needed to ease their minds was the assurance that services would be available to them when they were required. In the following example, a woman was very concerned that her son, who had a street drug addiction, might try to steal her opioid drugs. She also had concerns about care for her dependent husband, then, and after she died. The nurse developed a plan of care and the patient felt

confident that her medications would be safe, and that her husband would be cared for, which greatly relieved her suffering in these relationships.

> And she did seem to be suffering less once we had the shift care nurses* in there because she knew someone else was handling the situation (the drugs). She also knew that if her husband would need home care following him, we'd certainly offer it, and provide service for him if he needed it. She had been very afraid...She had a lot of emotional issues that caused her suffering...She did die peacefully because I think she thought as much as could be controlled was in control, and was in place before she died. (* Shift care nurses provided 24-hour home care for the last few days of life.)

Strategies for Finding Inner Peace

Although the nurses found that the three realms of suffering were often intertwined, they perceived that, generally, patients were more likely to find inner peace if bodily discomfort and issues of interpersonal discord had been resolved. Addressing physical symptoms was consistently mentioned as the single most important factor in preventing and relieving suffering. Dealing with bodily discomfort often required so much of patients' energy and attention that they had little left for emotional and spiritual work. To a lesser extent, the same was true for working through the turmoil of interpersonal discord before being able to find inner peace. Though it was important for patients and nurses to prioritize problems that needed to be addressed, the nurses felt they tried, when possible, to accommodate less urgent issues at the same time as the more complex ones.

Patients utilized five strategies to find inner peace: having a positive attitude, maintaining hope, achieving goals, resolving spiritual questions, and finding meaning.

Strategies Used by Patients for Finding Inner Peace

Having a positive attitude. According to the nurses, having a positive attitude meant different things to different patients. An attitude of acceptance of what was happening was a significant factor in patients who experienced inner peace. Some people

were at peace within themselves despite having significant, though not extreme, physical symptoms, which they accepted. There were also patients who dealt with physical suffering in a spiritual way. For example, some Christians identified what they were experiencing with the suffering of Christ. When the interpersonal issues of some patients remained unsettled, but they recognized that resolution was not possible, or were satisfied that they had done all they could, they were often able to put the situations aside, maintain a good outlook, and become peaceful in spite of their circumstances.

The nurses explained they were more likely to see a positive attitude evidenced when patients believed that they had had fulfilling lives. Doing life reviews helped some patients reflect on the good life they had, and for many patients this was a source of great satisfaction. The nurses maintained that patients with few regrets often had less personal suffering. As one nurse explained, "The people who've had a full life, I think they go gently into that good night. They go a lot easier...They're very fulfilled, or they are realistic and accepting - 'I don't need to do it all or have it all.' And that's okay."

Patients in a positive frame of mind had often deliberately worked on getting to know themselves and being in tune with their feelings. The benefits of their insight became obvious as they dealt with the issues of suffering facing them as palliative patients. Self-exploration started when patients realized something was missing in their lives, which occurred at different times: some had done this their whole adult life; others had begun at the time of their diagnosis; still others started this inner work only with the suffering that came with advanced illness. Many patients found inner peace, and one nurse used the term "soul pain", and described it as the state of patients "...who have been so angry and so anguished and tormented by their illness and their imminent death." She continued,

"To see that change, sometimes it's magical. But it doesn't happen like that, it's a process." Such a state of mind was most useful if it was already well-developed, but the nurses felt that most of their patients had done very little in this regard. Nevertheless, they believed self-awareness would benefit patients even if developed at the end of their lives.

The nurses described situations where patients did not accept they were going to die. Sometimes patients chose not to talk about their own death, which was effective for them because they preferred to work things through on their own. The nurses were concerned though, in situations where it seemed obvious to them that patients would benefit from talking or more formal counselling. When patients refused this, the nurses believed it increased patients' own suffering and often the suffering of their family and friends who felt helpless about what to do.

Maintaining hope. Maintaining hope was often key to patients' inner peace. Even in palliative care, patients maintained hope for a miracle cure or more time, as expressed by many of those who went to great lengths and expense for alternative treatment. For many patients though, hope was relative to their priorities. One nurse explained: "So I see that when their quality of life goes down, their hope sort of withers and it's the very little things they hope for." For some, having hope meant they could anticipate a good quality of life for some time to come. For others, having hope meant they could look forward to having a good day, and enjoying those days to the fullest when they became less frequent.

Achieving goals. Completion of goals as a strategy for finding inner peace extended from what the nurses discussed in two strategies for overcoming interpersonal discord - *Organizing affairs* and *Leaving memories*. For many patients, doing such things

for loved ones was also a way to find peace before they died. Completion of tasks related to business or family finances benefitted others, but also brought peace and sometimes meaning to patients because of a sense of accomplishment for themselves, a sense of responsibility fulfilled, and a feeling that their life's work was being completed. The nurses believed that such actions enhanced calmness, peace of mind, and emotional well-being, and thus minimized suffering.

Resolving spiritual questions. Patients often had questions of a spiritual nature that they dealt with through formal religion or in other ways, and explored their questions on their own or with nurses or clergy. Patients' issues included concern about not having a belief in God, not having a relationship with God, or that their illness was caused by that lack of belief or relationship with God, or was punishment for bad behaviour. Some patients experienced anger about their illness towards God or themselves. Dealing with their anger in a spiritual way often led to acceptance or self-forgiveness. Patients' guilt about unresolved situations with others could often be mitigated through counselling. One nurse told of a patient who contemplated suicide as a way to end his suffering, but felt he could not because he believed his church taught that he would go to hell if he did. Although he was so bound in fear to that idea, he refused to talk with a chaplain. He agreed to secular counselling, arranged by the nurse, which did help him.

Spirituality brought great comfort and peace to numerous patients. Some patients were confident enough to "allow God to be in charge" and they just followed along with whatever happened. Several nurses thought that patients who believed in an afterlife had an easier, more peaceful death than those who did not. One nurse related a poignant story of a patient and family whose faith "just enfolded them" in their suffering, bringing much

solace to each member. Formal religions offered rituals that were meaningful to adherents

preparing for death. Other patients, who had developed their own spirituality or

philosophy of life outside of institutional religion, also had ways of bringing meaning to

their final days. Experience taught some of the nurses that the transition from living for

the future to getting ready to die, which one nurse called "reversing the instinct for

survival", was generally easier for those patients whose spirituality had been part of their

lives for many years. At the same time, though, the nurses thought that those who

embraced spirituality during their last months, also benefitted from this.

Finding meaning. Finding meaning as a way of being at peace was related to

gaining insight into one's self and life, as described in the strategy *Having a positive*

attitude. The nurses explained that the significance of meaning varied from patient to

patient. Some patients were deliberately searching for meaning, a profound sense of what

life meant and "why they were put on this earth." These patients used strategies similar to

those used for creating interpersonal harmony such as, reading, talking, and sharing their

feelings. The nurses discussed how patients took those strategies further by being

vulnerable and open to what was in their hearts and to what others might say that would

be helpful, hoping that what they would say would be respected and accepted. For others,

meaning occurred vicariously as a result of doing other things. For example, completion

of tasks as discussed above could be meaningful for some people.

Several nurses believed that many ordinary people did not live their lives or think

about life in such a profound way as finding meaning. These nurses contended that it was

not crucial for such patients to find meaning in order to be at peace or to be free from

suffering. The nurses also maintained there were patients for whom the opposite was true.

Such patients were more philosophical about what was important in life, and would not be at peace until they had found meaning.

