

AN ANALYSIS OF ONCOLOGY NURSES' STATEMENTS
REGARDING THE ASSOCIATION OF PAIN AND
SUFFERING WITH REQUESTS FOR
ASSISTANCE IN DYING

A DISSERTATION
SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY
IN THE GRADUATE SCHOOL OF THE
TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

BY

Deborah Moorehead Thorpe M.S., R.N.

DENTON, TEXAS

August, 1993

TEXAS WOMAN'S UNIVERSITY
DENTON, TEXAS

May 10, 1993

Date

To the Associate Vice President for Research and Dean of the
Graduate School:

I am submitting herewith a dissertation written by

Deborah Moorehead Thorpe

entitled An Analysis of Oncology Nurses' Statements Regarding
The Association of Pain and Suffering With Requests
For Assistance in Dying

I have examined the final copy of this dissertation for form and
content and recommend that it be accepted in partial fulfillment
of the requirements for the degree of Doctor of Philosophy, with
a major in Nursing.

John Fehir
Major Professor

We have read this dissertation
and recommend its acceptance:

John Fehir
Quatha M. Garland
Anna Young

Accepted

Leslie M. Thompson
Associate Vice President for
Research and Dean of the Graduate
School

Copyright © Deborah Moorehead Thorpe, 1993

DEDICATION

This work is dedicated to Mary Mazzawy, RN, MS, OCN, who in life and death provided the inspiration for this study and taught us all about death with dignity.

ACKNOWLEDGEMENTS

The road to attaining a Ph.D. is not unexpectedly, a long and challenging one, and it is certainly not one that is taken alone. I owe much appreciation and gratitude to many colleagues, mentors, friends, and family members who supported and wished me well along the way.

To my daughter, Abigail, go special thanks for enduring much in the past few years, but most of all for being one of my biggest cheerleaders. The daunting task of culling through some 1200 questionnaires and sorting them numerous times in different ways would have been impossible without her very real help in the form of slave labor. It pleases me greatly that she too, has learned much in the process and has become an advocate for improving the treatment of the terminally ill so that physician-assisted death should not be necessary.

I am especially grateful to my dissertation committee, chaired by John Fehir with able assistance from Anne Young and Judith McFarlane. They not only helped me over some rough spots but served as mentors, exemplifying what a dissertation committee should really be like. It took a long time, but it has been worth the wait.

It would have been very difficult to get to this point

if it were not for a lot of support and encouragement from my mentors and colleagues at The M. D. Anderson Cancer Center, especially the members of the Pain and Symptom Management team who are very much a part of this work: Gloria Chabolla, Chyi Chou, Mary Cunningham, C. Stratton Hill, Linda McCrory, Lupe Palos, Richard Payne, and Sharon Weinstein. Thanks also are in order for the patience, prodding, and support from many in the Division of Nursing especially Virginia Romsdahl and Pat Tedder who shared my vision and tried to help me learn to say "no" to many enticing activities that could get in my way.

None of this work would likely have come to fruition without the vision of Mary Mazzaway who conceived the original idea and brought the study group together, and who lived and died with grace and dignity. It was also a pleasure and a privilege to work with the rest of the study group including Paula Reiger, Deborah Volker, and especially Anne Young who did double duty as collaborator and mentor by serving on my dissertation committee as well. The original study would not have been possible without the support of the Texas Division of the American Cancer Society who provided the funding for the original survey.

Lastly, I would be remiss in failing to mention two very special people without whom I would not have had the sense of purpose or direction to make nursing my life's

work. My parents, Lee and Betty Moorehead, through their life long faith and devotion in ministering to people, have instilled in me the values of caring and the confidence to succeed in realizing my goals.

ABSTRACT

AN ANALYSIS OF ONCOLOGY NURSES' STATEMENTS REGARDING THE ASSOCIATION OF PAIN AND SUFFERING WITH REQUESTS FOR ASSISTANCE IN DYING

Deborah Moorehead Thorpe
August, 1993

Fear of prolonged pain and suffering is among the reasons most frequently cited as justifying requests for Physician Assisted Dying (PAD). Unfortunately, pain is significantly undertreated and many suffer needlessly (Marks and Sachar, 1973; Melzack, 1990), leading some to consider such desperate choices as PAD. The purpose of this exploratory study was to analyze the statements of oncology nurses in response to a survey about PAD to determine the context within which judgements are made and from which interventions are derived. The study was designed to address: 1) the concerns identified in responses to a vignette in which "profound suffering" is a prominent feature, 2) the concerns identified in response to a question about the degree to which physical pain can be managed, and 3) concerns about the degree to which pain is actually relieved. The technique of content analysis was used to study the written comments supplied by the

respondents who were invited to elaborate on their answers to the vignette and pain questions. The sample was derived from a survey sent to 2,000 randomly selected oncology nurses. The survey instrument was the Nurses' Attitudes Regarding Physician Assisted Dying (NARPAD) Questionnaire. Of the 1210 surveys returned, 486 responded with narrative comments, including 64 (13%) hospice nurses. The comments were transcribed and read several times to identify key concepts which were coded and categorized. The categories were collapsed into three major themes that emerged for each question. The predominant theme in response to the vignette on suffering was beliefs. While a majority indicated acceptance of PAD in the context of suffering, their comments revealed many concerns about the process and the need to explore alternatives--especially to relieve pain and suffering--based on the belief that relief of pain and suffering is possible. The predominant theme in response to both pain questions was barriers. Nurses indicated that effective pain control is possible but described numerous barriers. Discrepancies in provider knowledge and attitudes as well as access to expert pain care for all patients were identified as the primary barriers.

LIST OF TABLES

1.	Practice Setting of the Respondents	63
2.	Frequency of Comments by Subcategory: Situation #4 (Vignette featuring suffering) ..	67
3.	Chi-square Analysis of Theme Categories for Situation #4	69
4.	Frequency of Comments by Subcategory: Question #4 (Ability to control pain)	72
5.	Chi-square Analysis of Theme Categories for Question #4	73
6.	Frequency of Comments by Subcategory: Question #5 (Adequacy of pain control)	75
7.	Chi-square analysis of Theme Categories for Question #5	76

LIST OF FIGURES

1. Model of Collaborative Nursing Practice 14

TABLE OF CONTENTS

DEDICATION	iv
ACKNOWLEDGEMENTS	v
ABSTRACT	viii
LIST OF TABLES	x
LIST OF FIGURES	xi
Chapter	
I. INTRODUCTION	1
Problem of Study	4
Rationale for Study	6
Conceptual Framework	13
Assumptions	20
Research Questions	21
Definition of Terms	21
Limitations	23
Summary	23
II. REVIEW OF LITERATURE.....	25
The Relationship of Pain and Suffering to Requests for PAD.....	26
Attitudes and Roles of Nurses.....	32
Attitudes and Roles of Other Health Care Providers.....	39
Professional and Public Debate.....	41
Summary.....	49
III. PROCEDURE FOR COLLECTION AND TREATMENT OF DATA	51
Setting	51
Population and Sample	52
Protection of Human Subjects	53
Instruments	55
Data Collection	57
Treatment of Data	58

IV.	ANALYSIS OF DATA	60
	Description of Sample.....	61
	Findings.....	63
	Research Question One.....	65
	Research Question Two.....	69
	Research Question Three.....	74
	Summary.....	77
V.	SUMMARY OF THE STUDY.....	78
	Summary.....	78
	Discussion of Findings.....	86
	Relationship of the Findings to the Conceptual Framework.....	88
	Conclusions and Implications of the Study.....	89
	Recommendations for Further Study.....	92
	REFERENCES	94
	APPENDICES	
	A. Survey Cover Letter.....	100
	B. Demographic Record.....	103
	C. Nurses Attitudes Regarding Physician Assisted Dying Questionnaire.....	107
	D. Comment Coding Schema.....	113
	E. Sample Transcription and Coding for Situation #4.....	115
	F. Preliminary Categories for Situation #4 With Comment Excerpts.....	123
	G. Sample Transcription and Coding for Questions #4 and #5.....	128
	H. Preliminary Categories for Questions #4 and #5 With Comment Excerpts.....	138
	I. Comparison of Responses to Original Sample.....	146

CHAPTER I

INTRODUCTION

The issue of withdrawing or withholding treatment for patients with little hope of recovery has been debated worldwide in recent years, particularly in response to the development of technology and the ability to prolong life. The health care professions have responded to this debate and policies have been established whereby "passive" termination of life through the withholding of treatment or discontinuing of life support systems has gained a certain degree of acceptance (Kuhse, 1988; Mappes & Zembaty, 1986). Attention to the ethical considerations required to make appropriate withdrawal decisions has brought with it a greater focus on the issue of "active" termination of life, variously referred to as euthanasia or physician assisted death. Although the focus thus far has been primarily on the physician's role, nurses are on the front line of patient care and play critical roles in patient evaluation and therefore must be proactive as this debate unfolds.

Physician assisted dying can be viewed as an extension of suicide. When suicide is committed, the act is entirely voluntary and independent. In promoting the concept of

death with dignity, Humphry (1991) refers to suicide as "self deliverance" and gives advice on preferred methods to accomplish it. However, when an individual is incapacitated by disease and unable to act independently, or seeks a more peaceful and humane end--in contrast to more violent means of self deliverance such as hanging or using a gun that may be more available--physicians may be approached for assistance in committing the act.

Inevitably, these issues will continue to confront nurses and other health care professionals who must respond by addressing the considerable moral, ethical and legal implications. Furthermore, it is incumbent upon these professionals to carefully examine the related issues of pain and suffering that plague this dilemma.

Among the reasons most frequently cited as justifying requests for active termination of life is the fear of prolonged suffering with pain and other distressing symptoms. Unfortunately, despite significant advances in pain and symptom management in the past few decades, pain continues to be significantly undertreated and many suffer needlessly (Marks & Sachar, 1973; Melzack, 1990; World Health Organization, 1986), leading some to consider desperate choices such as active termination of life through suicide or euthanasia.

Nurses, by the nature of the role, are in close and

intimate contact with patients nurses and therefore may be the first to learn of a patient's desire to seek an early end to life. Furthermore, one of the nurses' fundamental roles is to assess and counsel the patient and family in collaboration with the physician to address unmet needs that may contribute to a desire to hasten death.

While few studies have been done to determine the incidence of requests for euthanasia, work has been done focusing on the risk of suicide in cancer patients. Although the relative risk of suicide varies considerably among study reports, it is generally agreed that cancer patients are at increased risk (Bolund, 1985; Breitbart, 1982, 1990; Louhivuori & Hakama, 1979) and unrelieved pain, depression, and hopelessness/helplessness are cited as predominant factors in those who commit suicide or request assistance in dying.

The role of the nurse in managing pain is emerging as one that is pivotal in assuring effective care. While the prescription of analgesic medication is the purview of medical practice, the nurse is in an important position to intervene and influence the quality and quantity of pain relief afforded to patients by virtue of the nature of the nurse-patient relationship. In addition to being the health care professional that spends the most time with the patient, particularly in hospital settings, the nurse's

relationship is often of a very intimate nature that promotes the development of trust and communication. The nurse is in a key position to evaluate the efficacy of treatment and to serve as the patient's advocate in seeking appropriate medical and nursing care. Indeed, it may be the nurse at the bedside to whom the patient first discloses thoughts of suicide or requests for assistance in hastening death.

In this study a blend of quantitative and qualitative analysis, a process known as triangulation (Fields & Morse, 1985), was undertaken. The major themes that emerged from the analytical process will be compared to choices made in response to a vignette, and ratings of the efficacy and adequacy of pain control.

This research, although the second phase of a completed survey, comprised the first and original analysis of the qualitative data obtained at the time the survey was originally conducted. It is expected that the results of this study will yeild new knowledge that will contribute to the profession and science of nursing.

Problem of Study

The purpose of this descriptive and explanatory study was to analyze written responses of oncology nurses to a survey about physician assisted dying. The specific foci of this study were to analyze the statements and derive themes

describing oncology nurses' perceptions and beliefs about physician assisted dying in response to:

- 1) A vignette in which "profound suffering" is a prominent feature and for which the nurse is asked to indicate what nursing role would be chosen in that situation.

- 2) Questions asking the nurse to rate the ability to control physical pain effectively and the degree to which it is adequately controlled in cancer patients they know.

This study constituted the second phase of a survey begun in 1990 in which the purpose was to explore a variety of issues on the topic of physician assisted dying. In addition to the questions cited above, there were vignettes designed to identify factors that might affect nurses attitudes such as the influence of the nature of the nurses' relationship with the patient, and the willingness of nurses to be actively involved in administering the drugs that would cause death. Subjects were also asked to indicate their awareness of current events related to physician assisted dying. The data for this present study was collected at the time the survey was conducted and stored for later use. This present study constituted the first and original analysis of the stored data.

Rationale for Study

Nurses are becoming increasingly aware of the importance of being alert to issues and trends in the political and legal arenas, and of the tremendous challenges facing the health care system in today's social and economic environment. An issue as significant and emotionally charged as euthanasia is certainly one requiring a proactive approach. The publicity surrounding the release of the "suicide manual", Final Exit (Humphry, 1991) and the "suicide machine" invented by Dr. Jack Kevorkian (Belkin, 1990) has stirred considerable public debate.

To date, most of the discussion and debate centers on patient's rights and the ethics or morality of physicians being called upon to assist a suicide. Very little of the debate has included discussion of the nurses' potential role in counselling patients who may confide their wishes to a nurse, or what role they might play should physician assisted death become legal. It is likely that nurses will be called upon to be present when medications intended to terminate life are administered. Is it even conceivable that nurses might even be asked to administer such drugs as prescribed by a physician depending upon the language written into legislation, if passed. It is certainly incumbent upon nurses to reflect on these issues and to examine their own beliefs in order to respond to

intitatives that may have a significant impact on nursing practice (Miaskowski, 1992). Although euthanasia has been openly practiced in The Netherlands, and some physicians in this country have dared to speak openly of having actually assisted patients in dying, very little has been written about the impact these actions are likely to have on nursing practice.

The Dutch Experience

Since the early 1970's, the Dutch have become more open and vocal about the practice of active, voluntary euthanasia. Prior to the recent legalization of euthanasia (Jones, 1993) the Dutch courts were lenient and handed down decisions that changed the way physicians were held accountable. Court precedents acknowledged that there are circumstances in which voluntary active euthanasia is not a punishable offense (Kuhse, 1987). Known as the "Rotterdam Conditions" a set of guidelines have been established that specify that there must be no reason to doubt the patient's wishes; the decision must be well informed; there is no alternative to improve the patient's condition (defined as being acceptable to the patient); and that the physician must consult another independent physician to review the matter. The key is in establishing that the act is compassionate and the choice has been made autonomously by the patient (Kuhse, 1987). In February 1993, in a 91-45

vote the Dutch parliament promised immunity to physicians assisting patients in dying if official guidelines are followed (Jones, 1993.)

Movement in the United States

The Hemlock Society, founded in 1980, is a nonprofit organization dedicated to raising public awareness and promoting the cause of voluntary euthanasia. With over 31,000 members, this group has been active in pursuing legislative efforts to bring this issue to the forefront in the United States. The society is dedicated to providing opportunities for physician assisted dying or euthanasia and to de-criminalize this action. Three states (California, Washington, and Oregon) have active initiatives targeted to legalize physician assisted death. Each of these states has proposed a similar "Death With Dignity Act." Specifically these acts recognize the right of self-determination as a basic freedom, including the right to decide the time and place of death when one is terminally ill. Furthermore, it is maintained that this right should include the opportunity to enlist the help of the medical profession in making such a death as swift and painless as possible (Oregon Death With Dignity Act, 1990). Washington was the first state to put the question to a vote, and in November, 1991, the proposition was narrowly defeated. Proponents of the legislation cite certain weaknesses in the safeguards that

were written into the act and have announced their intent to address those areas and to continue to pursue passage of the legislation (Humphry, 1992). In 1992 Californians were asked to vote on similar legislation but despite attempting to improve the safeguards, this measure was narrowly defeated as well (The Washington Post, 1992).

Public Opinion

Several public opinion polls have reported that a majority of Americans support the concept of euthanasia. In 1986 the Roper Organization surveyed 1,998 adults and found that 62% responded that doctors should be allowed by law to end a patients life if requested by the patient in situations where there is no hope for recovery. In 1987 a California poll showed that 64% of the population surveyed felt that an incurably ill patient should have the right to ask for and get life-ending medication (Risley, 1987).

In a Gallup Poll commissioned by the Hemlock Society in 1990 (Humphry, 1992) 58% of the 1,018 adult respondents indicated they thought a person has the moral right to end his or her life when the person has an incurable disease. When great pain and suffering with no hope of improvement is factored into the equation, support rose to 66%, whereas only 33% felt it acceptable if the rationale was the heavy burden placed on the family. Only 16% favored ending life in an otherwise healthy person who desired to do so.