In addition, the nurses identified patients whose lives had lost any meaning: "And they (patients) can't do anything anymore. They're just existing. They're not living." "Suffering for her was that she'd wake up and she was still alive the next day. She'd say, 'Can't you give me something to end this...this is just existing." The nurses explained that some patients had to focus so much energy on other forms of suffering, such as dealing with physical pain, that "They just don't have the available resources at that point to enable themselves to go into greater philosophical depth."

Strategy Used by Nurses for Helping Patients Find Inner Peace

The nurses promoted patients' sense of inner peace in a number of ways, captured in one strategy: facilitating self-awareness.

Facilitating self-awareness. The interventions nurses applied to help patients find inner peace were similar to those they used to assist them in creating interpersonal harmony. These included facilitating introspection and expression of feelings, listening, being respectful and non-judgmental, and being present. The better the nurses knew their patients, the more effective they thought they were in helping them alleviate suffering. Their knowledge came from learning from patients and their families what patients were like before their illness. It was important to patients to be seen as whole persons with life stories, not only as "so-and-so who has cancer".

The nurses reflected that what some patients needed to do to resolve suffering and find inner peace was to come to terms with life and what it had given, to make sense of life, that is, find meaning. Patients experienced personal distress when they lacked a sense

of accomplishment or thought that they had not really left anything behind. Many suffering patients had unhappy lives and were disheartened because they saw nothing to feel good about. Others who had ordinary lives often did not see the value in the small but important ways they contributed to the lives of others. Sometimes patients came to a more positive view on their own, while others did so with assistance of nurses. Several nurses believed they facilitated the process by which patients tried to accept their lives as they lived them, find peace, or possibly find a sense of meaning. The nurses often assisted patients by helping them conduct a life review - to look at their lives, their school days, previous relationships, and employment.

Spiritual support was also helpful to many patients in coming to accept their lives as they had lived them. The nurses varied in their degree of comfort and skill in providing spiritual support to patients and helping them find meaning, but all were willing to do what they could. The nurses tried to demonstrate to these patients their worth and inherent human dignity, by their care and concern for them. If patients believed in God, some nurses suggested that they were a unique creation of God. The nurses spoke highly of the many representatives of denominational and non-sectarian pastoral care they had come to know and count on to help care for their suffering patients. The nurses differentiated between helping patients find acceptance, peace, or meaning, and convincing them that they had a good life; they were not trying to do the latter.

The nurses emphasized that sharing information, talking, and expressing emotion had to be appropriate to patient's cultural practices and personal preferences. The nurses spoke of cultures where people were not allowed to speak of death to the patient, and other cases where families chose not to tell patients of their prognosis. These approaches

were intended to help patients be at peace. The nurses believed that patients who were dying usually knew that they were dying, despite efforts of others to withhold this information. When patients in those circumstances asked the nurses directly if they were dying, the nurses responded by trying to elicit from the patients what they themselves thought. The nurses felt uncomfortable lying, and tried to avoid doing so, while at the same time trying to respect patients' requests for information and family wishes.

The nurses gave of themselves when they helped patients resolve interpersonal discord; they also used this strategy to help patients in their quest for inner peace. At times, the nurses had to be willing to be vulnerable too, to risk showing their feelings when they were touched deeply by patients' stories and experiences, and to persevere even when their nursing strategies did not seem to be working.

Intervening Conditions

Despite the efforts of patients and nurses to alleviate suffering through various strategies, several factors helped or hindered their interventions. These factors came from a variety of sources, including patients' own history, their social support, and even from other caregivers in the health system.

Background of Patients

Patients were unique in the way they individually dealt with suffering because they brought many personal factors to bear on their experiences of suffering with a terminal illness. These factors included previous suffering, previous life experience, and previous experience with death and other losses. One nurse observed:

How they (patients) deal with suffering depends on where they're at. Depends on their experience in life, how much suffering they've had, physical, emotional. I think it depends on their support system. Growing up and what experiences were there, the resources they have. And I think it depends on if they're young. They're disadvantaged in some ways. They haven't had the lengthy life or the maturity to deal with suffering.

Several nurses believed that patients who had known love and had experienced other positive influences throughout their lives, were generally better able to cope with the suffering of terminal illness: "I think anybody who's in their right mind and who's lived a life knowing love and those kinds of things, that they cope a lot better."

Several nurses thought there was some merit in the cliche that 'people die the way they lived'. One nurse commented about a patient who was 'too' stoic about his obvious symptoms and would not discuss any illness related issues with family or staff: "He stands out as someone I don't think was emotionally in touch with his feelings throughout his life. I would say not very much. But I don't know. That's a judgement." Regardless of such suppositions, the nurses did their best to help patients as they dealt with their suffering.

Social Support

Influence of Families

Patients' support systems (family, friends) played a major role in easing patients' suffering. When patients knew that loved ones were suffering because they were suffering, it was an affirmation of their love. One nurse described it as "spreading the suffering around". Sharing gave a sense of purpose, of being together, of being connected to other people. Patients felt cared for and believed they would be remembered. Such a positive atmosphere was helpful in alleviating suffering.

Conversely, patients who had no support system, or whose support system created a negative environment, had more difficulty doing what they needed to do to overcome suffering, and also benefitted less from nurses' strategies. As well, although families sometimes acted with the best of intentions, they were actually unhelpful. For example, there were spouses who discouraged patients from discussing their concerns about death because the healthy spouse was not yet ready to face the prognosis:

> And he (the patient's husband) had decided she (the patient) wasn't going to die and had gone to get shark cartilage, spending a lot of money that they didn't have to try and keep her alive. I felt like saying to this man, your wife's dying and you just need to enjoy the time that's left with her. But he wouldn't talk about it with me or with her.

At times, when patients were unable to make decisions, families argued against non-treatment of certain problems, or use of medications that would cause drowziness. Although the plan would allow patients to be more comfortable, the nurse believed these families felt like they were "giving up".

Influence of Location

The nurses indicated that for some patients, it was very important to die at home in familiar surroundings where they and their families felt comfortable, secure, and in control. The nurses supported the idea that being at home prevented a lot of interpersonal and personal suffering when home care was offered according to a palliative care philosophy. One nurse told of a patient whose seizures were so severe that she really felt the patient would be better off in a palliative care unit. But the patient, who was at that point unconscious, had previously expressed a strong desire to die at home, and her family insisted that she be at home. Fortunately, because of the commitment of the family, the

home care nurse, the family physician, and a pharmacist who provided expertise, the

patient's symptoms were well managed, and she died peacefully at home.

When patients wanted to be or had to be in hospital, the nurses agreed that a

palliative care unit provided an environment that was the next best thing to home. The

physical space was decorated to be as homelike as possible. Staff were welcoming, pets

could visit, and family members could stay overnight. The nurses explained that palliative

care units were planned specifically for the relief of suffering, and as unit staff integrated

the philosophy and principles of palliative care into their work, an atmosphere of caring

and compassion was created that enabled relief of suffering. One hospital nurse, who

spoke of a patient who was very anxious about coming to the palliative care unit,

explained:

> I do believe that first impressions and just how we receive these patients is especially
> important. We do put ourselves out to make them feel welcomed, and they're often
> just small things, like, I got a nicer chair for the husband because he would be staying
> so much. And there were some things about her room physically that she wanted
> changed. And I was able to do that right away. She (the patient) said later, "We
> liked you, we felt good right away." It was interesting, the level of trust, how quickly
> it happened. He (the patient's husband) said, "Right away, I knew we were in the
> right place."

Influences of Professional Caregivers

Nurse-Patient Relationship

The nurse-patient relationship could both help and hinder strategies to alleviate

suffering. Trust was the key element of a good nurse-patient relationship. The nurses

believed that trust created an environment that was conducive to overcoming patients'

suffering. Trust was often established when there was an opportunity for nurses to

"prove" themselves. For example, one nurse recognized the need for and organized a

commode for a patient who could no longer walk to the bathroom. It was a small thing, but one that made a big difference in the patient's comfort. When patients and families let nurses into their lives, the potential was there for nurses to be helpful:

> Once you prove that you can be of service, I think they start to develop a relationship with you and begin to trust you...When you're available to them, they're more willing to let you enter their realm. And then once you're in their realm, I think you can be really helpful.

The nurses believed that patients and families saw them as credible, reliable, and committed in their efforts to help them. When nurses and patients came to know each other well, the nurses felt they were better able to anticipate needs and respond to them effectively. The nurses explained that "...it's not death that frightens them, it's how they get there. And I think if they know that they have a companion (nurse) along the way, they feel much safer, it's not nearly so frightening." When the nurse-patient relationship was a good one, patients confided many personal things, even things that did not reflect well on them, because the patients knew the nurses would listen and help them in a respectful, non-judgemental way.

The nurse-patient relationship had to be established carefully, sometimes slowly, to allow patients and families to see that the relationship would be worthwhile. Often patients and families were so overwhelmed by a new diagnosis or a newly unfavourable prognosis that they just wanted time to themselves to take it all in. Even though patients or family members were polite or gracious, nurses could sense when people were not yet ready for nursing support. Some people were more direct, or even rude. In such situations, it was important for nurses to make an initial contact, let the patients and families know that the service was available to them, and that there was no need to rush

involvement. Home care nurses usually kept in touch with patients and families through monthly phone calls until they were "invited in". Similarly, palliative care nurses in hospital could provide routine care, but were always available to engage further when the time was right.

The nurses stressed the importance of establishing the relationship as early in the disease or palliative trajectory as possible because patients and nurses could get to know each other "before major problems started". The stage would then be set to be able to talk easily about difficult and sensitive issues when the need arose. In cases where no relationship had been established, the nurses found it difficult to address the "total pain" because they had to focus on alleviating the physical symptoms. Emotional comfort and spiritual support the nurses provided was not as meaningful or helpful as with someone they knew. Often, the patients' poor prognoses did not allow nurses to develop rapport slowly. The nurses then established relationships as quickly as possible, setting priorities, and making sure the time spent with patients was quality time. Appropriate touch was sometimes helpful in establishing relationships quickly. However, if patients were unable to communicate, development of nurse-patient relationships was limited. Nurses then got acquainted with patients indirectly through family and friends.

Having consistent nursing personnel was essential for establishing and maintaining the meaningful nurse-patient relationships the nurses contended were fundamental in relieving suffering well. Consistency was important enough to be considered in determining staffing levels in palliative care settings. Regular time off had to be accommodated, and at times nurses needed a break from intense situations. Consistency of care could still be provided when responsibility for care was shared among a number of

staff, through care plans and a commitment to palliative care principles. The hospital

nurses reported that patients had primary nurses, but got to know other staff as well.

Home care nurses were less able to share their patient load. However, in one home care

office, two primary nurses would care for patients with complex needs. This allowed one

or the other of the two nurses to have time away without disrupting the patient's care.

Nurse-patient relationships sometimes became so close that patients requested

particular nurses to be present at the time of death. Other nurse-patient relationships,

although reasonably friendly and relaxed, remained more distant because of patients'

communication style, low perceived need for palliative care, or because nurses and

patients simply did not "click" in a special way. In such situations nurses were less

involved, and the nurses' role in alleviating suffering was diminished. The nurses knew

when not to pursue or "push" the relationship, and if the relationship did not work at all,

another nurse was assigned.

<u>Quality of Physician Care</u>

The quality of physician care influenced nurses' abilities to alleviate patient

suffering. The nurses collaborated with physicians to provide palliative care to patients at

home and in hospital. Palliative patients at home were cared for by their own general

practitioners (GPs), who did not necessarily have preparation in palliative care, and who

did not always have an interest in or understanding of the principles of palliative care.

Some of these GPs did home visits, others did not. Palliative care consultation service

was available to GPs and to home care nurses, provided by a physician or nurse with

expertise in palliative care. GPs themselves chose how they utilized the consultation

service. Home care nurses reported that some GPs were using the service more and were

thereby improving their palliative care knowledge base. Patients in the hospital were attended to by their GP and/or the unit-based palliative care physicians, along with nurses and the rest of the interdisciplinary team. The hospital nurses also found that educational preparation of the GPs they dealt with varied, and that they often had to make suggestions for medical intervention: "I have attempted to be more assertive with physicians, especially GPs, because they're not as familiar with our (palliative care unit) medications or protocols that we use."

The nurses spoke positively of the high quality care many physicians provided. They described the excellent working relationships between nurses and physicians when physicians listened well and respectfully to nurses and other members of the interdisciplinary team. However, some nurses related experiences that caused them distress about the quality of medical care patients received. Their concern was particularly with GPs who had limited knowledge or experience in caring for palliative patients, especially the management of physical symptoms. The nurses reported that difficulties often arose because of poor communication between nurses and physicians, and that the situations were eventually resolved. Some physicians acted too slowly when managing physical symptoms, frequently because the physicians did not heed nurses' assessments of patients' conditions. These nurses believed they often had more knowledge and experience than the physicians with physical symptom management. One nurse expressed her dissatisfaction with a particular physician:

> It's the frustration of dealing with physicians whose pain management is so limited. And, I sound like I'm throwing stones and I guess I am. It's not that I don't understand it. If you don't have the knowledge, you don't have the knowledge. There's so many things I don't know about. But wouldn't you want to find out, if a nurse told you that your patient wasn't comfortable? Oh! Well, he dropped in and

saw her once a week and he knew she wasn't having any pain. And I just thought, I can't believe he thinks that.

The nurses indicated that some GPs still believed that opioid addiction was a problem with palliative care patients and consequently underdosed with opioid drugs. For example, when one nurse asked the GP to change a patient's analgesia from irregular dosing of Tylenol #3, to a slightly higher dose of continuous release codeine, the GP felt it was "a great leap" and that the next thing the nurse would be suggesting morphine.

When GPs chose not to incorporate palliative care into their practice, nor to utilize the palliative care home consultation service, the nurses believed these factors impeded alleviation of suffering in patients, sometimes increasing suffering and generally compromising patient care. In many situations, the nurses, with the goal of quality care for their patients, bypassed the physicians who were creating problems, and directly sought the assistance of the consultation service for home care patients, and nursing management or palliative care staff physicians in the palliative care unit.

<u>Health System</u>

Nurses in both home care and hospital settings expressed concern about time constraints, reduced personnel, and fewer resources that adversely affected their ability to provide care at the level prior to the financial cutbacks of recent years. As well, the nurses perceived that the reduction of hospital beds was not accompanied by adequate increases in home care services to help manage the higher numbers and greater acuity of patients at home. The hospital nurses also found that earlier patient discharge resulted in higher proportions of patients in hospital who had more complex needs. The nurses contended

that patient care was affected. For example, they thought that patients sensed when nurses were busy, and would not ask for time to talk.