Responses of Health Care Providers

The response by health care providers has been diverse, with general attitudes showing an inclination towards acceptance but with professional organizations officially rebuking the trend. Statements issued by the AMA Council on Ethical and Judicial Affairs (1986) and the California Nurses' Association (1987) oppose active euthanasia. The American Nurses' Association has not issued a position statement on euthanasia or physician assisted dying, but has issued several related statements that emphasize the nurses' role in providing expert care for the dying patient through aggressive pain and symptom management and sensitive, supportive care when a patient is terminally ill. In the position statement "Promotion of Comfort and Relief of Pain in Dying Patients" the American Nurses Association (1991) emphasizes the need for "full and effective doses of pain management" and clearly states that this is ethically justified "even at the expense of maintaining life or hastening death." In their position statement on "Foregoing Artificial Nutrition and Hydration" comfort measures are likewise encouraged and the withholding of nutrition is viewed as being "qualitatively different" from provision of nutrition by artificial means (American Nurses Association, 1992).

A poll conducted in 1987 by the Hemlock Society

revealed that 79 of 588 California physicians responding reported they had deliberately taken the lives of terminal patients who asked to die. Physicians surveyed in Australia in 1987 demonstrated that while the Australian Medical Association was firmly against active euthanasia, a clear majority of respondents support it. A British survey published in 1987, however, revealed that only 30% of general practitioners questioned favored "medical help to an immediate peaceful death" (Kuhse & Singer, 1988).

In 1989 Davis and Slater conducted one of the few studies that have focused on nursing. They compared U.S. and Australian nurses' attitudes about the "good death." They found that there were considerable differences among the nurses in what they felt would be done in certain situations and what they thought ought to be done. Lack of agreement was postulated to reflect differences in respective health care systems and existing laws. Certainly, it is incumbent upon nurses to examine the issues that will affect practice in the event such laws are passed. By addressing the issues proactively, nurses will be better prepared to respond appropriately to future decisions that must be made.

In a survey of members of the Oncology Nursing Society, nurses were asked to respond to a series of vignettes depicting hypothetical situations by indicating their

beliefs and actions they would take if physician assisted dying were legal, including the possibility of the nurse being asked to administer death-causing medications. The findings indicate that oncology nurses hold diverse views regarding the acceptability of physician assisted dying. While many nurses expressed acceptance of the practice, especially when the patient is perceived to be suffering, they were reluctant to be the one to administer the medications (Young, Volker, Reiger, & Thorpe, 1993).

One of the attendant benefits of this controversial debate, it is hoped, will be the increased recognition that greater attention to management of pain and suffering is critical. In order for a more rational debate to occur it must be understood that we possess the necessary methods and medications to relieve patients of pain and suffering to a much greater degree that is actually achieved at present. To that end, the World Health Organization (1990) has adopted a firm position stating that attempts to legalize voluntary euthanasia are unnecessary because of the ability to reduce the suffering that is so feared and that often leads to requests for euthanasia: "...there should be concentrated efforts to implement programmes of palliative care, rather than a yielding to pressure for legal euthanasia" (World Health Organization, 1990, p.55).

Conceptual Framework

The foundation for studying the problem of pain and its relationship to suffering and requests for assistance in dying is taken from a conceptual view of nursing developed as a model of care by the author, known as the Model of Collaborative Nursing Practice (MCNP). The MCNP, which is depicted in Figure 1, represents a dynamic, interactive process that focuses the care on the individual person. The MCNP is adapted from concepts found in the Orem Self-Care Model (Orem, 1985) and the Roy Adaptation Model (Roy, 1980). These concepts have been expanded to include emphasis on nurses roles and relationships in a collaborative practice setting that includes input from other health care providers.

The metaparadigm of person, health, environment and nursing form the fundamental components of the MCNP. The person is a composite of biologic, psychologic, and social components which make up the basic human dimensions. The person is constantly striving for a state of balance and harmony or equilibrium in each of the human dimensions.

Health is a dynamic state and is seen as an inevitable dimension of life characterized by a continuum of illness/wellness involving adaptation to change. Illness is a relative state in which there is disequilibrium in one or more of the human dimensions, whereas wellness is a state in

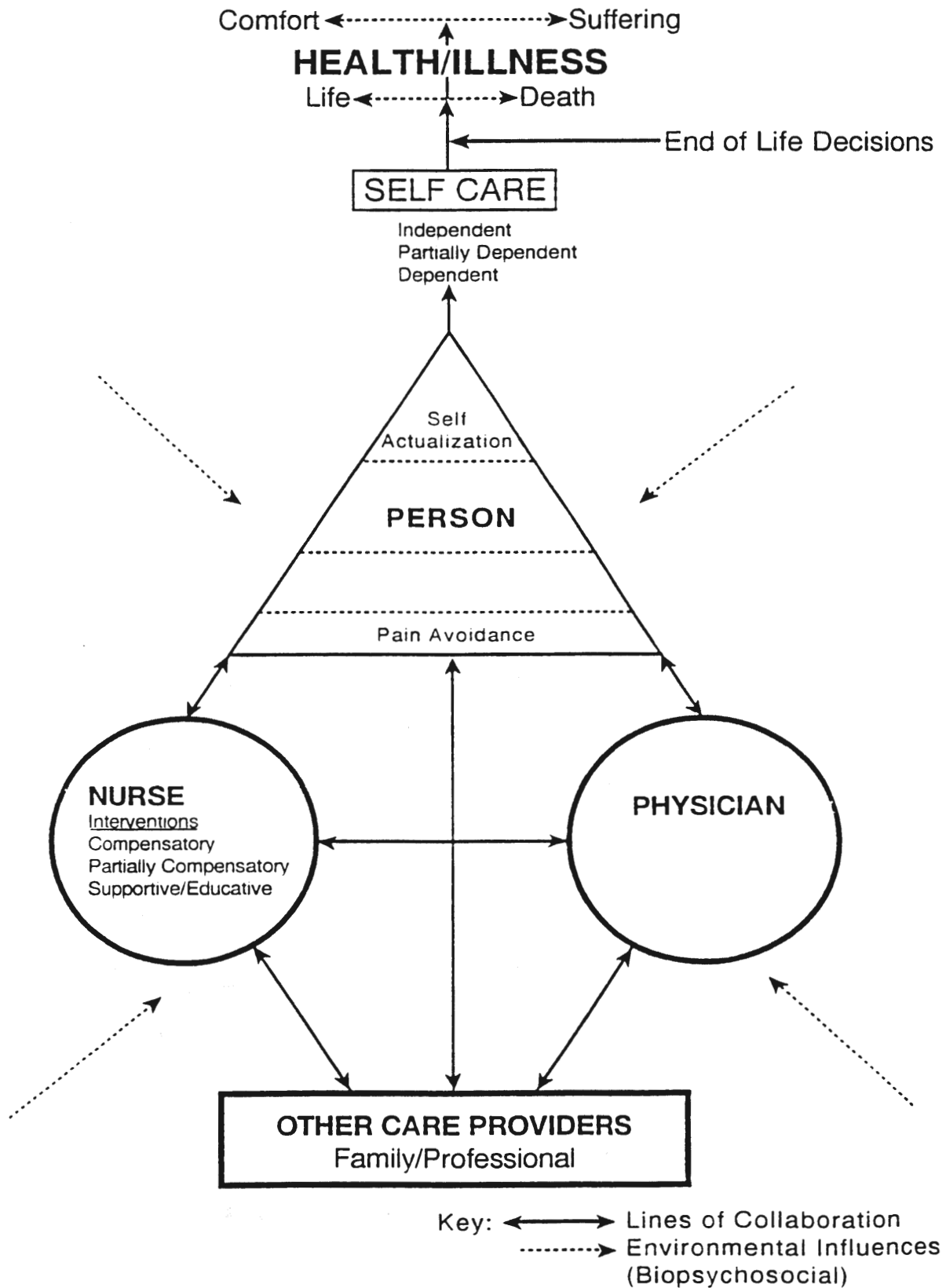


Figure 1. Model of Collaborative Nursing Practice

which there is a relative harmony and balance in the various human dimensions. A parallel continuum is that of life and death. The point on the continuum on which the patient exists may be influenced by their self care abilities, degree of adaptation, and to some extent the choices they make regarding their care.

The environment is the setting for the MCNP and is described as the sum of biologic, psychologic, and social stimuli and stressors experienced internally and externally in a dynamic state. There is constant interaction between the person (including those involved in the person's care) and the environment as the individual strives for adaptation (Roy, 1980).

Nursing is a therapeutic, interpersonal process conducted in a systematic and deliberate fashion with emphasis on collaborative activity, recognizing the interdependence of patients and caregivers (Roy, 1980). The goal of care is the restoration, stabilization, or control of environmental factors that guide the patient (individual) towards independence in self care and health or adaptation to the highest level of functioning possible (Orem, 1985). The nursing process components of assessment, diagnosis, planning, intervention and evaluation form the framework for the decision-making process. To implement this process the nurse draws from theoretical and scientific knowledge as a

basis for action.

The mode of action of the MCNP to accomplish balance and adaptation is collaboration. Collaboration is an interactive process involving the nurse, patient, physician, family and other members of the health care team. Each member of the health care team has independent and interdependent relationships with the patient and with each other. The goal of nursing activity is to coordinate care based on specific needs that have been validated and accepted by the patient whenever possible.

Health is a dynamic process involving change and adaptation and the ability for self care may change over time as the patient encounters illness. Self care is the relative ability of clients to meet their own biologic, psychologic, and sociologic needs. Self care includes the necessary planning and decision-making processes as well as specific actions needed to manage activities of daily living and comply with therapeutic care requirements (Orem, 1985). As Maslow (1954) has conceptualized, there is a hierarchy of needs and the most basic of these needs, such as for food and water, must be met to a satisfactory degree before higher level needs such as self-actualization must can be met. Pain avoidance is stipulated by Maslow to be a basic survival-level need.

When there is a state of disequilibrium in any of the

human dimensions, the degree to which the individual is able to achieve self care varies. Three basic levels of care identified by Orem (1985) are relevant to this model: totally dependent, partially dependent, and independent. Each level has nursing interventions appropriate to the degree of dependence or independence. At the totally dependent level of care--for example, the comatose patient--the nurse and other members of the health care team must act on behalf of the patient who is unable to communicate needs, make decisions, or participate in care. Nursing interventions at this level are characterized as wholly compensatory according to Orem.

At the partially dependent level, which can be a temporary or permanent state, some functions are assumed by the nurse or significant others, yet the patient maintains an active role to some degree. Corresponding nursing interventions are said to be partially compensatory (Orem, 1985).

When the patient is capable of carrying out all activities of daily living without assistance, the level of care is considered to be independent. Orem describes the nursing interventions at this level as consisting of activities that are primarily supportive or educative.

Use of the MCNP for Study

The MCNP serves as an organizing framework for the

study by identifying the relationships and interactions among the key members of the team: the patient, the nurse, and the physician. The MCNP illustrates the interdependence of nursing and medicine in making treatment decisions and facilitating care. For example, the medical care directed by the physician, who has primary responsibility for prescribing medications, is interdependent with the nurse's role in assessing and promoting self care. Thus, when quality of life is adversely affected by pain and suffering, the nurse's observations and recommendations about the patient's response to current treatment are crucial for appropriate adjustments to be made by the physician.

With respect to pain and other distressing symptoms, the nurse's observations and interventions are particularly vital. Many patients do not complain of pain, even when intolerable, for a variety of reasons. One of the key reasons is that among the unfortunate societal images of a diagnosis of cancer is the pervasive notion that cancer and death, and therefore pain and suffering, are inevitable and that little can be done to alleviate it, or that relief can only be attained by risking addiction or enduring sedation that precludes enjoyment of life.

The expectation that little can be done to relieve their pain is often reinforced by the patients own spiritual and cultural values that may encourage the patient to think

that, not only is the pain inevitable, but it is deserved as punishment for past sins (Johnson, 1989). The nurse, because of the close relationship and opportunity to assess the patient is able to identify and intervene with patients who remain silent about their pain under such circumstances. Another reason for failure to communicate about the nature and severity of pain is the subjective nature of pain and the difficulty inherent in measuring subjective phenomena. A key role of nursing is to collaborate with the patient to develop an individualized system for measuring and monitoring pain that effectively translates the subjective experience into one that can be communicated to others with responsibility for patient care. Unrelieved pain diminishes the patient's quality of life and the ability to cope with other aspects of care. By addressing these potential stressors the nurse enables the patient to conserve energy that is also needed to attend to the other demands of care and devote needed energy to coping with end of life issues. In her work on death and dying, Kubler-Ross (1975) talks about death as the final stage of growth during which one ought to "begin to transcend your individual existence...and face your final end with peace and joy, knowing that you have lived your life well" (p.145). However, as Aronheim and Weber (1992) point out fear of pain and the attendant sense of helplessness and hopelessness leads to despair even

in the patient determined to cope with a serious or terminal illness--the resolve to continue the struggle may diminish in the face of unremitting pain and suffering. The nurse is in a significant position, as illustrated by this model, to influence the degree to which the person is able to cope and adapt by attending to the basic level comfort needs. Ultimately this may influence the choices the person may make that affect positions on the life/death or comfort/suffering continuum, especially with regard to the desire for voluntary physician assisted dying.

Assumptions

The assumptions on which this study is based are derived from the author's model and current pain literature. Specifically, these assumptions include:

1. Many patients who experience pain suffer needlessly (Marks & Sachar, 1973; Melzack, 1990).
2. Patient advocacy is a fundamental nursing role.
3. Pain control is a basic physiologic level need and must be adequately controlled before the individual can achieve higher level needs (Maslow, 1954).
4. Fear of unrelieved pain contributes to feelings of helplessness and hopelessness and are significant factors in patient requests for physician assistance in dying (Aronheim & Weber, 1992; Breitbart, 1982, 1990).

Research Questions

The problem of study was to analyze and derive themes from the written responses of oncology nurses to a vignette about physician assisted dying and opinions about pain management. The themes were categorized and quantified to reveal the predominant concerns of the respondents and the context in which nursing practice decisions are made. Specific questions for this original research, not addressed in the previously collected data and analysis were:

1. What are the concerns of oncology nurses as identified in responses to a vignette on assisted dying in which "profound suffering" is a prominent feature?
2. What are the concerns of oncology nurses as identified in response to a question about the degree to which physical pain can be effectively managed?
3. What are the concerns of oncology nurses as identified in response to a question about the degree to which pain is adequately relieved in the patients for whom they care?

Definition of Terms

For the purposes of this study the following definitions have been applied:

Voluntary, Physician Assisted Dying (PAD): a medical

procedure that will humanely terminate the life of a **competent, terminally ill adult** who freely requests such assistance. This procedure could be carried out by the physician or a designee of the physician (Young et al., 1993).

Terminally ill: state of advanced disease for which there is no further treatment other than supportive care, operationally defined as having a prognosis of 6 months or less confirmed by two physicians (Young et al., 1993).

Adult: a mature individual able to make independent decisions, operationally defined as anyone 18 years of age or over.

Competent: an individual capable of making decisions affecting treatment, operationally defined as being oriented to time, place, and person; able to comprehend treatment options and outcomes of these options (Young et al., 1993).

Effective Pain Management: The degree to which it is believed that pain can be managed in cancer patients operationally defined as the rating selected in response to Question #4 of the NARPAD instrument where 1 = poorly controlled and 4 = effectively controlled (Appendix C).

Adequate Pain Management: The degree to which it is

perceived that pain is actually managed in cancer patients cared for by the respondent operationally defined as the rating selected in response to Question #5 of the NARPAD instrument where 1 = Almost Never and 4 = Most of the time (Appendix C).

Limitations

Participation in this study was limited to oncology nurses who are members of a national oncology nursing professional society. Nurses who are active in a professional organization and who take the time to respond to such surveys may represent different beliefs and values than nurses who do not belong to the society or those who do not respond. Therefore generalization of the findings to other oncology nurses or other nursing populations will be limited. One of the inherent limitations in qualitative research is the subjectivity of the process (Fields & Morse, 1985). In this study, the analysis of the data was undertaken by a single researcher with limited experience with the method, and as is true of most qualitative research, there are often many ways to interpret such subjective data. Interpretation may also be influenced by researcher bias.

Summary

The subject of euthanasia or physician assisted death

is controversial and often emotionally charged, not only for the individuals considering such options, but for their families and the professionals who care for them.