<center>Outcomes of Attempts to Alleviate Suffering</center>

Alleviation of suffering resulted when patients' and nurses' strategies were successful - bodily comfort was achieved, interpersonal harmony was created, and patients found inner peace. The nurses knew suffering was relieved when they observed positive changes in patients' condition such as peaceful facial expression, relaxed body position and movement, improved relations with others, verbal confirmation from patients, or a return to their "old self". However, the alleviation of suffering was often only partial, or was short-lived. Any of the conditions of suffering could recur, and the struggling would begin again.

When patients were imminently dying (within two or three days), and were comfortable and at peace with others and themselves, they were be able to "let go" and have a peaceful death. These patients begin looking inward, "loosening the strings of life". Some nurses believed patients were only able to truly let go "when they were no longer suffering". In a slightly different sense, the nurses claimed that some patients "lost the capacity to suffer". These patients were able to let go because they were "tired" and "the time was right". They no longer struggled, but accepted death with neither contentment nor despair.

Suffering persisted when patients' and nurses' strategies failed to achieve bodily comfort, create interpersonal harmony, or lead to inner peace. Patients continued their struggle, but if death was imminent (within two or three days), some patients would "give up". "Giving up" looked similar to "letting go" because in both situations patients turned

inward, but the nurses believe that patients who "gave up" were still suffering. They had used up their resources to deal with their suffering and had no energy left. Struggling become futile and patients lost hope. These patients wanted to die to get beyond their suffering. Occasionally, patients asked for assistance to die as a way of relieving their suffering. The nurses believed that patients resorting to such a request was indicative of "real suffering".

<p style="text-align:center">The Personal Impact of Caring for Patients who Suffer</p>

The nurses' personal responses to caring for patients who suffer was positive and negative, and influenced the strategies they employed when caring for other patients. In a positive way, the nurses' work was meaningful and rewarding because they made a difference in the lives of palliative patients. Even when they were exhausted from their efforts in a situation, nurses were relieved and happy they had done their best and had reduced or alleviated suffering. The nurses also felt they learned much from patients and their families, and received much more than they gave: "For me, absolutely the most rewarding part of palliative care is getting into some of those realms and talking about things...that's the gift that I think you get back.", and "You really learn a lot. It expands your own life so much."

Working in palliative care with suffering patients inspired some of the nurses to learn more about themselves, to develop personally or spiritually, and to become more skilled in dealing with the sensitive issues that arise from the context of suffering, dying, and death. Having insight into themselves and being grounded in who they were allowed them to reach out and respond effectively to patients who were suffering:

I do a lot of reading myself. And probably I've explored more and am more in touch with who I am myself. It supports me so I can understand the patients and where they are, and respecting that, allowing them to be who they are. And dealing with emotional issues and their fears and the psychosocial component.

The nurses' experience made them attentive to their own relationships; for example, they believed they listened and communicated more effectively with their own families. They were more easygoing, were able to view problems with a more balanced perspective, and were generally more appreciative of life. They were convinced that having fulfilling, stable, personal lives prepared them to cope with the stressful situations they faced when caring for patients who were suffering.

The nurses suffered in their own way when they could not relieve the suffering of their patients. At times, the nurses perceived patient suffering as unnecessary because it was not prevented when it could have been, or was prolonged by poor medical decisions. Helping to alleviate emotional and spiritual suffering was occasionally beyond the expertise of available staff. These kinds of situations broke the trust between nurses and their patients because patients had been let down. In such situations, the nurses felt "helpless" and "desperate". The nurses believed they suffered, and described their own suffering with words like "agony", and "absolutely gruelling", but they were usually able to resolve their own struggles. However, the emotional intensity at times resulted in their feeling burned out or doubting their own abilities. Occasionally when this happened, the nurses were inclined to get less involved with their patients, which meant less than optimal care for those patients. With support, the nurses felt they let go of situations, reflected on and learned from their practice, and were motivated to advocate more effectively for their patients. They also wanted to continue to upgrade their knowledge and skills.

Nurses expressed their frustration if they thought they should have done something differently when patients made decisions the nurses did not feel were in their best interest, and which did not help relieve patients' suffering. The nurses acknowledged that all they could really do was "their best", and that they needed to let go of unrealistic expectations of themselves. The nurses also acknowledged that they did not have all the answers.

The palliative care team's response to caring for suffering patients had bearing on the nurses, and at times, affected their nursing care of other patients. "Team" referred to physicians, management, and nursing colleagues, and to a lesser extent, other disciplines. Support from the team was necessary for the nurses to deal with the negative outcomes of working with suffering patients, and vice versa. The nurses received informal support on a situational or day-to-day basis. Being a part of good everyday working relationships with other staff, including physicians, was beneficial. As well, it was helpful for management to give recognition for good work and to listen when nurses had concerns outside of regular meetings. The nurses sought informal support, and most of them found their fellow nurses were usually aware of what was going on, knew when support was needed, and offered it without being asked. Sometimes nursing colleagues were not as supportive of each other as the nurses would expect; several nurses were selective when sharing or allowing themselves to be vulnerable. Support for palliative issues was not as consistently strong in the home care service. One nurse reported that she was basically told to "get on with it" when she sought emotional support.

Formal support from management was essential for nurses to maintain and develop both their knowledge and their morale. Palliative care education was available through journals, presentations, workshops, and conferences, but individual nurses' access to such

opportunities varied considerably, especially in the generalist model of home care nursing. Level and quality of formal support provided to nurses in situations of difficult symptom management, distressing family situations, or ethical decision-making also varied. The nurses agreed that regular rounds and critical case reviews were a good way for all team members to be heard, to participate, and to receive assistance, but these were infrequent in home care. One nurse said they were trying to get a "hospice group" going in her home-care unit. Another nurse stressed the need for regular meetings, especially for nurses who were too shy or embarrassed to ask for them.

The qualities that led these nurses to work in palliative care - openness, sensitivity, compassion - are the same qualities that made them vulnerable to suffering as they as they watched and attempted to alleviate the suffering of their patients. As a result, they too, had to work to relieve their own suffering. In doing so, they could experience personal growth and fulfillment, and be better able to care for other patients.

<div align="center">Summary</div>

The purpose of this study was to explore the perceptions of palliative care nurses about their patients' suffering. The nurses described situations of suffering, how they knew patients were suffering, how they responded to patients who were suffering, and how patients themselves responded to their own suffering. The nurses also discussed the personal impact of caring for patients who were suffering.

Palliative care is offered to people with a limited life expectancy due to a progressive, life-threatening illness. Cure is usually no longer the focus of care; rather, quality of life is maximized through symptom management and an open, supportive

approach to personal issues that cause suffering. Palliative care can be provided to patients at home or in hospital.

It was difficult for the nurses to precisely define suffering or to explain exactly how they knew when patients were suffering. There were more obvious signs for physical suffering, but it was patients' perception of the experience that determined whether it was suffering.

The nurses described three realms of suffering: bodily discomfort, interpersonal discord, and personal distress. Bodily discomfort resulted from various physical symptoms such as pain, nausea, and dyspnea. Bodily discomfort was often intimately connected to a sense of self, but could also cause suffering without emotional or spiritual dimensions. Interpersonal discord arose from problems in patients' emotional and social relationships. Common issues were rejection, unforgiveness, or secrecy about the illness. Personal distress occurred on a spiritual/philosophical level - struggles of an intimate, personal nature, and issues specific to patients' own characteristics, beliefs, and choices. Concerns ranged from spiritual doubts to regrets about previous life decisions. Patients experienced suffering in any one of the realms, or in combination.