Currently, active measures to end the life of a terminally ill patient is illegal in most of the civilized world. In The Netherlands euthanasia was recently legalized, but for years Dutch courts had been lenient and exercised restraint in taking action against physicians who openly assisted patient's voluntarily requesting such assistance. The relaxation of bans against euthanasia and intense media attention in the United States on movement by the Hemlock Society and the actions of Dr. Kevorkian have stirred a national debate on the many ethical, legal, religious, and moral issues surrounding the call for legitimate ways to end life in order to relieve pain and suffering.

Nurses play key roles in caring for the terminally ill, therefore it is critical that this issue be thoroughly examined for implications for nursing practice. There is very little precedent in the literature to guide nurses, who are on the front line in patient care, and likely to be involved in evaluating patients who wish to consider asking for assistance in dying. The purpose of this study was to explore answers to the research questions asked and to raise consciousness, encouraging nurses to work proactively to respond to issues that ultimately affect nursing practice.

CHAPTER 2

REVIEW OF LITERATURE

The issues surrounding the topic of euthanasia or physician assisted dying are many and varied ranging from intensely personal beliefs to those factors that shape professional, ethical, and social behavior (Jennings, 1991). Strong arguments exist in our society for autonomy of the individual and the debate to apply these arguments to end of life decisions that ultimately control the conditions of dying is increasing in frequency and intensity. The implications of such decisions are raising equally strong concerns about the potential impact on society. For nurses, these issues frequently converge, placing the nurse in a pivotal if tenuous position of influencing care with limited direct authority in the decision-making process and prescribing of care. This sometimes awkward position creates what Jameton (1977) has described as the "nurse in the middle" phenomenon. Robinson (1990) also addresses this issue in pointing out the difficult position nurses may be placed in when asked to carry out decisions (such as non-treatment orders, withholding food or fluids etc.) that they were not involved in making, placing nurses at odds with the

primary nursing duty of giving care and comfort.

This chapter addresses the significant research and writings that have shaped this study. First the relationship of pain and suffering to requests for assistance in dying will be discussed within the context of the patient with cancer. Subsequent sections will focus on the roles and attitudes of nurses, roles and attitudes of other health care providers, and professional and public debate on the issues. A summary of the discussion concludes this chapter.

The Relationship of Pain and Suffering to Requests for PAD

Fear of pain and suffering is an important contributing factor in placing patients at risk for suicide or influencing the decision to seek assistance in dying. The magnitude of that risk has yet to be adequately estimated, partly due to the difficulty in collecting data and separating out other factors that contribute to the death of a terminally ill patient. In 1979, Louhivuori and Hakama reported on a study of cancer patients in Finland based on a review of the Finnish Cancer Registry from 1955 to 1970. Although it was a limited, retrospective study, they found that the suicide rate among male cancer patients was 1.3 times higher ($p < 0.001$) and among females it was 1.9 times higher ($p < 0.05$) than in the general population.

A study conducted in Connecticut reported by Fox, Stane, Boyd, and Flannery in 1982 revealed no differences in suicide rates for the cancer patient population when compared with the general population. Bolund (1985a) reported on a study conducted in Sweden covering the years 1973 to 1976 in which it was found that among every 1,000 persons who died of cancer, one committed suicide. Therefore, suicides in cancer patients represent about 1.4 percent of the total population known to have committed suicide. Bolund (1985b) also reported that more than half of the suicides occurred in the first year following diagnosis, and that two-thirds had advanced disease with severe symptoms.

Breitbart (1982) examined the relationship of cancer pain to suicidal ideation with serious intent to act in a series of 71 cancer patients. It was found that virtually all of the suicidal cancer patients (those with intent to act) had a concurrent psychiatric disorder, such as mood disturbance or organic mental disorder, at the time they were evaluated. In a subsequent study, 185 patients with cancer-related pain were interviewed revealing that 17% of them reported suicidal ideation but had no plan to act. Breitbart states that this evidence suggests that it is not only the degree of pain, but the perception of suffering that plays a role in suicide in cancer patients. He also

concludes that perceptions of poor pain relief may have more to do with aspects of hopelessness than the intensity of the pain. Hopelessness was found to be the key variable linking depression to suicide.

Coyle, Adelhardt, Foley, and Portenoy (1990) also explored the prevalence of suicidal ideation and requests for euthanasia in a group of patients referred for supportive care during the last four weeks of life. Of the 90 patients studied, 18 (20%) acknowledged suicide as a potential option and 4 (4%) indicated they had a specific plan. The four patients with specific suicide plans were found to be clinically depressed. Two patients succeeded in committing suicide, both of whom had recurrent delirium. Four patients also made requests for euthanasia. All of the patients who reported considering suicide as an option had progressive disease with accumulating debility. The feature that appeared to be most prevalent in distinguishing the suicidal patients from those who were not, was a particularly severe degree of overall fatigue. Additionally, this study revealed that cancer patients have as many as 20 different symptoms interfering with quality of life in the last few weeks of life. Pain was ranked second to fatigue in incidence, with generalized weakness, sleepiness, confusion, anxiety, shortness of breath, nausea, and loss of appetite among the others.

In a review article, Foley (1991) emphasized that any debate on termination of life in patients with advanced disease must give adequate consideration to the level of care for patients with multiple, adverse symptoms, including pain. She concluded that the existing supportive care programs geared to managing the multiple symptoms found in advanced disease are insufficient to meet the needs of such a large population. Citing lack of knowledge, fear of addiction, and the existence of restrictions in the health care system as barriers to care, Foley asserts that "we need to address the access to expert care of distressing symptoms including pain and psychological distress as well as the quality of life of this patient population before we can fully address the options for terminating life (p. 289)".

One of the few concurrent studies examining patient attitudes towards suicide and euthanasia was conducted in Australia (Owen, Tennant, Levi, and Jones, 1992). One hundred patients were interviewed who were more than one month post diagnosis of cancer, and who did not have disturbed cognitive function. Patients were asked to consider a variety of potential final life events, including withdrawal from treatment, refusal of resuscitation, suicide and active euthanasia. A third of the patients interviewed perceived some role for suicide and/or euthanasia. An interesting and unexpected finding was that patients with a

worse prognosis were more inclined to reject suicide as an option while those within the group having a good prognosis showed a greater interest in suicide and/or euthanasia as a potential option ($p < 0.05$). The most common reason cited for considering these options was pain (18%). In addition to the interviews, subjects were asked to complete several questionnaires that included measures of anxiety and depression among others. There was a 63% completion rate of the questionnaires. Of those returning those questionnaires, scores on the depression and anxiety scales reflected low mean levels for both. The investigators concluded that those with the greatest distance from imminent death expressed the greatest interest in suicide and euthanasia. While the authors recognize the limitations of this study - particularly that those completing the questionnaires probably reflected a biased subpopulation (increased representation of those with a good prognosis who were better able to complete the extensive questionnaire) they project that good quality terminal care and increased patient education including methods of pain control may be a useful means of decreasing the desire to hasten death.

Suffering and pain are consistently mentioned as key variables when patients seek assistance in dying, yet the issue of suffering covers a much broader context than the physical pain or other symptoms such as fatigue, nausea, or

weakness that are so prevalent in terminal illness. Cassell (1982) elucidates the distinction between pain and suffering by pointing out that it is the body that experiences the pain or physical distress, but it is the person that suffers. Furthermore, suffering has at its core, challenges that threaten "the intactness of the person as a complex social and psychological entity" (p. 639). Because suffering is unique to each individual that it affects, it is difficult to define or measure suffering in a meaningful way that can be generalized to all individuals. Cassell (1991) has also noted that persons begin suffering with the "inability to accomplish their previously important purposes," and when they "become aware of what the future holds" (p.25). He further states (1982) that failure to understand and address suffering can result in interventions that, while they may be technically adequate, not only fail to relieve suffering but actually become a source of suffering.

For many the distinction between withholding treatment and active termination of life is blurred. Furthermore, many are concerned that the treatment of pain to the degree necessary to provide relief of suffering is, in itself, a measure that hastens death. There continues to be much fear that pain treatment, particularly with narcotics in high doses, is equivalent to euthanasia.

Concern that treating pain will contribute to death has been raised in numerous ethical discussions and has given rise to what is known as the "principle of double effect." Latimer (1991) describes this as a procedural principle that guides decision-making when there is a difference between the intended effects of an action such as providing medication for pain relief, and the foreseen but nonintended effects such as respiratory depression. The Catholic Church officially recognized this principle in 1980 in its Declaration on Euthanasia read by Pope Pius XII stating "In this case, of course, death is in no way intended or sought, even if the risk of it is reasonably taken; the intention is simply to relieve pain effectively, using for this purpose painkillers available to medicine" (p.4). Experts in palliative care, however, challenge the notion of the principle of double effect by pointing out that, for various reasons (including tolerance to respiratory depressing effects of the narcotics), death is rarely linked to pain-relieving doses of narcotics and fear of causing death should not interfere with effective pain management (Coyle et al., 1990, and Foley, 1991).

Attitudes and Roles of Nurses

In order to shed light on the implications euthanasia holds for nurses, Kuhse and Singer (1992) conducted a parallel survey to one conducted in 1988 with physicians.

They surveyed Australian nurses using the same questions asked of the physicians with some additional questions related to the specific roles of nurses. In the nursing survey, questionnaires were sent to 1942 nurses in the Australian state of Victoria. A response rate of 49% was achieved. Fifty-five percent (502) of the respondents indicated they had been asked by a patient for assistance in hastening death through the withdrawal of treatment or more active steps. When asked to rank order six listed reasons for such requests, persistent and unrelievable pain was ranked first by 165 nurses followed by terminal illness (71), infirmities of old age (54), incurable condition (42), not wanting to be a burden (22), and being afraid of a slow dying process (21). In another question, 95% indicated that they believed a patient's request to hasten death can sometimes be rational. While 5% of the respondents indicated they had complied with a patient's request to directly end his or her life, more than 50% responded that they had not complied, but did not believe that active euthanasia is morally wrong. Sixteen percent said they rejected the request either primarily or solely on the basis that such action is morally wrong. When asked if they felt it would be a good thing for Australia to adopt regulations similar to those in the Netherlands allowing euthanasia in controlled situations, 75% responded positively. Two

thirds of the nurses also indicated that it would be proper for nurses to assist doctors in actively and directly ending a patient's life under circumstances such as those adopted by the Dutch.

Most of the findings of the Australian nurses' study paralleled those of the earlier physician study. The key difference was that nurses were more willing to be involved in the practice of voluntary euthanasia (68% compared with 40% of the physicians). The investigators concluded that greater support for voluntary euthanasia among nurses may reflect the close relationship they have with patients and consequently, a greater understanding of their circumstances.

In a comparison of U.S. and Australian nurses', Davis and Slater (1989) studied attitudes and beliefs about the "good death" by asking nurses to respond, in an interview setting, to eight hypothetical vignettes depicting situations in which patients were likely to die. The vignettes covered a broad variety of situations ranging from a 33 year old quadriplegic who wanted to die and was refusing to eat to an elderly woman with terminal cancer. The investigators asked the subjects to respond to each by answering the questions, "What is usually done?" and "What ought to be done?" Of the eight vignettes, there were only two in which the American and Australian nurses agreed on

both what was usually done and what ought to be done. In general, where there was disagreement between the two groups, the Americans reported believing that the patient would be treated more often than did the Australians. Americans were also found to be more ambivalent about the withholding of food and fluids. The Americans tended to separate feeding - seen as a duty of nurses to provide - and medical care that could be withheld ethically. The investigators concluded that the lack of agreement between Australian and American nurses is most likely a reflection of the differences in the health care systems, social position of nursing as a profession, and the role of law in health care decisions.

Attitudes of registered nurses toward euthanasia were studied by Shuman, Fournet, Zelhart, Roland, and Estes (1992) in order to identify variables that contribute to attitude and behavior, based on their observation that most of the research to date has been done on attitudes and little on behavior. They hypothesized that attitudes may not predict the behavioral response related to life and death choices. Using the Euthanasia Ideology Scale (EIS) to measure beliefs and the Euthanasia Behavioral Items Scale (EBIS) to measure endorsement of cases involving active or passive acts of euthanasia, 137 subjects who responded to the mailed survey and were later contact by phone for an

interview, were studied. Their findings suggest four factors underlying euthanasia attitude: belief in an afterlife, nursing experience, liberal or conservative political view, and personal values. Those with strong religious beliefs and years of nursing experience, along with a view of death as an end (as opposed to a beginning) were more likely to oppose euthanasia. Subjects reporting they had a liberal political view, who worked with the terminally ill and believed patients should have personal responsibility for health care decisions were more likely to favor euthanasia.

In the quantitative analysis of the data collected for this study Young, Volker, Rieger, and Thorpe (1993) explored oncology nurses' attitudes in a survey sent to 2000 randomly selected members of the Oncology Nursing Society. Subjects were asked to respond to four vignettes depicting different situations in which a competent, terminally ill adult requested physician assisted dying (PAD). Responses to the vignettes indicated what actions the nurse would take in that situation if PAD were legal. Each vignette addressed a different issue designed to illicit the importance of relationships with patients in assisted dying, the willingness of the nurse to actually administer medications to cause death, and the influence of pain and suffering on beliefs about the appropriateness of PAD. Nurses were also

asked to indicate their awareness of the existence of various organizations involved in death issues, project how they might vote on proposed legislation, and to express their opinions about the status of pain control for cancer patients.

The key finding was that nurses hold varied beliefs regarding PAD. Those beliefs range from being willing to accept PAD as a legitimate choice and offering full support of patients in the process to not only believing that such action is wrong, but being unwilling to participate in any way. In the first vignette, in which the nurse had a long-term relationship with the patient, 44% agreed with PAD and would be present with the patient as requested when medication was administered to cause death. Another 2% agreed with PAD but would not be present. Twenty-nine percent disagreed with PAD but would be present, while 24% indicated they neither agreed nor would be present.

In the second vignette, one in which there was no prior nurse-patient relationship, 37% agreed with PAD and would be present, 8% agreed and would not be present, 23% disagreed and would be present, and 30% neither agreed nor would be present. The third vignette asked the respondents to consider whether they would actually administer medications to directly cause death if asked to do so, assuming such action was legal. Only 15% indicated that under such

circumstances would they agree with PAD and administer the medication. Another 34% agreed with PAD but would not administer the drugs. Two percent would administer the medication in spite of being opposed to PAD, and 47% disagreed with PAD and would not administer the medication.

The final vignette, and one that serves as a focus for this study, dealt with the issue of suffering. Nurses were asked to consider a situation in which the patient tells them repeatedly that she has "suffered too much, too long." Under these circumstances 48% indicated they agreed with PAD and would be present to support the patient, and an additional 9% agreed, but would not be present. Although disagreeing with PAD, 16% would be present and another 24% disagreed and would not be present.

In the awareness and opinion section of the questionnaire, nurses indicated that they were relatively aware of the various organizations and initiatives in support of PAD such as the Hemlock Society. Nurses were evenly divided as to whether they would support legislation to legalize PAD with 47% indicating that they would vote favorably and 46% would vote against it. Five percent were unsure how they would vote.

In comparing nurses responses to various demographic characteristics the only significant association was with religious beliefs. In each of the vignettes, nurses who

identified themselves as Catholic were less likely to accept PAD than those who were Protestant, while nurses who were Jewish, agnostic, or athiest were stronger supporters of PAD. Catholic nurses were also the least likely to vote for legalization of PAD. Analysis of practice setting and responses revealed no strong associations. While support for PAD was lowest among hospice nurses, the difference was not statistically significant.

One of the more revealing findings of this study was that many nurses who do not believe in PAD would still be willing to support patients who request it, and a few would even be willing to administer the drugs prescribed to cause death. This suggests that many nurses are able to separate their own beliefs from those of their patients. This ability may be a reflection of how nurses view their role as patient advocates and the empathy they are able to offer in difficult situations.

Attitudes and Roles of Other Health Care Providers

In the study that preceded their nursing study, Kuhse and Singer (1988) reported on the results of a survey of attitudes and practices of physicians in Australia with respect to patient requests for assistance in dying. Of the 2000 randomly selected doctors contacted, 869 returned completed questionnaires. A majority of the respondents

(62%) indicated they felt it was right for a doctor to take active steps to bring about the death of a patient who has made such a request. Of those respondents 354 (40%) indicated they had been approached by patients who asked them to hasten death (including withdrawal of treatment as well as active assistance). One hundred and seven (29%) of the respondents replied that they had actually taken steps to bring about death at the request of a patient. The reason cited by most of the physicians who rejected assisting patients related to the illegality of the act.

In 1990 the Journal of Long-Term Care Administration conducted a survey of its readers to examine the issues related to euthanasia and assisted suicide (Hiller and Sugarman). Of the 6425 surveys published, 193 were returned. A majority of the respondents (74%) held non-clinical, administrative positions in long-term care facilities. Of those responding, 76% indicated they believe terminally ill patients should have the legal option of ending their life. Respondents were also asked their opinions about keeping patients alive with life-support systems despite stating their wishes to the contrary, to which 95% responded no. In a related question, relevant to the issue of euthanasia, the respondents were asked: "Do you believe the cost of prolonged life (i.e., financial hardship on the family and/or the state), should be a consideration

in the decision to end life-support systems?" Responses were divided with nearly 46% indicating "yes" and 49% indicating "no." Respondents were also asked to indicate who should be allowed to assist in hastening death. Physicians were identified by 58%, family members by 39%, nurses by 18%, patient's designee by 54%, and nursing home personnel or others by 13% (respondents could check all individuals who should take part in the process).

Professional and Public Debate

Admiraal, a Dutch anesthesiologist and well known proponent of euthanasia (1988), believes "that every doctor has the right and the duty after prolonged and thorough deliberation to carry out euthanasia" (p.368). He maintains that this should only be an act of last resort and assumes that such decisions are the result of a lengthy discussion and decision process by a patient who is fully aware of the consequences of his request. In such a context Admiraal sees euthanasia as "the ultimate act of care for the dying" (p.362). With respect to the issue of pain, he admits that not all methods of controlling pain are known or available everywhere, but does not specifically address the consequences or implications of undertreatment as an issue. He focuses most of his argument on the long list of potential causes of physical and psychological suffering.

In 1987 a special panel of physicians (Wanzer, Federman, Adelstein, Cassel, Cassem, Cranford, Hook, Lo, Moertel, Safar, Stone, and van Eys) was convened under the auspices of the Society for the Right to Die to discuss physician responsibilities towards patients who are hopelessly ill. One of the principle issues addressed was the problem of undertreatment of pain and its contributions to suffering and requests for assistance in dying. The panel acknowledged that one of the most pervasive causes of anxiety among patients, their families, and the public is the perception that pain will not be adequately treated, and that to a large extent those fears are justified. The key role identified for the physician was to provide a flexible and individually tailored plan of care to meet changing needs as disease progresses. This they referred to as "the principle of continually adjusted care." They concluded that if such care is administered properly at the end of life, only the rare patient should be so distressed as to seek assistance in hastening death. Although the panel did not openly endorse assisted suicide (in which the final act is performed by the patient) or euthanasia (final act performed by physician) they emphasized the need for the physician who might consider assisting in death to carefully determine that the patient is, indeed, beyond all help and not simply suffering from a treatable depression. The

majority of the panel members agreed that it is not immoral for a physician to assist in the rational suicide of a terminally ill patient. Two of the panel members (van Eys and Cassem) offered dissenting views of the morality of such acts.

Following publication of the controversial column written by an anonymous doctor "It's Over, Debbie" in The Journal of the American Medical Association (1988) in which the physician recalls the details of his act of active euthanasia, Fowler (1988) responded with a rebuttal. Pointing out prohibitions against killing by health professionals by both the American Medical Association (AMA) and the American Nurses' Association (ANA), she emphasized that "killing is intrinsically incompatible with the ends that both professions seek, and that killing is a violation of the social contract that these professions have with society" (p. 323). Fowler also noted that both the AMA and the ANA have produced statements labeling participation in the administration of capital punishment as being morally impermissible (ANA, 1988; AMA, 1986) citing that participation in such acts would violate the trust patients place in their relationships with physicians and nurses. "Taking human life whether 'innocent and suffering' or 'criminally guilty' is generally considered to exceed the moral boundaries of both professions" (p. 323).

In a poignant commentary affirming opposition to euthanasia, Scott (1988) warns of the likelihood that a patient's laments and cries for an end to suffering will be misinterpreted. The lament expressed by patients is an expression of total pain, a state of suffering encompassing the physical complaints, sorrow over unfulfilled dreams, loss of function and role, and anticipatory grief over the family's future distress. He maintains that rather than rushing to end the patient's struggle, health care providers need to learn to listen actively and provide pain relief and palliative care.

Concern for potential abuse of power has led many other professionals to oppose legalization of euthanasia or assisted suicide. Lynn (1988) states that "there are too many people whose hold on life is fragile and whose existence is burdensome on others, who might be induced to make this choice if it were readily available" (p.102). She acknowledges that some patients might reasonably prefer assistance in dying and that if their choice is denied, they would be forced to suffer against their wills. However, in attempting to weigh these issues, she believes that the potential number of "unwilling survivors" would be very small and that with effective palliative care, the burden of their suffering can be substantially mitigated.

Unfortunately, many barriers exist to the provision of

effective pain management and palliative care. In 1989, Hill, Fields, and Thorpe issued a "Call to Action" in summarizing the proceedings of a national conference held to address the issue of the treatment of pain in a drug-oriented society. They cite three categories of barriers that need to be addressed to assure that effective pain management is available to all. Those key barriers include: cultural and attitudinal barriers such as the failure to distinguish between legitimate and illegitimate use of narcotics and the influence of the values of the care-giver on the quantity and quality of pain relief offered the sufferer; knowledge deficits regarding the pharmacology of narcotics and the distinction between dependency and addiction; and influences of governmental regulations including ambiguous drug laws and regulations and the "criminalization" of narcotic use by regulatory officials.

The public response to the myriad of issues surrounding the right to die and death with dignity movements has been gaining momentum in recent years. Beginning with the book Jean's Way (1978) and culminating in the publication of Final Exit (1991), the so-called "suicide manual", Derek Humphry has led the Hemlock Society he formed in 1980 to the forefront of the public debate. Many see his efforts as the answer to untold suffering and loss of dignity for those facing terminal illness. Betty Rollin, who in her own book

Last Wish (1985), recounts her mother's experience with ovarian cancer and her role in assisting her mother's "fight to die," has added to the groundswell of support for legalized euthanasia.

In a Gallup Poll commissioned by the Hemlock Society in 1990 (Humphry, 1992), 58% of the 1,018 adult respondents indicated they thought a person has the moral right to end his or her life when the person has an incurable disease. When great pain and suffering with no hope of improvement is factored into the equation, support rose to 66%, whereas only 33% felt it acceptable if the rationale was the heavy burden placed on the family. Only 16% favored ending life in an otherwise healthy person who desired to do so.

The activities of Dr. Jack Kevorkian, the Michigan pathologist known as "Dr. Death" has stirred the debate even further. Shortly after Kevorkian aided his first patient, a 54 year old woman afflicted with Alzheimer's disease, The New York Times and CBS News conducted a telephone poll (Malcom, 1990) asking the question: "If a person has a disease that will ultimately destroy the person's mind or body, and the person wants to take his or her own life, should a doctor be allowed to assist the person in taking his or her own life?" Fifty-three percent responded "yes" and 42% responded "no". Six percent didn't know or didn't offer an opinion. Those most likely to agree included

younger adults, liberals, and men.

In an editorial published in The Los Angeles Times during Dr. Kevorkian's first trial, Bolte (1990) a writer and polio victim confined to a wheelchair, raised the concerns of many disabled people who both welcome and dread the ensuing debate. He raises the fear that Kevorkian's trial would "provide a platform for the hidden prejudices against disabled people - and end with a judicial imprimatur for killing us" (p. B7). He recounts his own despair and deep depression at one point in his life and reveals that if Dr. Kevorkian had been available to him at the time, he might not be living and writing today. He also points out that if people more carefully examined the issue, projecting themselves into positions of disability and despair, they would realize that the impulse to die comes more from the fears of financial devastation, being a burden, and being isolated and unloved - factors that "have nothing to do with the disability itself and everything to do with the response of society to the disabled" (p.B7).

In a subsequent editorial following later suicides assisted by Dr. Kevorkian, Ellen Goodman (1992) recalls the onslaught of protest mail she received following an earlier column in which she depicted Dr. Kevorkian as a "serial mercy killer" and suggested that he had stepped outside the boundaries of ethical behavior. The mail she received was

from people "who fear dying more than death" and who view Kevorkian variously as a "patron saint of medicine" or as "an angel of mercy" (p. A21). She goes on, however, to point out the pitfalls of Kevorkian's methodology and raises serious questions about his lack of clear guidelines, stating that he is "pouring grease down a slippery ethical slope" (p.A21).

While there is general recognition that pain is undertreated, the degree to which undertreatment is a factor has not been clearly established. Admiraal (1988) and Humphry (1991) seem to imply that, given the lack of access by all patients to the most skilled pain treatment, euthanasia and suicide are acceptable alternatives. A review of the works by those who advocate for better implementation of known, effective methods of pain treatment (Wanzer et al., 1987, Fowler, 1988, Lynn, 1988, Scott, 1988, and Foley , 1991) suggests that increasing emphasis on euthanasia as a way out abrogates the professional's responsibility to treat pain and suffering and underscores the concern that many have that hastening death is merely an expedient measure that is subject to considerable potential abuse.

In their book Final Passages: Positive Choices for the Dying and Their Loved Ones, Ahronheim and Weber (1992) strive to show how the dread of facing pain and suffering at

the end of life can be controlled and overcome. Intended to offer medically sound advice to the dying and their families, the authors address how medical technology can help manage pain and depression by taking control of the dying process and alleviating the fears patients have of "being rendered passive victims of their disease" (p.114). Furthermore, they emphasize the right to effective control of pain and suffering, and urges patients and family members to demand such treatment when it is not readily offered.

Summary

Clearly the debate surrounding the acceptability of euthanasia and related issues is far from settled. Ending life in the face of terminal illness is an emotional issue that sparks many strong feelings on both sides of the debate. While there is a discrepancy in views among health care providers, there tends to be a more consistent trend towards acceptance by the public as reflected in various opinion polls, although the size of the majority is variable (Malcom, 1990, Humphry, 1992).

While there is no concrete data to date to provide answers to health professionals in determining the roles they should play, there is evidence that nurses are important to the assessment and decision-making process. Nurses have more intense relationships with patients than most other health care providers and those relationships are

important to patient outcomes (Kuhse and Singer, 1992, Young et al., 1993). Nurses, by the nature of their relationship are in a position to have a greater appreciation for the plight of their patients. Furthermore, nurses may be better able to separate their personal values and beliefs from those of their patients in order to support patients in their decisions (Young et al., 1993).

CHAPTER 3

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

The methodology for this study consisted of a descriptive, explanatory research design using the technique of content analysis and a grounded theory approach to study the perceptions and concerns of oncology nurses who care for patients with persistent physical pain and its attendant suffering and who may ultimately request assistance in hastening death. The grounded theory approach is considered to be a form of ethnographic research and is primarily an inductive approach to theory development. Ethnographic findings can be used to generate new research questions and establish a basis for subsequent quantitative and predictive studies (Leininger, 1985).

Setting

Data collection for the study was accomplished by sending the surveys to oncology nurses using a randomly selected list of mailing addresses of the members as supplied by the Oncology Nursing Society. The Oncology Nursing Society maintains both work and home addresses of its members but conducts its mailings based on the address the member indicates is preferred for the receipt of mail

from the society. The survey was then completed at the discretion of the recipient and returned in an addressed, stamped envelope supplied with the survey.

The survey was conducted during the summer of 1990 when considerable attention was given to this subject by the media and public awareness of the issue was heightened.

Population and Sample

The population for this study consisted of members of a professional specialty organization who practice nursing in the United States. The sample was derived from a survey sent to 2,000 randomly selected oncology nurses across the United States who are members of the Oncology Nursing Society. This sample represented approximately 10% of the membership and included a subset of 150 nurses who were identified as working in hospice settings. This stratification of the sample was chosen to assure representation of nurses who actively care for terminally ill patients.

The Oncology Nursing Society was established in 1975 and to date has nearly 20,000 members representing all states, U.S. territories, and 22 foreign countries. Its membership consists of nurses practicing in a variety of clinical, academic, and private practice or business settings. The members function in a variety of roles

including direct patient care, management, advanced practice, education and research. All levels of professional basic and advanced nursing preparation are represented in the membership. Members of the society may also join a variety of special interest groups that have been organized to meet the needs of nurses practicing in subspecialty areas. Among these groups are the Pain Management Special Interest Group and Hospice Special Interest Group. Both special interest groups have been active in addressing the issues of patients requiring specialized nursing care for the alleviation of pain and suffering in terminal illness.

Protection of Human Subjects

This study was exempt from review by the human subjects committee as the data had been obtained from a survey previously conducted and no new participation of human subjects is required. The earlier study in which the survey was conducted was reviewed and subsequently funded by the Texas Division of the American Cancer Society. In this process, due attention was given to protection of the subjects. No other institutional review was required prior to conducting the survey.

A cover letter explaining the study and requesting consent to participate accompanied the survey (Appendix A). Emphasis was placed on the voluntary nature of the study

and that subjects were free to refuse to participate or withdraw from the study at any time without penalty. Confidentiality was assured in the letter, and no names or identifying marks were placed on the questionnaire. Findings of the portion of the study already completed have been reported by grouping data so that individual identities are protected. The findings of this portion of the study will be reported in the same manner. Participants were also given a phone number of one of the researchers they were free to contact if they had any questions to be answered. Follow-up post cards were sent to nonrespondents three weeks after the initial mailing to encourage added response. Although not planned by the investigators, the survey was conducted approximately one month following the occasion on which Dr. Kevorkian first assisted a woman in committing suicide by providing her with a specially constructed intravenous delivery system--the so called "suicide machine"--that allowed the patient to actually start the flow of the medication that would cause her death (Belkin, 1990). Subsequently, awareness of this issue was greater and may have contributed to the attainment of a 61% response rate (n=1210) and the wealth of comments to the open ended portions of the survey and from which this study was derived.

Instruments

Data were collected using a demographic data record (Appendix B) and the Nurses' Attitudes Regarding Physician Assisted Dying (NARPAD) Questionnaire (Appendix C).

Demographic Record

The demographic data collected includes age, gender, state of residence and practice, number of years in oncology nursing, position and functional area, patient population, type of practice setting, area of practice, and religious affiliation.

NARPAD Questionnaire

The NARPAD questionnaire was developed for the purposes of the survey by the researchers (Young et al., 1993). It consists of four vignettes depicting hypothetical situations that nurses might encounter. Each vignette has four options dealing with the beliefs of the nurse and actions the nurse might take in that situation. Respondents were asked to select the response that most closely reflects the decision that would be made in that situation. Space was provided following each vignette and respondents were encouraged to comment regarding the choice that was made. Each vignette is introduced with the following statement in bold type: "Assuming that physician assisted dying for competent, terminally ill patients requesting such assistance is

legal:...." This phrase was intended to establish a uniform context for the responses. The options for each vignette address the nurse's beliefs and willingness to act as requested.

The first vignette (Situation #1, Appendix C) relates a situation in which the nurse has been caring for the patient for several years who has chosen to have his physician assist him to die and requests the nurse to be present when the drugs that will cause his death are administered.

The second vignette (Situation #2, Appendix C) is similar except that the nurse does not know the patient. In the third vignette (Situation #3, Appendix C) the focus is on the possibility that a physician has written an order for medications to cause death but the nurse is asked to carry out the order by actually administering the drugs.

The final vignette (Situation #4, Appendix C), and the one most relevant to this study, describes a situation in which the patient repeatedly voices that she "has suffered too much, too long" and wishes to have her life terminated.

Following the vignettes, subjects were asked to respond to questions indicating their degree of awareness about issues related to the topic. Specifically, they were asked if they were aware of existing organizations involved in death issues and proposed legislation aimed at legalizing physician assisted death practices. They were also asked to

indicate whether or not they would favor such legislation.

To further address the issue of pain and its impact on terminally ill patients who might consider requesting assistance in dying, subjects were asked two questions accompanied by a likert scale for rating the responses. First, subjects were asked for their opinion on the degree to which physical pain can be controlled in the terminally ill. They were then asked to rate the degree to which they believed cancer patients they know receive adequate relief of physical pain. Again, for each of these questions, space was provided for open-ended comments regarding their choices.

Content validity of the instrument was established through consultation with a panel of experts consisting of two ethicists and an oncology nurse specialist whose area of expertise includes grief counseling and hospice care. A pilot study was conducted with 76 members of a local Oncology Nursing Society chapter to assess the readability and clarity of the instrument. Several changes in wording were made as a result of the pilot study.

Data Collection

The material studied was taken from the open ended responses to Situation #4 and questions four and five of the NARPAD instrument. This study represented the first qualitative analysis of this portion of the survey data.

The content specific to the purpose of this study is taken from the comment sections following Situation #4 (dealing with the issue of suffering), the question regarding voting choices, and the two questions asking for ratings about pain relief. A total of 486 questionnaires (40% of the parent sample) with 643 responses (254 to Situation #4 and 389 to questions four and/or five) was received and were analyzed.