Patients and nurses each used strategies to alleviate patient suffering. Their goals were to achieve bodily comfort, create interpersonal harmony, and find inner peace. The strategies, which were explained in full, are outlined as follows:

Strategies for Achieving Bodily Comfort

Strategy Used by Patients   Strategies Used by Nurses

Making decisions.   *Communicating information.*
                                          Supporting choice.
                                          Doing for.
                                          Advocating.

Strategies for Creating Interpersonal Harmony

Strategies Used by Patients   Strategies Used by Nurses

Optimizing relationships.   *Facilitating communication.*
Organizing affairs.   *Facilitating coping.*
Leaving memories.   *Coordinating resources.*

Strategies for Finding Inner Peace

Strategies Used by Patients   Strategy Used by Nurses

Having a positive attitude.   *Facilitating self-awareness.*
Maintaining hope.
Achieving goals.
Resolving spiritual questions.
Finding meaning.

The work pattern of patients and nurses was unique; as suffering became progressively less tangible through the bodily, interpersonal, and personal realms, the work of patients increased, and the work of nurses decreased. Physical suffering was more amenable to direct nursing interventions; suffering at the interpersonal and personal levels was something only patients could resolve, and the nursing role became more supportive.

There were several intervening conditions that the nurses believed could help or hinder the strategies for alleviating suffering. Among these were background of patients;

patients' social support: family support and location of care; and professional influences: nurse-patient relationship, quality of physician care, and health system.

Caring for patients who suffer affected the nurses positively and negatively. The nurses derived great satisfaction from being able to help alleviate suffering. As well, they gained an appreciation of what was important in life, and were inspired to nurture self-awareness and personal growth in themselves. Unfortunately, the nurses, too, suffered when they could not prevent or relieve suffering in their patients. They coped with these difficulties by setting realistic expectations of themselves, being able to learn from their experience, and being supported by their colleagues and by management.

In Chapter 5, the findings will be discussed and nursing implications for practice, education, administration, and research will be suggested.

CHAPTER 5

DISCUSSION

Introduction

The purpose of the study was to explore and describe the experience of palliative

care nurses who care for patients who are suffering. The idea resulted from a literature

review of suffering that revealed limited research with nurses in general and none at all

about the experiences of nurses specifically working with palliative care patients. From

the nurses' stories, the data provided answers to the four research questions that had been

formulated, as well as additional information. In this chapter, selected elements from the

data will be compared with the literature, and implications for practice, education,

administration, and research will be suggested.

Defining and Recognizing Suffering

The literature review first raised questions about palliative care nurses' perceptions

of the nature of suffering: How do palliative care nurses define suffering? How do

palliative care nurses know when someone is suffering? The nature of suffering has been

well documented, but it was hoped the study would provide new knowledge specifically

about suffering in palliative care. As discussed in Chapter 4, the nurses believed that the

lack of a definition of suffering and limited use of the word 'suffering' with patients did

not prevent them from recognizing situations of need and attending to them. Patient

confirmation of the nursing assessments was a significant factor in knowing when patients

were suffering, a finding that is supported by the definitions of Benedict (1989), Cassell

(1991), and Cherny, Coyle, and Foley (1994a), and the work of Kahn & Steeves (1986).

Although the data do not reveal a concise definition of suffering, nor an exact means of recognizing suffering, they do portray characteristics of suffering that can be compared to some of those described in the literature. The nurses identified three realms of suffering - bodily discomfort, interpersonal discord, and personal distress - which indicates that they are in clear agreement with authors such as Travelbee (1971), Salt (1997), and Byock (1996), who believe that suffering commonly results from a combination of physical, emotional, social, and spiritual factors. Several nurses named the presence of all forms of suffering 'total pain', the classic term originated by Saunders (1978). Total pain as a concept is often introduced to nurses in basic preparation for working in palliative care. In the researcher's clinical experience, and in the nursing practice described in the data, nurses tend to speak of specific observations and relevant qualities of the total pain or suffering patients are experiencing, rather than use the expressions 'total pain' or 'suffering'. In practical terms, this is a useful way for nurses and other team members to communicate precisely about what is affecting patients in given situations.

In contrast to situations of total pain, the nurses thought it possible that an extreme manifestation of a physical symptom, without an emotional or spiritual dimension, could constitute suffering. This idea is not supported by authors such as Frankl (1984), Loewy (1991), and Gregory (1994), who maintain that physical symptoms create suffering only if there is a lack of meaning. The nurses also believed that some emotional and spiritual issues could give rise to suffering in and of themselves. There are no sources in the literature that challenge that contention, perhaps because it is more apparent that emotional and spiritual issues usually involve meaning on some level.

Several nurses talked about the threat to self-integrity, but not as much as might be expected, because in the literature, numerous authors, including Cassell (1982, 1991), Chapman and Gavrin (1993), and Kahn and Steeves (1986), maintain that threat to self integrity is essential for a given experience to be called suffering. The nurses discussed suffering in concrete terms of physical symptoms and emotional or spiritual issues, and although many of the situations could be seen as threatening to self-integrity, the nurses did not usually ascribe this more abstract quality to the suffering of their patients.

It is prevalent in both the nursing (Barkwell, 1991; Ersek & Ferrell, 1994; Steeves & Kahn, 1987) and the non-nursing literature (Byock, 1994a; Frankl, 1984, Salt, 1997), that negative meaning, or a lack of positive meaning, is a quality that must be present to call an experience suffering, and that suffering can be alleviated by finding positive meaning in the experience. As explained above, the nurses believed that this was not necessarily so, especially for suffering caused by physical symptoms. They also thought that less tangible processes such as finding meaning could only be attempted when patients were physically comfortable, a point with which Byock (1996) concurs.

Though the nurses did not articulate a role for meaning in suffering as described above, they did discuss meaning in two ways. One was a form of personal distress characterized by a lack of meaning in life, and the other, *Finding meaning*, was one of several strategies they described patients using to overcome personal distress to achieve inner peace. The nurses explained further that that many ordinary people do not think about life in terms of having meaning. Patients may not have articulated to the nurses what was important to them in such a philosophical way, but some of the circumstances described could be said to be meaningful, and as well, negative meaning could be inferred

from many of the situations of suffering in their stories. In addition, the nurses explained how patients often needed to resolve spiritual questions to be able to find inner peace. Spirituality can be related to the experience of creating meaning in life (Fitcher, 1981; Mellors, Riley, & Erlen, 1997; Moburg, 1982; Reed, 1992), and in particular to palliative patients finding meaning in suffering (Byock, 1994a; Cherny, Coyle, & Foley, 1994a; Ersek & Ferrell, 1994; Reed, 1986).

As outlined in Chapter Two, a number of authors discuss personal growth as an outcome of suffering (Ersek & Ferrell, 1994; Hinds, 1992; Salt, 1997; Starck & McGovern, 1992). Such growth results from all that people go through to overcome their suffering. For example, Lentz (1985) suggests that people see suffering and express it, weep over it, and then transform it. The nurses spoke about the change and relief that come with alleviation of suffering, but did not specifically comment that personal growth resulted from the struggle of overcoming suffering. Several nurses did believe that the personal development and insight that some patients had nurtured in themselves enabled them to better deal with their suffering.