Treatment of Data

The written comments obtained from the survey were transcribed and compiled using a word processing program identifying each with the subject number assigned to the survey to allow for comparison of the responses to the demographic data. The investigator first read through each response to become familiar with the content, an immersion process, that leads to formation of concepts (Leininger, 1985). This process is also described as latent content analysis in which the major thrust and significant meanings of the material are identified (Fields & Morse, 1985).

During the second reading of the material the data (consisting of words and phrases surrounding a distinct concept) were highlighted, coded, and categorized. These codes were entered into the computer to facilitate a quantitative analysis of the content allowing for reduction of the categories to establish the major themes. This phase is referred to as manifest content analysis and affords a

measure of reliability because of its numeric objectivity (Fields & Morse, 1985). In this way categories can be linked, higher-order categories can be developed, and a taxonomy of the concepts can be formulated (Fields & Morse, 1985; Leininger, 1985).

Once the themes were identified, categorized, and coded, they were examined for frequency of citation of the various themes. The themes were then collapsed into three higher level categories and subjected to chi-square analysis in order to reveal the key concerns of the oncology nurses who responded to the survey. The final process then, will be to begin the process anew by formulating new propositions and hypotheses for further study.

CHAPTER IV

ANALYSIS OF DATA

In this exploratory study the technique of content analysis was used to study the perceptions and concerns of oncology nurses who care for patients with persistent physical pain and its attendant suffering, and who may ultimately request assistance in hastening death. Specifically, the investigator sought to identify: (a) the concerns identified in responses to a vignette on assisted dying in which "profound suffering" is a prominent feature, (b) the concerns identified in response to a question about the degree to which physical pain can be effectively managed, and (c) the concerns identified in response to a question about the degree to which pain is adequately relieved in the patients for whom they care.

The study was undertaken in order to determine the context within which oncology nurses make judgements that are necessary to formulate nursing interventions to treat pain and suffering and to respond to requests for assistance in dying. Through the use of a blend of quantitative and qualitative techniques the focus of nursing concerns emerged. A description of the sample, analysis of the

findings, and a summary are presented in this chapter. Examples of comments are provided to illustrate the major themes and subcategories that emerged from analysis of the data.

Description of the Sample

The sample was derived from questionnaires returned by 486 oncology nurses who added comments in the space provided on the Nurses' Attitudes Regarding Physician Assisted Dying (NARPAD) survey. There were 254 narrative comments to Situation #4 (a vignette dealing with the issue of profound suffering) and 389 narrative comments to questions four and/or five (providing ratings on the ability to control physical pain and the degree to which it is actually controlled). The age range of the sample was 26 to 72 years with a mean age of 42. The sample was predominantly female (475, 97.7%) and had a mean of 17.9 years experience in nursing with a range of four to 48 years. The mean experience in oncology nursing was 11.3 years with a range of zero to 47 years. Basic nursing education preparation consisted of 246 nurses (50.6%) holding a bachelors degree, 158 (32.5%) with a diploma, 73 (15%) with an associate degree, and 9 (1.9%) in other categories. A substantial number, 244 (50.2%), of the nurses attained a degree beyond their basic education including 219 (45.1%) with masters degrees and 17 (3.5%) with a doctorate.

Religious preference was cited as Roman Catholic by 197 (40.5%), Protestant 196 (40.3%), Agnostic/Athiest 30 (6.1%), Jewish 19 (3.9%), and Other 35 (7.5%) by the respondents. Most (386, 79.4%) were employed full time, while 85 (17.5%) worked part time, 5 (1%) indicated they were retired, and 9 (1.9%) were unemployed. The majority (376, 77.4%) indicated they worked with adults while 8 (1.6%) indicated they worked with a pediatric patient population. Seventy (14.4%) indicated they work with both adults and children while 24 (4.9%) indicated they had no patient population. Practice area was listed as patient care for 290 (59.7%), administration 67 (13.8%), education 58 (11.9%), research 19 (3.9%), and other 51 (10.5%). The practice settings were more diverse and are illustrated in Table 1.

The sample of nurses responding with narrative comments following one or more of the vignettes and questions closely reflects the original sample of 1210 who returned surveys with only one exception. Nurses who indicated they practice in a hospice setting represent 12.6% (n=61) of this study sample compared with 7% (n=90) of the original sample (Young, et al., 1993). Therefore, 67.7% of the hospice nurses responding to the survey did so with explanatory comments compared with only 37.9% of nurses from other practice settings. When subjected to chi-square analysis

Table 1

Practice Setting of the Respondents

	<u>n</u>	<u>%</u>
Hospital	196	(40.3)
Ambulatory Care	64	(13.2)
Hospice	61	(12.6)
Comprehensive Cancer Center	41	(8.4)
MD Office/Pvt Practice	33	(6.8)
School of Nursing	28	(5.8)
Home Care	20	(4.1)
Public Health/Community	5	(1)
Other	31	(6.4)
No Response	8	(1.6)
Total	486	

it was found that this represented a significant difference between samples ($X^2 = 5.56, df 1, p 0.05$).

Findings

The surveys were initially sorted by separating those with narrative comments from those with only forced-choice responses. The written comments were then transcribed and compiled using a word processing program identifying each with the subject number assigned to the survey to allow for comparison of the responses to the demographic data. The investigator first read through each response to become familiar with the content in an immersion process designed to lead to concept identification (Leininger, 1985). This process is also described as latent content analysis in which the major thrust and significant meanings of the

material are identified (Fields & Morse, 1985).

During the second reading of the material the identified themes (consisting of words and phrases surrounding a distinct concept) were highlighted and notes were made in the margins to facilitate subsequent categorization. The themes were then listed and grouped into general categories and the key concepts began to emerge. The comments were separated into two general lists: those relating to Situation #4 (vignette featuring suffering) and those relating to Questions #4 and #5 (pain control ability and adequacy). The comments relating to the two pain questions were considered together because the same concerns or themes were found in responses to both questions. Examples of the preliminary categorization will be provided when the specific findings are presented.

The preliminary categories were then examined closely for similarities and collapsed into more comprehensive categories with common themes. Once the categories were reduced to the key concepts, a coding system (Appendix D) was devised and a third reading of the data was begun. The purpose of the third reading was to code the comments to facilitate the quantitative portion of the analysis. The codes were then entered into the computer to determine the frequency with which the various comments were cited and for further analytical procedures. This phase is referred to as

manifest content analysis and affords a measure of reliability because of its numeric objectivity (Fields & Morse, 1985). In this way categories can be linked and higher-order categories can be developed, and a taxonomy of the concepts can be formulated (Fields & Morse, 1985; Leininger, 1985).

Research Question One

The first research question asked: What are the concerns of oncology nurses as identified in responses to a vignette on assisted dying in which profound suffering is a prominent feature? The responses to the vignette that is the focus of this research question were rich in their content and revealed a great diversity of views and opinions. A sample of the transcription of the narratives and the assigned codes is provided in Appendix E. The preliminary themes that were identified included statements detailing recommendations for establishing review process and criteria for decision-making, conditions that should apply for carrying out PAD should it become legal, the need for assessment and evaluation, specific interventions, the role of the multidisciplinary team, as well as symptom management and treatment issues. Nurses also expressed feelings affirming their positions, both acceptance and opposition, described the difficulty they have in judging patients, and acknowledged the conflicts in values that

often arise with this complex issue. The preliminary categories with excerpts illustrating the nature of the comments are more fully demonstrated in Appendix F.

The categories were then grouped into three higher order (Level II) categories based on the major themes identified: 1) conditions, 2) roles, and 3) beliefs. Each theme included several subcategories derived from the preliminary categories found in Appendix F.

The theme category labeled conditions includes all statements that describe the decision-making process, situations for which assisted dying would be acceptable, and conditions that should apply if assisted dying is carried out. The theme category labeled roles includes all statements describing what the nurse perceives are actions to be taken when patients request assistance in dying. The theme category labeled beliefs includes all statements that reflect the respondents own beliefs as well as the concerns, questions, and conflicts posed by those beliefs. These categories were then used as the basis for coding and were entered in the computer. The comments by subcategory are demonstrated according to frequency of citation in Table 2.

Table 2

Frequency of Comments by Subcategory: Situation #4 (Vignette
Featuring Suffering)

<u>n</u>	<u>%</u>	
85	(17.5)	Review Process/Criteria (Conditions)
66	(13.6)	Expression of Difficulty/Conflicts (Beliefs)
60	(12.3)	Specific Interventions (Roles)
49	(10.1)	Symptom Management/Treatment Issues (Beliefs)
43	(8.8)	Affirming Opposition to PAD (Beliefs)
32	(6.6)	Affirming Acceptance of PAD (Beliefs)
17	(3.5)	Conditions/Process for Carrying Out (Conditions)
12	(2.5)	Assessment/Evaluation (Roles)
12	(2.5)	Multidisciplinary Approach (Roles)

The theme category is indicated in parentheses. The coding schema is provided in Appendix D and sample transcriptions of the responses coded are provided in Appendix E.

To further reduce the data for analysis, a randomly selected sub-sample was chosen by reviewing the responses a fourth time and highlighting every fifth one going from beginning to end then reversing the process until a sample of 102 was identified. This sample was then reviewed to determine how many of the responses included: 1) at least one condition, role, and belief statement, 2) at least one

condition and role statement, 3) at least one condition and belief statement, 4) at least one role and belief statement, 5) only role statement(s), 6) only condition statement(s), or 7) only belief statement(s). These responses were then entered in the computer and subjected to chi-square analysis. The results of the chi-square analysis are shown in Table 3.

The theme category of beliefs clearly dominated the statements made by the respondents. Thirty-five nurses made single comments that indicated their beliefs and concerns about the issue of assisted dying. When combined with the responses of those making multiple comments, belief statements were found in 63% of the responses. Upon combining the results from multiple category responses, condition statements were found in 49% of the comments and role statements were found in 22%. The distribution of the theme categories was compared with the respondents practice setting and religion but no significant differences were found.

Table 3

Chi-Square Analysis of Theme Categories for Situation #4

<u>Category</u>	<u>Observed</u>	<u>Expected</u>	<u>Residual</u>
Conditions/Roles			
Beliefs	1	14.29	-13.29
Conditions/Roles	5	14.29	-9.29
Conditions/Beliefs	21	14.29	6.71
Roles/Beliefs	6	14.29	-8.29
Conditions	22	14.29	7.71
Roles	10	14.29	-4.29
Beliefs	35	14.29	20.71
Total	<u>100</u>		
Chi-Square	D.F.	Significance	
61.840	6	0.000	

Research Question Two

The second research question asked: What are the concerns of oncology nurses as identified in response to a question about the degree to which physical pain can be effectively managed? During the first and second readings of the comments it became clear that the nature of the comments in response to questions four and five were very

similar. For this reason the categories gleaned from the comments were grouped together for coding purposes. The preliminary categories that emerged in response to the questions about pain control included statements describing knowledge and attitude barriers affecting patients and professionals, legal and regulatory barriers, discrepancies in knowledge and attitudes of various providers, and discrepancies in access to effective treatment depending upon the setting in which the care was being offered. Nurses also revealed their concerns regarding the difficulties in achieving balance of pain control with side effects and provided insight regarding the distinction between pain and suffering. Many respondents offered testimony establishing their philosophical orientation to pain management and provided examples of specific interventions they knew to be effective. The role of the nurse was depicted as being instrumental in promoting effective pain relief. The preliminary categories with excerpts illustrating the nature of the comments are more fully demonstrated in Appendix H.

The same process used in Situation #4 was applied to Questions #4 and #5. Preliminary theme categories developed include: 1) roles, 2) barriers, and 3) problems. The theme category labeled roles includes all statements that describe the interventions nurses cite as producing effective pain

management as well as their philosophical orientation towards care. The theme category labeled barriers includes all statements describing what the nurse perceives as barriers to providing effective pain management for oncology patients. The theme category labeled problems includes all statements that reflect the respondents concerns about pain management including balancing relief with side effects and the suffering experienced by patients not related to physical pain. These categories were then used as the basis for coding the responses for quantification and the codes were entered in the computer. The comments, for research question two, by subcategory are demonstrated according to frequency of citation in Table 4. The theme category is indicated in parentheses. The coding schema is provided in Appendix D and sample transcriptions of the responses coded are provided in Appendix G.

To further reduce the data for analysis a randomly selected sub-sample was chosen by reviewing the responses a fourth time and highlighting every fourth one going from beginning to end then reversing the process until a sample of 100 was identified. This sample was then reviewed to determine how many responses included: 1) at least one role, barriers, and problem statement, 2) at least one role and barrier statement, 3) at least one role and problem

Table 4

Frequency of Comments by Subcategory: Question #4 (Ability to Control Pain)

<u>n</u>	<u>%</u>	
89	(18.3)	Knowledge/Attitudes (Barriers)
73	(15)	Philosophical Orientation/Factors Influencing Care (Roles)
52	(10.7)	Difficulties Achieving Balance With Side Effects (Problems)
48	(9.9)	Specific Interventions (Roles)
30	(6.2)	Variability/Individual Patient Factors (Problems)
24	(4.9)	Setting/Access Discrepancies (Barriers)
18	(3.7)	Provider Discrepancies (Barriers)
17	(3.5)	Suffering Issues (Problems)
6	(1.2)	Nursing Role Identification (Roles)
6	(1.2)	Legal/Regulatory (Barriers)

statement, 4) at least one barrier and problem statement, 5) only role statement(s), 6) only barrier statement(s), or 7) only problem statement(s). These responses were then entered in the computer and subjected to chi-square analysis. The category groupings and frequency of responses are shown in Table 5.

The majority of responses were for single categories. The theme category of barriers dominated the statements made

Table 5

Chi-Square Analysis of Theme Categories for Question #4

<u>Category</u>	<u>Observed</u>	<u>Expected</u>	<u>Residual</u>
Roles/Barriers/ Problems	1	14.29	-13.29
Roles/Barriers	9	14.29	-5.29
Roles/Problems	3	14.29	-11.29
Barriers/Problems	4	14.29	-10.29
Roles	23	14.29	8.71
Barriers	35	14.29	20.71
Problems	25	14.29	10.71
Total	<hr/> 100		
Chi-Square	D.F.	Significance	
74.020	6	0.000	

by the respondents. Thirty-five percent of the nurses made comments indicating that knowledge deficits and attitudes are the barriers most affecting the management of pain. Role and problem statements as single responses were similarly represented at 23 and 25 respectively. Accounting for the statements in the single and combination responses, barriers were identified by 49% of the respondents. Roles were identified by 36% and problems by 33%. The distribution of the theme categories was compared with the

respondents practice setting and religious preference but no significant differences were found.

Research Question Three

The third research question asked: What are the concerns of oncology nurses as identified in response to a question about the degree to which pain is adequately relieved in the patients for whom they care? Because of the similarity in comments to both pain questions (Question #4 asking for a rating of the ability to control pain and Question #5 asking for a rating on the degree to which pain is actually controlled) the same subcategories and major theme categories (shown in Appendix H) used to code the responses in research question two were used for research question three. The comments by subcategory are shown, according to frequency of citation in Table 6. The theme category is indicated in parentheses. The coding schema is provided in Appendix D and sample transcriptions of the responses coded are provided in Appendix G.

As was done for research questions one and two, to further reduce the data for analysis a randomly selected sub-sample was chosen by reviewing the responses a fourth time and highlighting every fourth one going from beginning to end then reversing the process until a sample of 102 was identified. This sample was then reviewed to determine how many responses included: 1) at least one role, barriers, and

Table 6

Frequency of Comments by Subcategory: Question #5 (Adequacy of Pain Control)

<u>n</u>	<u>%</u>	
94	(19.3)	Knowledge/Attitudes (Barriers)
59	(12.1)	Philosophical Orientation/Factors Influencing Care (Roles)
59	(12.1)	Provider Discrepancies (Barriers)
44	(9.1)	Setting/Access Discrepancies (Barriers)
25	(5.1)	Nursing Role Identification (Roles)
22	(4.5)	Specific Interventions (Roles)
12	(2.5)	Difficulty Achieving Balance With Side Effects (Problems)
9	(1.9)	Legal/Regulatory Issues (Barriers)
9	(1.9)	Suffering Issues (Problems)
6	(1.2)	Variability/Individual Patient Factors (Problems)

problem statement, 2) at least one role and barrier statement, 3) at least one role and problem statement, 4) at least one barrier and problem statement, 5) only role statement(s), 6) only barrier statement(s), or 7) only problem statement(s). These responses were then entered in the computer and subjected to chi-square analysis. The category groupings and frequency of responses are shown in Table 7.

The majority of responses, again, were for single categories. The theme category of barriers dominated the statements made by the respondents. Fifty-one or 50% of the nurses singled out knowledge deficits and attitudes as affecting the management of pain. Role and problem statements as single responses were represented at 22 and 9 respectively. Accounting for the statements in the single and combination responses, barriers were identified by 66% of the respondents. Roles were identified by 37% and problems by 17%.

Table 7

Chi-Square Analysis of Theme Categories for Question #5

<u>Category</u>	<u>Observed</u>	<u>Expected</u>	<u>Residual</u>
Roles/Barriers	12	17.00	-5.00
Roles/Problems	4	17.00	-13.00
Barriers/Problems	4	17.00	-13.00
Roles	22	17.00	5.00
Barriers	51	17.00	34.00
Problems	9	17.00	-8.00
Total	<hr/> 102		
Chi-Square	D.F.	Significance	
94.588	5	0.000	

Summary

The findings of this study reveal oncology nurses specific concerns surrounding the issue of patient requests for physician assisted death. In the initial study (Young, et al, 1993) it was found that nurses hold diverse views regarding the acceptability of PAD. The comments provided by the 486 subjects who provided additional illumination of their views mirror that diversity.

The development of the broad theme categories for the statements pertaining to each research question was both an inductive and deductive process. The comment groupings were reviewed for content similarities and theoretical commonalities. The categories were shaped by the investigator's knowledge of the literature and how these related to the themes that emerged. Although the process reported here represents an orderly progression of activities, many of the processes occurred simultaneously and later steps provided new perspective, allowing for clearer identification of the concepts imbedded in the statements yielding new ways of viewing the data.

CHAPTER V

SUMMARY OF THE STUDY

This final chapter presents a summary of the study and includes a discussion of the findings. From this discussion conclusions are drawn and implications for nursing practice and further research are presented.

Summary

The issue of intentional termination of life, whether through suicide or assistance from professional health care providers is one of the more disturbing and controversial moral and ethical dilemmas facing nurses today. Among the reasons most frequently cited when patients request assistance in dying are unbearable pain and suffering.

Although this is an age-old problem, the events in recent years have brought considerable attention to the issue as society has been forced to confront the realities of advancing health care technology that has changed the face of life and death decision-making. The ability to prolong life with high technology life support systems has spawned much debate with subsequent legal challenges, legislative pursuits, and policy formulation by various health care institutions and professions (American Medical Association, 1986; Oregon Death With Dignity Act of 1990;

American Nurses Association, 1991, 1992.) Public concern has been heightened by the attention given in the press to the right to die movement and highly publicized incidents such as the deaths assisted by Dr. Kevorkian, the so-called "Dr. Death" and the publication of Derek Humphry's "suicide manual" Final Exit, by the Hemlock Society.

Research Question One

The issue of suffering and how it relates to patient requests for assistance in dying is certainly one that is difficult to define. In both the comment and original samples over 50% (comment = 53.1%, original = 57%) agreed that suffering provided sufficient justification for PAD (combined responses 1 and 3 indicate approval but differ with respect to the nurses' actual participation.) The content of their written responses, however reveal concerns about the process and difficulty in interpreting suffering and dealing with their own personal beliefs or convictions.

The key finding of the analysis of the narrative comments was that the theme dominating the concerns of oncology nurses is that of beliefs. This theme includes beliefs both affirmative and questioning in nature. Many affirmed that both pain and suffering are treatable while pointing out that many patients do not receive adequate attention to these problems. One response stated "It is not necessary to suffer - with proper management patients

would not make this request," and another points out that "If patients feel this desperate we have failed to do our job." Of those affirming their opposition to assisted dying, several commented that this is a "slippery slope" or that "euthanasia is not the answer to poor pain management." Of those that affirmed their acceptance of assisted dying comments revealed that "suffering makes a difference" and that "suffering is justification if the patient's wishes are clear." Another "doubts the need with available pain treatment, but would be present with convincing reasons."

Following beliefs is the theme category of conditions in which respondents identified specific concerns and conditions that would need to be addressed should assisted dying become accepted, legal practice. These included criteria such as institutional review procedures, requirement for repeated requests, informed consent, and review of efforts made to relieve patient. Several raised concerns about the potential for abuse, such as to what degree financial burdens might weigh in the decision-making process. Others emphasized the need for carefully developed guidelines and review processes such as one who stated "there is too much room for misinterpretation if competence is judged only by one MD." The concerns identified by oncology nurses reiterate those found in the public and professional literature, and are reflective of the great

diversity of opinion on the topic of euthanasia. Concerns offered by the respondents especially mirror those cited by Foley (1991) calling attention to the need to address access to expert palliative care for all before a reasonable debate on the options for terminating life can be fully addressed.

Research Question Two

The issue of treating pain in the context of requests for assistance in dying was clearly a focus of oncology nurses concerns. When asked to rate the degree to which it is possible to control physical pain in cancer patients both the comment sample (the focus of this study) and the original sample (those returning questionnaires from the original study) indicated that it is, indeed possible to control pain. In both samples over 90% rated the ability to control pain at 3 or 4 (1 = poor control, 4 = effective control). A more detailed comparison of the ratings given is contained in Appendix I.

The key finding of the analysis of the narrative comments related to the ability to control pain was that the theme dominating the concerns of oncology nurses is that of barriers. The barriers identified include attitudes - held by patients and caregivers, knowledge deficits, and legal and regulatory influences. These barriers mirror those described by Hill et al. (1989) in a call to action to improve the treatment of pain in our drug-oriented society.

Attitude barriers are reflected in a statement by one nurse who shared that "physical pain could be controlled if we could overcome professional fears and reluctance to address pain control." Another emphasized the patient and public aspects by identifying a "lack of public education - patients need to demand pain relief."

Among the key legal and regulatory barriers cited is the influence the various drug control measures has on the use of narcotics: "Many MD's do not obtain triplicates to be able to order morphine" and that it is "difficult to obtain appropriate Class II and III narcotics from local pharmacies." Underscoring the prevalence of these barriers were statements indicating that there are considerable discrepancies in the status of pain management depending upon the knowledge and attitude of the person(s) caring for the patient as well as the setting in which that care takes place. A typical statement included at least one qualifying conjunction: "It depends on the physician's knowledge, attitudes, and openness to suggestions" or "If attention is paid - alas attention is not always paid so some people suffer needlessly." Several indicated that pain control was better if managed by an oncologist by comparison to other medical doctors or surgeons. There were contrasting views about discrepancies according to setting. One nurse indicated that a "small, rural setting often means lack of

willingness or knowledge of the MD's and nurses" while another noted that "care is fragmented in a large university setting" and that it is "better in a smaller community cancer treatment center." Hospice was frequently cited as the type of setting that makes a difference as reflected in one nurse's observation that "patients in hospitals probably fare worse than those at home with hospice care." The barriers identified by the nurses in this study closely parallel those cited by Hill et al. (1989) who established three key categories that need to be addressed in their "call to action": cultural and attitudinal barriers, knowledge deficits, and governmental/regulatory influences.

Following barriers the emphasis on roles and problems was fairly evenly distributed. Role statements included many specific interventions that the nurses cite as promoting pain control. Many emphasized the role nurses play as one who identified the "need for nurses to be aggressive in assessment and in prompting doctors for orders." Comments also revealed the need for effective collaboration with other disciplines in effecting adequate care.

Among the problem statements were those reflecting concerns about the side effects of pain treatment and other quality of life issues. There was concern about "achieving balance between pain control and maintaining alertness."

Others revealed a fear of contributing to the patient's death because of the "large doses needed - in some cases causes death due to respiratory arrest." Others, however, saw a clearer distinction in treating pain referring to the "double effect" and stating that "increasing narcotics is acceptable even if it shortens life" reflecting the discussion by various ethicists (Latimer, 1991) and the Catholic Church (1980) on the topic.

As noted in several of the statements accompanying Situation #4, the problem of suffering is a broader issue than pain alone. One nurse noted that "pain is not always the greatest concern - psychic pain is some times the harder burden" while another nurse responded that "physical pain is difficult to isolate from emotional stress." Again, the concerns identified by oncology nurses in this study are reflective of the same issues cited in the review of the literature, especially those cited by Coyle et al. (1990) who emphasized the multiple symptoms that need to be addressed in the terminally ill patient.

Research Question Three

As has been previously noted, the types of comments made in response to both questions about pain control (Question #4 relating to the ability to control pain, and Question #5 relating to the adequacy of actual pain control)

were similar, and for coding purposes the comments were classified using the same categories. The quantitative ratings, when asked to what degree patients the respondent knows receive adequate pain relief (1 = poorly controlled, 4 = effectively controlled), were reflective of the original sample. In both samples greater than 75% of the respondents gave a rating of 3 or 4 in contrast to the 90% or greater ratings regarding the ability to control pain. These sample comparisons are more fully demonstrated in Appendix I.

The principal theme identified in the comments to Question #5 was, as for Question #4, barriers. There was however increased emphasis on this as a response. This category was included in 50% of the statements as a single response, and when combined with those including more than one theme, barriers were cited in 66% of the responses compared with a combined 49% to Question #4. In looking at the responses by subcategory, as noted in Table 6, there was a greater frequency in responses citing provider or setting/access discrepancies than for Question #4. The category of roles received about the same emphasis in Question #5, while the category of problems decreased by about half from its incidence of response to Question #4.

The prevalence of barriers to adequate pain and palliative care revealed in the comments of the respondents reflects concerns identified in the review of the

literature, particularly those expressed by Foley (1991) and the World Health Organization (1990). These experts have emphasized the importance of removing treatment barriers before a reasonable debate on euthanasia can take place, or that euthanasia as a solution is even unnecessary.

Discussion of the Findings

Although the responses by oncology nurses, in both the quantitative and qualitative portions of this study, reflect a great diversity of views and opinions, several distinct themes emerged to form the basis for continued work and to support the Model of Collaborative Nursing Practice in which this study was rooted.

As shown in the analysis of research question one, while nurses clearly made affirmative statements regarding their roles, particularly with regard to careful assessment and evaluation of patients and offered examples of interventions that work, belief and condition statements were more dominant in the responses. This suggests that while oncology nurses are cognizant of the importance of their roles, they approach this controversial issue with respect for patient autonomy and have given considerable thought to the complexities involved. While the majority of respondents did indicate acceptance of assisted dying in the context of profound suffering, their comments reveal concern for assuring that the decision-making process is a reasoned

one, and that appropriate interventions and alternatives are thoroughly explored. While many voiced feelings of conflict and distress, either from past experience or anticipated experience, they also commented on the need to separate their own beliefs and convictions from those of the patient. A concurrent theme throughout, that was difficult to isolate in the coding process, was the need for greater attention to the treatment of suffering - including suffering of a physical, spiritual, or psychosocial nature.

The quantitative analysis of responses pertaining to research questions two and three demonstrates that oncology nurses believe that pain control is not only possible most of the time, but that in the patients for whom they care pain is effectively controlled. However, this positive outlook is tempered by serious concerns about the degree to which this occurs for all patients. The finding of increased identification of barriers in adequately controlling pain, particularly the discrepancy in providers and settings, suggests that while barriers do indeed have an impact on the ability to control pain, barriers figure even more prominently in the discrepancy between the ability to control pain and the degree to which it is actually controlled in patients cared for by oncology nurses. Many nurses pointed out that much work needs to be done to educate nurses, physicians, and the public about the ability

to control pain with currently available methods in order to decrease the needless suffering experienced by many.

Relationship of the Findings to the Conceptual Framework

The various concerns expressed by oncology nurses in response to the issues of pain, suffering, and requests for assistance in dying fit well with the Model of Collaborative Nursing Practice that provided the theoretical framework for this study. The importance of collaboration as a key activity came through in numerous responses as revealed in one nurse's comment that "patients experience adequate pain relief when there is excellent communication in the patient-nurse-physician triad."

Another key element of the model is the importance of addressing patient needs according to the a hierarchy (Maslow, 1954) in which the most basic needs must be met before higher level needs can be satisfied. This concept was clearly affirmed in one response to the vignette dealing with profound suffering, stating that "the patient has a right to be comfortable before considering this choice (Maslow)."

Examples of nursing interventions for each of the levels of care (wholly compensatory, partially compensatory, and supportive/educative) were found throughout the comments in response to the issues analyzed in each of the three

research questions. Patient advocacy and aggressive pursuit of appropriate medications as well as timely administration of medications were prominent in the responses. These are examples of wholly or partially compensatory interventions that would be necessary at the totally and partially dependent levels of care. The need for patient and family education, which was cited frequently, represents the supportive and educative interventions that are key to the independent level of care.

Conclusions and Implications of the Study

The implications for nursing practice based on the findings are varied and point to much work that needs to be done to adequately address the issues of pain and suffering and their relationship with requests for assistance in dying. Specific conclusions derived from the study include the following:

1. Oncology nurses hold diverse views regarding the acceptability of physician assisted dying (PAD) but are more likely to support it when suffering is a clearly defined feature.

2. The predominant theme of comments in response to a vignette describing a patient's request for assistance in dying in which "profound suffering" is a prominent feature is beliefs.

3. When asked to rate the ability to control pain in the context of a questionnaire dealing with PAD, oncology nurses affirm the ability to control pain but indicate that the degree to which pain is actually controlled is less than adequate much of the time.

4. The predominant theme of comments in response to questions about pain control in the context of a questionnaire dealing with PAD is barriers.

5. Hospice nurses are more likely to respond to questions about pain and suffering with comments that illuminate their concerns.

The implications of these conclusions for nursing are viewed as follows:

1. There is considerable need for education of nurses, physicians, and the public to heighten the awareness and utilization of available means to treat pain and suffering. Educational efforts must be directed at not only providing accurate information about pain and symptom management, but at developing means of changing the attitudes that interfere with implementation of pain management as well.

2. Greater efforts need to be undertaken to assure that all patients have access to knowledgeable health care providers who give a high priority to relief of pain and suffering regardless of their practice setting.

3. Nurses need to take leadership roles in assuring that evaluation and treatment of pain and suffering are adequately addressed as various states pursue legalization of PAD and as policy is developed in that regard. Nurses should be at the forefront in monitoring and responding to proposed legislation relating to PAD and other right to die initiatives. Nurses should be encouraged to participate in organizations such as the various state cancer pain initiatives that have been formed throughout the country to educate professionals and the public in an effort to eliminate the barriers to adequate pain control.

4. Nurses need to be aware of their own beliefs and values related to PAD in order to be able to respond appropriately and to be able to respect patient beliefs and values, providing care and support even when those beliefs and values may conflict.

5. The hospice model of care, which is based on symptom relief and attention to quality of life issues, is highly relevant to oncology nursing practice. Educational curricula and nursing interventions should be designed to promote the integration of the concepts of the hospice philosophy to assure that basic comfort level needs of all patients are met, thus decreasing the incidence of factors that may lead a patient to seek assistance in dying.

Recommendations for Further Study

The findings explicated in this study represent the most basic beginning of the work that needs to be done before clearer answers to the many questions posed can be devised. While there is, no doubt, still need to continue raising the collective consciousness of the health care professions through surveys of opinions and beliefs about the issues, it will be important to move swiftly to address the issues and questions already raised. Among the priorities identified through the analysis of this study data are:

1. The need to identify sensitive means of assessing and measuring suffering and explication of the factors that constitute suffering as differentiated from physical pain.

2. The need to devise and test more effective educational strategies that will break down some of the barriers to effective pain control and yield greater application of current knowledge in actual practice.

3. The need to focus on the nurses' role in assessement, intervention, and evaluation of pain and symptom management and the potential impact on decreasing requests for assistance in dying.

The close, sometimes intense, nurse patient relationship that occurs, particularly in caring for the terminally ill, is one that uniquely qualifies nurses as

experts in palliative care. Nurses are in pivotal positions to promote not only improved pain and symptom management to improve quality of life for their patients, but to assume leadership roles in policy development and research that will lead the way to a more rational approach to end of life decisions that the terminally ill and their families make.

REFERENCES

- Admiraal, P.V. (1988). Euthanasia in The Netherlands: Justifiable euthanasia. Issues in Law and Medicine. 3(4) 361-370.
- Ahronheim, J. and Weber, D. (1992). Final passages: Positive choices for the dying and their loved ones. New York: Simon & Schuster.
- American Medical Association, Council on Ethical and Judicial Affairs. (1986). Current opinions of the Council on Ethical and Judicial Affairs of the American Medical Association. Chicago: Author.
- American Nurses Association (1988). Position statement on nurse participation in capital punishment. Kansas City: Author.
- American Nurses Association (1991) Position statement on promotion of comfort and relief of pain in dying patients. Washington, D.C.: Author.
- American Nurses Association (1992) Position statement on foregoing artificial nutrition and hydration. Washington, D.C.: Author
- Anonymous. (1988). It's over, Debbie. The Journal of the American Medical Association. 259:2.
- Battin, M.P. (1991). Euthanasia: the way we do it, the way they do it. Journal of Pain and Symptom Management. 6(5)298-305.
- Belkin, L. (1990). Doctor tells of first death using his suicide device. The New York Times. 139(48,258)1,B6.
- Berg, B.L. (1989). Qualitative research methods for the social sciences. Boston: Allyn and Bacon.
- Bolte, B. (1990). Make life worth living. The Los Angeles Times. December 8: B7.
- Bolund, C. (1985a). Suicide and cancer: I Demographic and social characteristics of cancer patients who committed suicide in Sweden, 1973-1976. Journal of Psychosocial Oncology. 3(1)17-31.