Responding to Suffering

The third research question, "How do palliative care nurses respond to patients who are suffering?", elicited the most information from the nurses. The nurses discussed the many ways they help to alleviate the suffering of their patients, but could not do so without describing the work that patients do as well. When both patient and nursing strategies are presented together, as in this study, the large amount of work that patients do to overcome their suffering becomes clear. According to the data, as patients move through the three realms of suffering, from bodily discomfort to interpersonal discord, and

personal distress, their work tends to increase, and that of the nurses decreases. The focus of nursing is often on physical tasks, and in the suffering of palliative care, achieving bodily comfort is where nurses can intervene most directly. Patients who are suffering physically often do not have the ability, the energy, or the concentration to do more for themselves. Nursing interventions for creating interpersonal harmony and finding inner peace are more indirect; they take more time and need different skills. The essential work in these areas must be done by patients - individual, personal things that no one else can do. The nurse's role becomes more supportive.

As stated earlier, the delineation of suffering into the three realms of physical discomfort, interpersonal discord, and personal distress, concurs with the literature on suffering. The nursing strategies described are consistent with the palliative care literature about care for those who are suffering (Barkwell, 1991; Breitbart, 1996; Burnard, 1993; Cherny, Coyle & Foley, 1994a; Ersek & Ferrell, 1994). Compassion is one characteristic of nursing care that was mentioned throughout the study, and is consistently raised in the literature as essential for caring for people who are suffering (Byock, 1994a; Gregory, 1994; Younger, 1995). Davies and O'Berle (1990) looked at the nursing care of palliative and oncology patients, though not specifically at the nursing care of those who are "suffering". The dimensions of the Supportive Care Role they described, include *Valuing, Connecting, Empowering, Doing For,* and *Finding Meaning,* and all are reflected in the nursing strategies from this study. In addition, the dimension of *Preserving Own Integrity,* parallels the nurses' thoughts about the personal impact of caring for patients who suffer. The consistencies in portrayals of nursing care throughout the literature indicate that nurses think about their care in similar ways whether they are

asked about AIDS patients, oncology patients, palliative patients, or patients who are

suffering. Descriptions focus on practical observations and solutions, using comparable

terminology.

Most of the guidelines available for the care of palliative patients who are suffering

are written to direct the work of nurses and other members of the interdisciplinary team.

It is implied that patients do their part, but what they actually do is not usually specified.

As well, in the literature, the impression is given that patients just wait, while they are

assisted or 'done to', or that the care is 'done for' them by the various team members.

As discussed in Chapter 2, there are many writers who believe that

physician-assisted suicide and euthanasia (together called assisted death) are reasonable

options when physical and existential suffering cannot be alleviated through palliative care.

They maintain that sedation is not an acceptable alternative for some people who would

prefer death to being rendered unaware, and see little difference between the two.

Because unresolved suffering is central to the debate on assisted death, it was hoped that

the results of the present study would add another nursing perspective to the debate

through an expanded understanding of suffering and its alleviation in palliative care

patients. The nurses were not specifically asked about their thoughts on assisted death,

but the issue did arise in some of the interviews. Several nurses were decidedly against it,

and several thought they would support the practice should legislation allow it. Sedation

as a treatment option in palliative care is well documented in the literature (Cherney &

Portenoy, 1994; Senate Committee, 1995; Waller & Caroline, 1996), and is sometimes

the only way to alleviate suffering. It was surprising that several of the nurses felt they did

not know enough about sedation to be comfortable with it, and several of the nurses knew nothing about it at all.

Intervening conditions are factors that can influence how well patient and nurse strategies work to overcome suffering. One factor is the nurse-patient relationship, the importance of which is documented extensively in the literature (Aranda & Street, 1999; Deeny & McGuigan, 1999; Gastmans, 1998; Jenks, 1993; Johns, 1996; Peplau, 1952; Vaillot, 1966). The nurse-patient relationship is central to the care of patients in many areas of nursing, as well as palliative care. Much is written about development and maintenance of effective relationships and their role in nursing care. Advocacy is described in the current study as a nurse strategy used to help alleviate patient suffering. In the literature, advocacy is discussed as an aspect of the nurse-patient relationship (Mallik, 1997, 1998; Rafael, 1995). Rafael delineates five levels of advocacy from the simplistic to the existential, and qualities of each can be found in the stories from the nurses in the current study.

Another intervening condition that clearly created problems for the nurses was the variation in community physician knowledge of palliative care management. Inadequate palliative care knowledge is a recognized problem in medical circles, and attempts are being made to improve the situation through education in undergraduate and graduate medical programs, learning opportunities for practising physicians, and making current information easily available (Brenneis & Bruera, 1998; Hall, Hupe, & Scott, 1998; MacLeod, Nash, & Charny, 1994; Shvartzman & Singer, 1998; Yuen, Barrington, Headford, McNulty, & Smith, 1998).

The nurse-physician relationship is a separate issue, but is related to the problem of physician knowledge. In the traditional nurse-physician relationship, physician knowledge and authority supersede those of nursing; thus, many physicians do not collaborate well with nurses. For example, physicians may not heed nursing observations or suggestions about decisions for patient care, even when the nurse is more knowledgable about the situation than the physician. This imbalance is long-standing, is found in most areas of health care, and is well documented in the literature (Bunting & Campbell, 1990; Campbell-Heider & Pollock, 1987; Doering, 1992; Hedin, 1986). The pattern is generally attributed to hierarchical gender structures in society - in this case the control that male physicians and administrators have had over nursing education and function in health care. In contemporary society, more men are opting for nursing as a career and many more women are becoming physicians. Progress towards interdependence has been made and will continue as nursing and medical practice become more clearly defined as distinct from each other, and as the benefits of collaboration are acknowledged by practitioners of both professions (Campbell-Heider & Pollock; Dudgeon, 1992). For example, though nursing autonomy is often limited by the power of physicians and institutions, increasingly, nurses are participating in what have traditionally been regarded as medical decisions, such as when to cease treatment (Liaschenko, 1993).

<div align="center">Personal Impact on Nurses</div>

The fourth research question was, "What is the personal impact of caring for patients who are suffering?" In the present study, palliative care nurses were asked about their experiences working with patients who were suffering, and as well about the personal impact of that experience on themselves. Steeves, Kahn, and Benoliel (1990) conducted a

study, in which graduate nursing students from a variety of backgrounds were asked about their interpretation of the suffering of their patients. Though the results differ, there are a number of points common to both studies. Both groups identify physical, emotional, social, and spiritual components of suffering, and that patients' interpretation of the experience is essential to it being deemed suffering. Patients' and nurses' responses to suffering are similar, though more detailed in the present study.

The nurses from the Steeves et al. research and the present study feel they suffer themselves because of what their patients experience. Interestingly, the nurses from the Steeves et al. study thought that part of their own suffering was because they felt responsible for causing some of their patients' suffering with the treatment they had to provide. The nurses from the present study did not mention this, perhaps because with palliative patients, the goal of care is more likely to be quality of life than prolonging life, as it would be with patients who are acutely ill. Therefore, palliative care practitioners are unlikely to recommend treatment that will cause more suffering. In addition, the Steeves et al. study concludes that nurses who continually care for patients who are suffering are at risk of withdrawing from clinical nursing. In contrast, the palliative care nurses felt that by taking time for reflection, drawing on their own strengths, and being supported by colleagues and management, they were able to deal with their feelings of stress in a positive way, learn from difficult situations, and continue to care well for patients who were suffering.