- Bolund, C. (1985b). Suicide and cancer: II Medical and care factors in suicides by cancer patients in Sweden, 1973-1976. Journal of Psychosocial Oncology. 3(1)31-52.
- Breitbart, W. (1982). Suicide in cancer patients. Oncology. 1,49-54.
- Breitbart, W. (1990). Cancer pain and suicide. Advances in Pain Research and Therapy, Vol. 16 (pp. 399-412). New York: Raven Press.
- Brescia, J.F. (1991). Killing the known dying: notes of a death watcher. Journal of Pain and Symptom Management. 6(5)337-339.
- California Civil Code, Title 10.5. The Humane and Dignified Death Act.
- California Nurses' Association. (1987) Position statement on nurse participation in active euthanasia for the Terminally Ill. Sacramento: Author.
- Cassel, E.J. (1982). The nature of suffering and the goals of medicine. The New England Journal of Medicine. 306(11)639-645.
- Cassel, E.J. (1991). Recognizing suffering. Hastings Center Report. 21(3)24-31.
- Clouser, K.D. (1991). The challenge for future debate on euthanasia. Journal of Pain and Symptom Management. 6(5)306-311.
- Coyle, N., Adelhardt, J., Foley, K.M., and Portenoy, R.K. (1990). Character of terminal illness in the advanced cancer patient: pain and other symptoms during the last four weeks of life. Journal of Pain and Symptom Management. 5(2)83-93.
- Davis, A.J. and Slater, P.V. (1989). U.S. and Australian nurses' attitudes and beliefs about the good death. Image. 21(1)34-39.
- Fields, P.A. and Morse, J.M. (1985). Nursing research: The application of qualitative approaches. Rockville, MD: Aspen.

- Foley, K.M. (1991). The relationship of pain and symptom management to patient requests for physician-assisted suicide. Journal of Pain and Symptom Management. 6(5)289-297.
- Fowler, D.M. (1988). On killing patients. Heart and Lung. 17(3)322-323.
- Fox, B.H., Stanek, E.J., Boyd, S.C., and Flannery, J.T. (1982). Suicide rates among cancer patients in Connecticut. Journal of Chronic Diseases. 35:85-100.
- Goodman, E. (1992). Killing one's own cause. The Washington Post. August 1:A21.
- Hill, C.S., Fields, W.S., and Thorpe, D.M. (1989). A call to action to improve relief of cancer pain. In C.S. Hill & W.S. Fields (Eds.) Advances in Pain Research and Therapy Vol.11. (pp.353-361). New York: Raven Press, Ltd.
- Hiller, M.D. and Sugarman, D.B. (1990). Euthanasia and long-term care: values of the long-term care professional. The Journal of Long-Term Care Administration. 18,123-30.
- Humphry, D. (1991). Final exit. Eugene, OR: The Hemlock Society.
- Humphry, D. (1992). Dying with dignity. Eugene, OR: The Hemlock Society.
- Jennings, B. (1991). Active euthanasia and forgoing life-sustaining treatment: can we hold the line? Journal of Pain and Symptom Management. 6(5)312-316.
- Johnson, T.M. (1989). Contradictions in the cultural construction of pain in America. In C.S. Hill & W.S. Fields, (Eds.), Advances in Pain Research and Therapy, Vol 11 (pp. 27-37). New York: Raven Press, Ltd.
- Jones, T. (1993) Dutch adopt law allowing euthanasia. Houston Chronicle. Feb 10:10A.
- Klagsbrun, S.C. (1991). Physician-assisted suicide: a double dilemma. Journal of Pain and Symptom Management. 6(5)325-328.
- Kubler-Ross, E. (1975). Death: The final stage of growth. New York: Simon & Schuster.

- Kuhse, H. (1987). Voluntary euthanasia in The Netherlands. Medical Journal of Australia. 147(8)394-396.
- Kuhse, H. and Singer, P. (1988). Doctors' practices and attitudes regarding voluntary euthanasia. Medical Journal of Australia. 148(12)623-627.
- Kuhse, H. and Singer, P. (1992). Euthanasia: a survey of nurses' attitudes and practices. The Australian Nurses Journal. 21(8)21-22.
- Latimer, E.J. (1991). Ethical decision-making in the care of the dying and its applications to clinical practice. Journal of Pain and Symptom Management. 6(5)329-336.
- Latimer, E.J. (1991). Euthanasia: a physician's reflections. Journal of Pain and Symptom Management. 6(8)487-491.
- Leininger, M.M. (1985). Qualitative research methods in nursing. Orlando: Grune & Stratton.
- Louhivuori, K.A. and Hakama, M. (1979). Risk of suicide among cancer patients. American Journal of Epidemiology. 109(1)59-65.
- Lynn, J. (1988). The health care professional's role when active wuthanasia is sought. Journal of Palliative Care. 4(1&2)100-102.
- Malcom, A.H. (1990). Giving death a hand: rending issue. The New York Times. June 9:6.
- Mappes, T. and Zembaty, J. (1986). Euthanasia: the dying adult and the defective newborn. Biomedical ethics (2nd ed., pp. 378-427). New York: McGraw-Hill, Inc.
- Marks, R.M. and Sachar, E.J. (1973). Undertreatment of medical inpatients with narcotic analgesics. Annals of Internal Medicine. 78,173-181.
- Maslow, A.H. (1954). Motivation and personality. New York: Harper & Row.
- Melzack, R. (1990). The tragedy of needless pain. Scientific American. 262(2)27-33.
- Miaskowski, C. (1992). A question of "doing the right thing" or "doing the thing right". Oncology Nursing Forum. 19(1)5.

- National Hemlock Society (1989). Three states move to leagalize physician aid-in-dying. Hemlock Quarterly 36,1.
- National Opinion Poll Market Research (1987). Attitudes towards euthanasia among Britain's GPs. London: NOP Market Research Ltd.
- Oregon Death With Dignity Act of 1990, Oregon Revised Statutes, Chapter 97, Section 1, 2525-2526.5.
- Orem, D. (1985). Nursing: Concepts of practice. (3rd ed.) New York: McGraw Hill.
- O'Rourke, K.O. (1991). Assisted suicide: an evaluation. Journal of Pain and Symptom Management. 6(5)317-324.
- Owen, C., Tennant, C., Levi, J., and Jones, M. (1992). Suicide and euthanasia: Patient attitudes in the context of cancer. Psycho-oncology. 1:79-88.
- Painter, K. and Peterson, K.S. (1991). Suicide primer stokes debate on euthanasia. USA Today 8/13,1-2.
- Risley, R.L. (1987). A Humane and dignified death: A new law permitting physician aid-in-dying. Glendale, CA: Americans Against Human Suffering.
- Robinson, J. (1990). Euthanasia: The collision of theory and practice. Law, Medicine and Health Care. 18(1-2)105-107.
- Rollin, B. (1985). Last Wish. New York: Linden Press/Simon and Schuster.
- Roy, C. (1970). Adaptation: a conceptual framework for nursing. Nursing Outlook. 18(3)42.
- Scott, J.F. (1998). Lies and lamentation - a solid no to euthanasia. Journal of Palliative Care. 4(1&2)119-121.
- Shuman, C.R., Fournet, G.P., Zelhart, P.F., Roland, B.C. and Estes, R.E. (1992). Attitudes of registered nurses toward euthanasia. Death Studies. 16:1-15.
- Vatican Congregation for the Doctrine of the Faith. (1980) Declaration on Euthanasia. 3:4.

- Wanzer, S.H., Federman, D.D., Adelstein, S.J., Cassel, C.K., Cassem, E.H., Cranford, R.E., Hook, E.W., Lo, B., Moertel, C.G., Safar, Pl, Stone, A., and van Eys, J. (1989). The physician;s responsibility toward hopelessly ill patients: a second look. New England Journal of Medicine. 320(13)844-849.
- World Health Organization (1986). Cancer pain relief. Geneva: Author.
- World Health Organization (1990). Cancer pain relief and palliative care. Geneva: Author.
- Young, A., Volker, D., Rieger, P.T., and Thorpe, D.M. (1993). Oncology nurses' attitudes regarding voluntary, physician assisted dying for competent, terminally ill patients. Oncology Nursing Forum. 20(3)445-451.

APPENDIX A

Survey Cover Letter

July 1, 1990

Dear Colleague,

The purpose of this letter is to ask you to be a part of a study about the concept of physician assisted dying for patients who are terminally ill and request such assistance. This study is being conducted to help us learn about the attitudes and feelings registered nurses working in oncology hold about physician assisted dying. Because this topic is becoming a greater concern for terminally ill patients and the public in general, this information is important and should benefit registered nurses as they deal with this issue in practice.

Your participation in this study is voluntary and will be greatly appreciated. The only perceived risk in this study would be fear of disclosure of information. To protect you from this risk, individual responses will be anonymous. Please do NOT place your name or any identifying marks on the questionnaire. Your decision to participate or not participate in this study will not affect your work status in any way.

This questionnaire will take approximately 15 minutes to complete. There are no right or wrong responses. We are interested in your views and feelings about physician assisted dying. Directions are included for each portion of the questionnaire. This questionnaire has 5 pages. Please be sure that you complete all pages, responding to each question.

After you have completed the questionnaire, place it in the stamped, return envelope sent with the questionnaire. Please return the questionnaire by July 31, 1990.

A grant application for this study was made to the Texas Division of the American Cancer Society in January 1990. Approval and funding were received in May 1990.

If you have questions about this study or if you are interested in the results of the study, please contact Mary Mazzawy at (713) 667-6729 or write to Mary Mazzawy, 2823 S. Bartell #211, Houston, Texas 77054.

Sincerely,

Mary Mazzawy, RN, MS, OCN
Paula T. Rieger, RN, MS, OCN
Deborah Thorpe, RN, MS, CS
Deborah Volker, RN, MA, OCN
Anne Young, RN, EdD

Completion of this questionnaire indicates your informed consent to participate in the study.

APPENDIX B

Demographic Record

**NURSING ATTITUDES REGARDING
PHYSICIAN ASSISTED DYING**

INSTRUCTIONS: Please fill in the blank or check the appropriate response for the following questions. **Select only one response per question.**

1. **GENDER** ☐ Female ☐ Male

2. **AGE** Years

3. **STATE IN WHICH YOU PRACTICE**

4. **BASIC LEVEL OF NURSING EDUCATION**

☐ Associate Degree ☐ Baccalaureate Degree

☐ Diploma ☐ Other, Please specify

5. **HIGHEST LEVEL OF EDUCATION**

☐ Associate Degree ☐ Baccalaureate Degree

☐ Diploma ☐ Masters Degree

☐ Doctoral Degree ☐ Other, Please specify

6. **YEARS IN NURSING PRACTICE** Years

7. **YEARS AS A PRACTICING ONCOLOGY NURSE** Years

8. **EMPLOYMENT STATUS**

☐ Full time ☐ Part Time

☐ Unemployed ☐ Retired

9. **PRIMARY FUNCTIONAL AREA**

☐ Administration ☐ Education

☐ Research ☐ Patient Care

☐ Other, Please specify

10. PRIMARY POSITION

☐ Staff Nurse ☐ Head Nurse/Asst. Head Nurse
☐ Clinician ☐ Nurse Practitioner
☐ Educator ☐ Clinical Nurse Specialist
☐ Supervisor ☐ Director/Assistant Director
☐ Researcher ☐ Consultant
☐ Other, please specify _____

11. PATIENT POPULATION

☐ None ☐ Adult
☐ Pediatric ☐ Both

12. PRIMARY PRACTICE SETTING

☐ Hospital ☐ Outpatient Ambulatory Care Clinic
☐ Hospice ☐ Public Health/Community Nursing
☐ Home Care ☐ School of Nursing
☐ Physician's Office ☐ Private/Group Practice
☐ Comprehensive Cancer Center
☐ Other, Please specify _____

13. PRIMARY AREA OF PRACTICE

☐ Chemotherapy ☐ Hematology/Oncology
☐ Biotherapy ☐ Radiation Oncology
☐ Surgical Oncology ☐ Head and Neck Oncology
☐ GYN Oncology ☐ Other, Please specify _____

14. RELIGIOUS AFFILIATION

☐ Agnostic ☐ Atheist
☐ Jewish ☐ Protestant
☐ Roman Catholic ☐ Other, Please specify _____

INSTRUCTIONS: Please read each of the situations. Answer the questions that follow the situation by circling the response that **most** closely reflects the decision you would make in that situation. **SELECT ONLY ONE RESPONSE.** After each situation, there is an area where you may comment on the situation if you wish.

DEFINITIONS: Words used in this study will be defined as follows:

Physician assisted dying--medical procedure that will humanely terminate the life of a competent, terminally ill adult who freely **requests** such assistance. This procedure could be carried out by the physician or a designee of the physician.

Adult--anyone 18 years of age or over.

Terminally ill--prognosis of 6 months or less confirmed by two physicians.

Competent--oriented to time, place, and person; able to comprehend treatment options and outcomes of these options.

APPENDIX C

Nurses Attitudes Regarding Physician Assisted Dying Instrument

SITUATION 1:

You are the nurse who has been caring for Mr. A for the past 2 years. Mr. A is terminally ill with cancer and has chosen to have his physician assist him with dying. The physician is entering the room to administer a drug that will cause Mr. A's death. Mr. A would like for you to be in the room with him.

Assuming that physician assisted dying for competent, terminally ill patients requesting such assistance is legal:

- A. You agree that physician assisted dying is appropriate, and would go with the physician and stay with Mr. A while he receives the drug and subsequently dies.
- B. You do NOT agree that physician assisted dying is appropriate, BUT would go with the physician and stay with Mr. A while he receives the drug and subsequently dies because you want to cooperate with the patient's request.
- C. You agree that physician assisted dying is appropriate, BUT would be unable to accompany the physician and stay with Mr. A because of your long term nurse-patient relationship with him.
- D. You do NOT agree that physician assisted dying is appropriate and would NOT accompany the physician and stay with Mr. A.

COMMENTS: Are there any comments that you would like to make regarding your choice in this situation?

SITUATION 2:

Mrs. C, a terminally ill cancer patient you have never met before, has requested physician assisted death. She requests that a nurse be in the room with the physician when he administers medications to end her life.

Assuming that physician assisted dying for competent, terminally ill patients requesting such assistance is legal:

- A. You agree that physician assisted dying is appropriate and would go with the physician and stay with Mrs. C while she receives medication and subsequently dies.
- B. You do NOT agree that physician assisted dying is appropriate, BUT would go with the physician and stay with Mrs. C while she receives the medication and subsequently dies because you want to cooperate with the patient's request.
- C. You agree that physician assisted dying is appropriate, BUT would be unable to accompany the physician and stay with Mrs. C even though you have no prior nurse-patient relationship with her.
- D. You do NOT agree that physician assisted dying is appropriate and would NOT accompany the physician and stay with Mrs. C.

COMMENTS: Are there any comments that you would like to make regarding your choice in this situation?

SITUATION 3:

Mr. M, a competent terminally ill cancer patient, has requested physician assistance with dying. The physician has written the order for medications to cause his death. Mr. M requests that you now give him the ordered medication.

Assuming that physician assisted dying for competent, terminally ill patients requesting such assistance is legal:

- A. You agree that physician assisted dying is appropriate and would administer the medication to Mr. M.
- B. You do NOT agree that physician assisted dying is appropriate, BUT would administer the medication because you want to cooperate with the patient's request.
- C. You agree that physician assisted dying is appropriate, BUT would be unable to administer the medication to Mr. M.
- D. You do NOT agree that physician assisted dying is appropriate and would NOT administer the medication to Mr. M.

COMMENTS: Are there any comments that you would like to make regarding your choice in this situation?

SITUATION 4:

Mrs. W is a competent, terminally ill cancer patient who requests physician assisted dying. She tells you repeatedly that she "has suffered too much, too long" and requests that you be present when medications are administered to assist her dying.

Assuming that physician assisted dying for competent, terminally ill patients requesting such assistance is legal:

- A. Because profound suffering is a sufficient justification for termination of life, you would cooperate with Mrs. W's request for physician assisted dying.
- B. Although you do NOT believe profound suffering is sufficient cause for terminating life, you would still cooperate with Mrs. W's request for physician assisted dying.
- C. Although you believe that profound suffering is sufficient justification for terminating life, you would NOT cooperate with Mrs. W's request for physician assisted dying.
- D. Because profound suffering is NOT a sufficient justification for terminating life, you would NOT cooperate with Mrs. W's request for physician assisted dying.