Numerous authors comment on the stress that health care providers, including nurses, experience in palliative care (Cherny, Coyle, & Foley, 1994a; Harris, Bond, & Turnbull, 1990; Rutman & Parke, 1992; Vachon, 1998). Vachon (1995) reviewed more

than 20 studies on stress of palliative care staff (mainly nurses). Perhaps surprisingly, it generally seems that palliative care nurses have less stress than nurses in other areas, including oncology and critical care (although not all the studies showed such positive results). Authors attribute the difference to the support that is offered to staff - support that was recognized early in the palliative care movement as essential for staff well-being and productivity. Such a program includes regular staff meetings, opportunities to discuss difficult cases, participation in decision-making, having supportive colleagues, positive affirmation from management, being "allowed" to grieve, and ongoing professional development. The nurses from the study also identified these factors as helpful.

The nurses described the learning process of experienced nurses and those new to palliative care, which is in keeping with Benner's five levels of proficiency: novice, advanced beginner, competent, proficient, and expert (1982). The nurses believed that palliative care nurses at all levels need to continue to learn, and suggested ways of doing so. It was clear from the interviews that the palliative care knowledge base of the nurses varied considerably within the group. Some of the range was likely due to personal characteristics and motivation for ongoing learning. However, the difference was particularly noticeable with the home care nurses who did not have palliative care experience from a specialized setting. This might be because in the generalist model there are many other areas to focus on in addition to palliative care issues. As well, there are a number of geographic bases from which home care nurses work in this city; perhaps the palliative care 'culture' is stronger in some than others because of higher numbers of home deaths.

The nurses also raised the importance of staff suitability to palliative care. Careful staff selection has been a key element of palliative care over the years (Dunlop & Hockley, 1990; Latimer, 1991; McArdle, 1985; Saunders, 1978, 1997). The emphasis on such qualities as a stable, fulfilling personal life and a well-founded motivation for working in palliative care is relevant because these characteristics help staff to deal well with suffering and death and maintain a balance in their own lives. However, with downsizing, amalgamation, and layoffs, managers may no longer have the option of being so selective of nursing staff for palliative care. As well, several of the nurses in the study expressed their concern that some home care nurses who would prefer not to provide palliative care, had to because of the generalist model of care. The nurses from the study were quite happy in their work, but some of the home care nurses felt they did not get the emotional support they needed from colleagues and management in their workplace. As mentioned above in the comments about knowledge, the palliative care 'culture' may be stronger in some units than others.

Implications for Nursing

A number of nursing implications were identified from discussion of the data. In this section, nursing implications for practice, education, and administration will be outlined and accompanied by implications for research.

By asking the nurses about their own experience of working with patients who suffer, the researcher expected to obtain information that would enhance descriptions of the nature of suffering, provide a useful basis for identifying supportive nursing interventions, and possibly offer a beginning theory of the process by which palliative care nurses respond to patients who are suffering. The results of the current research reflect a

general consensus in the literature that suffering can be of three realms - physical discomfort, interpersonal discord, and personal distress. The findings also confirm much of what has been described in the literature as good practice. In addition, the findings highlight the amount of work and the nature of the work that is involved for patients who are suffering and for the nurses who care for them. Much of the published work about alleviating suffering has been written from the personal experience of the authors, based either on their own experience of working with patients who suffer or from studies with various clinicians. This project represents one of the first attempts to systematically explore the experience of nurses caring for patients in palliative care who are suffering.

Little qualitative research has been done with patients who are suffering. Palliative care practitioners would do well to conduct research with patients to explore their perspectives on what suffering means to them, what must be done to relieve suffering, or to verify the observations and beliefs of practitioners about what constitutes good care of patients who are suffering. The ethical implications of doing research with patients in palliative care must be considered (Bruera, 1994; Kristjanson, Hanson, & Balneaves, 1994; Wilkie, 1997). In addition to usual ethical research principles, researchers must bear in mind a number of points, for example, the effect that opioids, disease process, and psychosocial distress can have on mental and physical capacity to consent, participate, and withdraw from research. On the other hand, clinicians, (who often screen for potential subjects), and researchers should not be paternalistic and assume that participation would be too much of a burden for palliative patients. Patients often view research as an opportunity to contribute to improvements in care, even though they themselves may not benefit.

The nurses were generally not familiar with the literature on suffering, and did not think of their work in terms of philosophical discussions or taxonomies. As described earlier, the nurses expressed their thoughts about what needed to be done about suffering in practical terms, whether discussing bodily discomfort, interpersonal discord, or personal distress. The researcher had hoped that the nurses would articulate more of their thoughts on the philosophical aspects of suffering - threat to personal integrity, spirituality, meaning, transcendence of suffering, and personal growth. Several of the nurses interviewed were very comfortable with these ideas and had obvious insight into their own feelings as well. The other nurses were less comfortable and a couple of them were quite honest about this. Authors from nursing and other disciplines write that being able to help patients explore their spirituality and experience of suffering on more than a basic level is important for creation of meaning and transcendence of suffering. Assuming that research with patients would affirm this, nurses would require a degree of comfort with these concepts to help effectively. There is ample literature from which to draw to familiarize nurses with these ideas and to make them comfortable putting them into practice. Initial preparation of nurses new to palliative care should introduce the concepts, and regular opportunities should be created for further learning in the form of discussions, seminars, or retreats. Research that explores palliative care nurses' understanding of these processes, how to best learn about them, and how to use them effectively as interventions in suffering, would be invaluable.

As discussed earlier, the problem of unrelieved physical and existential suffering is at the heart of the debate on assisted suicide and voluntary euthanasia. Nurses in palliative care need to be cognizant of the issues, and how to meet the challenge of responding to

patients who raise the issue in relation to themselves. Less tangible aspects of alleviation of suffering, such as spirituality and meaning, are often at the root of a request for assisted death. Increasing nurses' comfort in dealing with these issues, as suggested above, may enhance quality of life enough to reduce perceived need for requests for assisted death. Palliative care nurses working in home or hospital settings need to understand the rationale and the practical aspects of sedation for the same reasons.

It was hoped the study would yield information that could improve the work life of palliative care nurses, better enabling them to provide good patient care. Managers are the key to planning and implementing the kinds of supports that nurses have identified as being helpful, which are also validated in the literature. It is possible that it is easier for a palliative care program, than a generalist home care service, to provide the kinds of support identified in this study as helpful for nurses' well-being and productivity. However, to ensure that generalist home care services are able to offer the palliative care they claim to offer, managers need to establish education and clinical opportunities and other personal and professional supports. These practices need to promote good morale and be sufficient for the nurses who care for palliative care patients to maintain high quality knowledge and skills.

In practice, the problem of physician knowledge is something about which nurses can do little on a large scale. On a day-to-day basis, nurses can contribute to better working relationships with physicians by utilizing good communication techniques and continuing to update their own knowledge and skills. Managers can work with the appropriate physician management to inform them of problems and encourage solutions, as well as to cooperate with them to help implement those solutions.

Conclusion

There is a wealth of literature about suffering from the perspectives of religion, art, philosophy, and many of the health disciplines. Nursing has contributed both philosophical perspectives and research using quantitative and qualitative methods. Some of the literature focuses on suffering unique to palliative care, and this study explored palliative care nurses' perceptions of their patients' suffering in home and hospital settings.

Suffering is often a major component of the experience of progressive, life-threatening illness. The results of this study offer nurses new ways of thinking about the nature of suffering, how patients respond to suffering, how nurses themselves can more effectively relieve suffering, and how other conditions can help or hinder efforts to alleviate suffering. The findings also describe the personal impact, positive and negative, of caring for suffering patients, and reveal the supports that help nurses deal with those effects. Nurses who can learn and grow from their experience, and care for themselves, will be better able to care for patients who are suffering.

Summary

In this chapter, a number of elements from the data were compared to the literature. Although there are numerous definitions of suffering in the literature, the nurses could not articulate their own definitions, nor were they able to explicitly explain how they recognized suffering. Despite these limitations, the nurses believed that they still knew when patients were suffering, and were able to address those situations. The nurses did not specifically identify a number of characteristics of suffering that are prominent in writing about suffering, such as threat to self-integrity, meaning, and personal growth, but the presence of those characteristics could be inferred from their stories of patients'

suffering. These finding suggest that the nurses generally thought about suffering in practical ways that had direct impact on their patients' suffering, rather than theoretically.

The nurses' descriptions of suffering in the three realms of bodily discomfort, interpersonal discord, and personal distress were consistent with delineations of suffering in the literature. The patient and nursing strategies that the nurses described for achieving bodily comfort, creating interpersonal harmony, and finding inner peace reflected much of what is written about the principles of palliative care and alleviation of suffering in palliative patients. Unique to this study was the idea that patients themselves must do a considerable amount of the work for alleviation of their suffering, especially for suffering that is less tangible.

The literature confirms the positive and negative effects of the three conditions that the nurses identified could help or hinder efforts to alleviate suffering: nurse-patient relationship, physician knowledge of palliative care, nurse-physician relationship. The results of the present study suggest that planned education and clinical opportunities must be provided for palliative care nurses to learn and upgrade the knowledge and skills they need to use in their work with patients who suffer. The literature strengthens the nurses' contention that such learning and other workplace supports are essential for nursing effectively, promoting good personal morale, and enhancing the positive personal impact while reducing the negative on nurses caring for patients who suffer. As well, the following implications for nursing were discussed:

<u>Practice</u>

Suffering can be considered to be in one of three realms: bodily discomfort, interpersonal discord, and personal distress, or a combination of any of these.

Patients and nurses both use strategies to alleviate suffering, resulting in bodily comfort, interpersonal harmony, and inner peace, respectively.

As the suffering becomes less tangible through the three realms, the work of patients increases, and that of nurses decreases and becomes more supportive.

Education

In addition to basic preparation for working in palliative care, nurses need ongoing learning in a number of areas:

- spirituality and meaning in the context of suffering;

- issues of assisted suicide and voluntary euthanasia;

- rationale and practical aspects of sedation and other symptom management in palliative care.

Administration

Managers in palliative care must be able to work with physician managers to resolve problems such as inadequate physician knowledge in palliative care and conflicted nurse-physician working relationships.

Managers in palliative care programs must create program supports that are conducive to staff well-being, knowledge, and productivity. Managers in generalist home care services need to ensure the same for nurses who provide palliative care.

Research

Qualitative research with patients who are suffering could reveal patient perspectives on what suffering means to them, what alleviates suffering, and could confirm or challenge clinicians' perspectives about what relieves suffering.

Qualitative research with palliative care nurses could provide insight into their understanding about meaning in suffering, transcendence of suffering, and how to best increase their skill and comfort in addressing these issues with patients who are suffering.

Qualitative research with palliative care nurses could provide insight into their thoughts on assisted suicide and voluntary euthanasia, and how to best increase their skill and comfort in addressing these issues with patients who are suffering.

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APPENDIX B

LETTER OF INFORMATION ABOUT PARTICIPATION
IN THE RESEARCH PROJECT

"PALLIATIVE CARE NURSES' PERCEPTIONS OF SUFFERING
IN PALLIATIVE CARE PATIENTS"

Dear Nurses,

I am a registered nurse and a student in the Master of Science in Nursing program at the University of British Columbia. In partial fulfillment of the requirements of my graduate education I am conducting a study to look at palliative care nurses' experience with patients who are suffering. I hope the results of my research will increase nurses' understanding of suffering and contribute to the nursing care provided to palliative patients.

I will be interviewing eight to twelve nurses from two agencies, and would like to include nurses from your unit / Vancouver/Richmond Health Board. The nurses selected will meet the following criteria:

- are registered nurses;
- have worked on the palliative care inpatient unit of the 12th and Oak Site of the Vancouver Hospital and Health Science Centre for at least one full year / have worked in the role of primary nurse for palliative patients on the Vancouver/Richmond Health Board home care service for at least one full year.

You are being asked to participate in this study because you work in palliative care and have cared for patients who were suffering. Your participation in this study is completely voluntary. You may choose not to participate in this study without penalty or risk to you or to your employment.

If you choose to participate, you can expect that:

- you will be interviewed one or two times by the researcher;
- the interviews will be approximately one to one-and-a-half hours long;
- you may be asked to do a followup interview to verify the accuracy and meaning of what you said;
- you may refuse to answer any question during an interview;
- you may stop an interview at any time.

    As well, you can expect that:

- the interviews will be audiotaped and transcribed, and then the tapes will be erased;

APPENDIX D

INTERVIEW GUIDELINES

I will precede the interview with an introduction...

From my experience as a nurse in palliative care, I know that many patients suffer, and that nurses provide much of the care to relieve that suffering. I have also found from the literature about suffering, that there have been studies done with nurses who work with patients who suffer, but none of them has specifically asked palliative care nurses about their experience. As a result of my reading, I had a number of questions about the work that palliative care nurses do when they care for people who are suffering. I think that the information that you share with me will increase understanding of suffering, contribute to more effective care for people who are suffering, and help nurses to better understand how they themselves can be affected by caring for people who are suffering.

I will begin the interview with the question:

Please tell me about a time that you were caring for a patient who was suffering.

I have prepared the following questions as guidelines only, to which I will be able to refer if there is a need for specific direction from me to facilitate the participant in providing information.

Recognizing Suffering

1. How do you know when a patient is suffering?

   Do you ask?

   How do people who are suffering describe their experience?

2. How do you know when the patient is no longer suffering?

   Do you ask?

   How do people describe their situation when they feel they are no longer suffering?

Responses to Suffering

1. What do you do to help someone who is suffering?

   ...physical or technical interventions...

   ...psychosocial interventions...

...spiritual/existential interventions...

2. What can the person do to help ease their own suffering?

   Who or what else can help ease their suffering?

3. Do you think all people suffer in the same way in similar situations?

   If no...why is it that people respond differently?

   If yes...can you tell me more about what you mean?

4. Can suffering be prevented?

   If no...can you tell me more about what you think?

   If yes...how can that be done?

Personal Impact of Suffering on Nurses

1. How does the suffering of your patients affect you personally?

   What do you do about that?

   Do you receive support from other people?

   If no...can you tell me more about that?

   If yes...how is that helpful?

   What else do you find supportive?

   Does your own way of looking at life - your own beliefs and values - help you to deal with this?

2. How do you feel when you can't relieve someone's suffering?

   What do you do about that?

   Do you receive support from other people?

   If no...can you tell me more about that?

   If yes...how is that helpful?

What else do you find supportive?

Does your own way of looking at life - your own beliefs and values - help you to deal with this?

The Nature of Suffering

1. What does suffering mean to you?

2. What makes suffering different from other difficult, but less distressing circumstances?

3. How would you define the suffering of palliative patients?

4. Is the suffering of people in palliative care - different from the suffering of others, for example, people with acute illness or injury?

5. How is it the same as the suffering of those other people?

6. Can someone suffer if they are not in physical pain?

    If no...can you tell me more about what you think about that?

    If yes...can you tell me more about what you mean?

7. Are there different kinds of suffering in palliative care patients?