COMMENTS: Are there any comments that you would like to make regarding your choice in this situation?

INSTRUCTIONS: Please respond to the following questions:

1. Are you familiar with organizations such as:

The Hemlock Society YES____ NO____

Americans Against Human Suffering YES____ NO____

2. Are you aware that there is proposed legislation in some states that would legalize physician assisted death for competent, terminally ill adults who request to die?

YES____ NO____

3. Would you vote in favor of legislation that would legalize voluntary, physician assisted death for competent, terminally ill adults?

YES____ NO____

COMMENTS:

4. To what degree do you feel that the physical pain of terminally ill cancer patients can be controlled? (Circle one response)

4	3	2	1
Effectively			Poorly
Controlled			Controlled

COMMENTS:

5. Do you believe that cancer patients you know of receive adequate physical pain relief? (Circle one response)

4	3	2	1
Most of Time			Almost Never

COMMENTS:

Thankyou for completing this questionnaire. Please be sure you have answered each question. Place it in the stamped, addressed return envelope.

APPENDIX D
Comment Coding Schema

SITUATION #4

<u>Codes</u>	<u>Category</u>
DECISION MAKING/ETHICAL CONSIDERATIONS	
A1	Review Process/Criteria
A2	Conditions/Process for Carrying Out PAD
INTERVENTIONS	
B1	Assessment/Evaluation
B2	Multidisciplinary Involvement/Consultation
B3	Specific Interventions
BELIEFS/CONCERNS/QUESTIONS	
C1	Symptom Management and Treatment Issues
C2	Expression of Difficulty With the Issue/Conflicts
C3	Affirming Opposition to PAD
C4	Affirming Acceptance of PAD
QUESTIONS #4 & #5	
<u>Codes</u>	<u>Category</u>
FACTORS GENERATING SUCCESS	
A1	Specific Interventions
A2	Nursing Role Identification
A3	Philosophical Orientation/Factors Influencing Care
BARRIERS	
B1	Knowledge/Attitudes
B2	Legal/Regulatory
B3	Provider Discrepancies
B4	Setting/Access Discrepancies
PROBLEMS RELATED TO TREATMENT/ COMPLICATING FACTORS	
C1	Difficulties Achieving Balance With Side Effects
C2	Suffering Issues
C3	Variability/Individual Patient Factors

APPENDIX E

Sample Transcription of Responses With Codes

Situation #4

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
Profound suffering is not necessary in this age of adequate pain relief. What will keep a physician from ordering sufficient pain-relieving medication under such a law? What happens if a patient refuses pain relief meds and asks for meds to terminate life?	means to relieve suffering available legal "what ifs"	C3 C2
This one is more difficult. What kind of "suffering?" Has her quality of life fallen to a point that she considers this the "suffering"? Is there no end to "suffering" from <u>pain</u> ? Pain can - in most cases- be controlled; therefore, there must be more to her "suffering."	defining suffering need for pain control	C2
I would only consider 'A' after I had talked with pt regarding what her interpretation of "suffering too much and too long" entailed and explored alternative interventions for these beliefs.	need to interpret/ explore pts concept of suffering, explore all alternatives	A2 B1 A1
The administration of a medication with a primary purpose of ending life would be unacceptable to me. However, if a medication were given for the primary purpose of achieving comfort and the dying process was accelerated by its administration I would find it acceptable and administer the medications.	double effect of giving medication OK - not primary intent to kill	C3 C1
<u>Good, sound, compassionate</u> , palliative care could reduce the level of suffering - maintain comfort and dignity.	suffering can be relieved	C3

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
This also depends on relationship with patient. I have heard too many patients utter similar phrases and I don't feel that they really would want to die at the time they said it.	importance of relationship difficulty interpreting statements	A2 C2
One person's definition of profound suffering may not be that of another. Who can decide which is right?	variable definitions who has authority to judge?	C2
There is no excuse for physical suffering given the state of the art for pain relief. I would consider it my responsibility to work to ease any emotional suffering Mrs. W. had.	means available to relieve pain/suffering	B3
This is very hard. My gut feeling is that sufficient therapy (morphine drip) could be given to decrease the suffering and the patient could be eased in dying. But then how is this really different than physician assisted dying?	means available to decrease suffering is this different from assisted dying?	C2 B2
I have difficulty defining "profound suffering" in this situation because it is such a subjective measure.	difficulty defining	C2
I would accompany a MD but at this time I'm not certain I could push the drug. I <u>could</u> push whopping doses of analgesics/narcs for pain etc.	would not administer but would support high doses of pain meds acceptable	B3

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
These are very tough questions - very difficult to answer from a hypothetical point of view. Each situation is a struggle.	difficult decision making	C2
She knows her limits and what is enough. How could I judge that for her? <u>I</u> couldn't.	pt choice pt knows own limits	C2
As previously stated. Do not wish to judge others tolerance of pain - however do not want to be part of their own suicide.	respect pt choice - would not be a party to it	C2 C3
I don't think that I would need to have "sufficient justification" from anyone making a request - this is a matter of individual or personal consciousness (conscience) and not a matter of "sufficient justifications".	patient right to choose	A1
Alleviate the suffering - often when this is done a patient finds time to do his/her death work. In this day it is <u>not</u> necessary for patients to suffer.	means available to treat suffering	B3
One could explore her meaning of suffering - and possibly do something to alleviate part of it - especially if it was related to pain management, or a variety of other reasons - personal intervention and team conferences might make a difference.	need to explore alternatives interventions can make a difference team approach	B1 B2

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
She may be competent but is her choice rational or due to depression, pain etc? More information needed on which to base a decision.	? role of depression explore alternatives	A1 B1
Again, some knowledge of patient is implied in this situation. I believe much can be done to relieve suffering and all possible should be done. But if that has taken place and the patient is still suffering too much I can understand making this kind of request	OK if all possible done to relieve suffering	A2 C4
My comment pertains to all the situations. The medical center at which I had student nurses to supervise was a very <u>caring</u> place. Pain was controlled. A multidisciplinary team cared for these patients and they were all very aware of and involved in their plan of care. Families (of all ages) were involved. Patients and families knew that pain would be controlled - and many had narcotic IV continuous drips titrated untill the moment of death - no one "assisted" death.	role of caring symptom management important multidisciplinary/family involvement specific interventions	B1 B2 B3
I do not want or like to see profound suffering but I do not feel we have the right to assist the patient to die. That is up to God. I would be with the patient if he or she requested it, but I would not give the medication.	religious beliefs conflict - up to God to decide would support but not administer	C2 B3

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
I do not believe that people have to suffer with cancer given the pain relieving medications available. If in relieving that pain you secondarily cause respiratory arrest then I believe that is acceptable.	suffering not necessary- pain can be managed double effect OK	C1 C3
"Profound suffering" tells me the patient has had very poor pain management - perhaps with proper management the patient would not be making this request.	need for better pain control	B3 C1
I believe in relief of suffering. I believe many instances of suffering are caused by the physician or nurse using insufficient dosages of pain meds to keep the patient from becoming "addicted"	means available to treat suffering fear of addiction a barrier	C1
Profound suffering means many things - physical pain, mental anguish, etc. I am terribly concerned that patients suffer pain becuse health care providers do not understand, learn or give adequate pain control.	lack of pain control due to lack of knowledge	C1
Would review each case individually, no blanket, generalizing laws.	each case individual - no blanket laws	A1
<u>Cooperate</u> meaning be present and bring the patients request to the attention of her MD, but not administer.	define cooperate	A1 B3

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
Given her requests are not a side effect of depression or other mood disorders and that she repeatedly reported her desire over time of several weeks and that all therapies for pain had been used if pain was the cause of her "suffering" I still would not administer.	OK if depression treated, repeated requests would not administer	A1 C1 C4
I have no information about my relationship with this patient. I believe the suffering and relationships over time should be addressed by the staff and not "cop-out" by ending a life.	suffering needs to be treated - ending life is a "cop-out"	A1 C3
I would first ensure the patient had had psychiatric counselling, and had received pain and symptom control, preferably by a group of specialists in pain control.	OK after sufficient efforts to tx suffering need for specialists	A1 C1 B2
I would feel more comfortable if provision was made for institutional review on a case by case basis to insure/reassure medical profession of pt's competence and frame of mind to make such a decision... philosophically, I feel pt's wishes are most important and any assistance I can offer to help in a way the patient feels is right for them. I feel this is my correct role, even if it means I may aid or condone their self-chosen path. I would want an independent panel to review cases - I feel there is too much room for misinterpretation of pt wishes if judgement of patient competence was left only to MD.	case by case decision-making pt autonomy too much room for misinterpretation of pt wishes determination of competence needed nursing roles	A1

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
Although my religious convictions prevent me from believing in MD assisted dying, I do not define my pt's conviction nor can I judge their suffering, but it would be difficult if I do not know the person and too hard for me to participate in such an intimate part of someone's life that I do not have much of a relationship with.	values conflict - but could support if had relation- ship with pt	A1 C2 C4
I feel that with proper pain management intervention resulting in good control of her pain increasing her quality of life she would view the need to end her life in a different light - Euthanasia is not the answer to poor pain management!	proper pain management would shed different light euthanasia not answer	C1 C3

APPENDIX F

Preliminary Categories for Situation #4 With comment Excerpts

Preliminary Categories Identified for Situation #4 With
Comment Excerpts

Review Process/Criteria

Determining prognosis is problematic but the patient has the right to make the decision

The patient has a right to choose (self-determination)
- any guidelines should be based on this

Concern about financial burden and its relationship to decisions

Each case should be decided on its own merits - no blanket laws

Need for institutional review/independent panel (too much room for misinterpretation if competence judged only by one MD)

Repeated requests must be made

More acceptable if death is imminent or patient is considered terminal

There must be adequate informed consent

Would need to know more about efforts to make the patient comfortable

Conditions/Process for Carrying Out PAD

Need for anonymity on part of person administering (compared to firing squads)

Medications should be self-administered by patient

Law should not hold those who choose to help responsible

Should not be the responsibility of MD - but there are exceptions - severe pain is worse than death

Preliminary Categories for Situation #4

Assessment/Evaluation

All alternatives must be explored

Address quality of life issues

Evaluate role of depression

Need to interpret/explore the patient's concept of suffering and pursue relationship of suffering to patient's perception of quality of life

Multidisciplinary Involvement/Consultation

Need for multidisciplinary and family involvement

Need for treatment by specialist in pain control

Psychiatric counselling needed

Specific Interventions

Would support/be present but not assist/administer directly

Need for caring approach

Nurses responsibility to ease emotional suffering

Symptom Management and Treatment Issues

Means are available to relieve physical suffering

Profound suffering is very rarely necessary with today's technology

It is not necessary to suffer - with proper management pts would not make this request

Interventions can make a difference

Preliminary Categories for Situation #4

The patient has a right to be comfortable before considering this choice (Maslow cited)

Death will follow naturally if treatment is withdrawn - focus should be on treating suffering

Suffering needs to be treated - ending life is a "cop out"

If patients feel this desperate we have failed to do our job

Double effect - OK to administer meds if primary intent is not to kill (narcotics may decrease life)

Expression of Difficulty with the Issue/Conflicts

Who can judge? Who is the authority to determine suffering?

Is the use of drugs to relieve pain/suffering different from assisted dying?

Does not want to "Play God" - but feels in ways giving high doses of drugs or withholding fluids is the same

PAD is not acceptable, but neither is prolonging life - Difficult to distinguish PAD versus allowing life to end

Conflict with personal versus patient religious beliefs/values

Affirming Opposition to PAD

Suffering can be a stepping stone to a different life

Affirming the sanctity of life - capital punishment only justifiable means

Preliminary Categories for Situation #4

PAD equated with murder, Nazi experimentation

This is a slippery slope

Euthanasia is not the answer to poor pain management

PAD is expedient for caregivers

Affirming Acceptance of PAD

Suffering makes a difference - removes doubt (this was the easiest situation to answer)

Suffering is justification if patient wishes are clear

Acceptable if all possible has been done and patient is still suffering

Doubts need with available pain treatment, but would be present with convincing reasons

APPENDIX G

Sample Transcription of Responses With Codes
For Questions #4 and #5

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
#4: In most cases (if properly managed) pain is effectively controlled - the key is effective management which is not the rule now but the exception.	can be controlled - but is the exception	A1 B4
#5: Yes, because we are trained and experienced with pain control as hospice nurses.	hospice influence	A3
#4: In my experience I have found that physical pain and emotional pain are inseparable for terminal cancer patients. Just treating physical pain is temporary at best and setting both patient and family up for failure in adequate pain control.	treatment of physical and emotional pain are inseparable	C2 A3
#5: When a terminal cancer pt is willing to be compliant with a pain med regime and psychosocial changes they can have their pain controlled almost 100% - at least 95% - 28 out of 30 days a month - it takes work and patience with families and patients.	need for pt compliance takes work/patience with pts/families	B1 A3
#4: Effectiveness is often determined by dr/nurse willingness/knowledge in pain control area.	effectiveness determined by willingness/knowledge	B1 B3
#4: This is my work - my commitment and my belief - this is what I devote my efforts to!	affirmation of nursing roles	A3
#5: Yes - I make it my business to see to this = education, consultation, clinical follow-up, re-assessment and sustained efforts.	interventions that work - consultation, education, re-assessment	A2 A3
#4: We need more good "pain management" programs.	need for pain management programs	A1

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
#5: Some patients have a physician who is not very knowledgeable of "pain management" or has a poor attitude toward "pain management."	MD's knowledge/ attitude barrier	B3 B1
#5: But I work in a NCI designated comprehensive cancer center.	<u>but</u> works in a CCC	B4
#4: If adequate analgesia is given <u>most</u> pain can be controlled; other pain relieving measures can be attempted.	<u>if</u> adequate analgesia given other methods available	A1
#5: Many do not because of fears of addiction and/or respiratory depression on the part of the physician, patient and/or family. The relief of pain can give an entirely new outlook on living.	respiratory depression/ addiction fears (pt, MD)	B1 A3
#4: This question is hard to answer because pain is so subjective and there are so many factors involved that influence pain relief such as anxiety, mental anguish and even guilt.	subjectivity of pain other factors influence pain	C3 C2
#5: Although I agree that this law should be passed, I can see where there is a potential for abuse by some unscrupulous persons. Also the question arises, will insurance companies see this as a suicide and not want to pay death benefits to families of these persons?	agree with law - concern about abuse potential ? insurance benefits payable	B2
#4: Too many Drs are still afraid of "killing" patients with narcotics - decreasing respiration etc. Should be used to keep comfortable.	fear of killing pt/ respiratory depression	B1

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
#4: I believe pain can be controlled <u>IF</u> the physician is willing to try varieties of protocols with sufficient room for nursing judgement to increase doses as needed, when needed.	possible if MD willing need for nursing judgement to adjust doses	B1 A2
#5: Most MD's I know are just not willing to write orders to the magnitude needed for effective pain control.	most MDs not willing	B1
#5: Not enough professional education - and public needs to be educated to demand relief. Should not need to suffer so much that death is requested.	lack of professional/public education-pts should demand relief - suffering not necessary	B1 A3
#4: Especially if pain relief is the priority, <u>not</u> worrying about addiction, respiratory depression etc. I would strongly support legislation allowing terminally ill patients with pain to have maximum pain relief measures if requested, even if life might be shortened in the process.	<u>if</u> pain is a priority need for legislation for pain relief double effect	A3 B1 C1 B2
#4: <u>If only</u> physicians were willing. I once had a 15 year old pt with nasopharyngeal Ca with brachial involvement who was receiving <u>1000</u> mg morphine every hour and remained lucid up to approx. 800 mg. It can be done!!	willingness personal experience - positive	B1 A1
#5: Not here ... - MD's are <u>not</u> educated in pain control.	lack of MD education - discrepancy in location	B1 B4

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
#5: Legally physician-assisted death is against the oath dr's take to preserve life. It is a concept that has great potential for interpretation and misuse. Terminally-ill patients, generally in my experience, have their pain controlled with morphine drips. The morphine is increased with signs of agitation or "perceived" agony often resulting in death. Oncology Drs and RNs have a low tolerance to increase the morphine dose even though it results in death in a hopeless situation. It would be better to strive for "adequate pain control" in terminally ill than euthanasia.	PAD against MD oath Potential for abuse pain control possible MD/RN low tolerance for neccesary doses double effect pain control preferable to euthanasia	A1 B1 A3
#4: In my 10 years of nursing, I have had many patients say they wanted to die. Once they were comfortable, or treated for an underlying psychiatric illness or given adequate counselling to help process their feelings along with providing them with options. Almost all patients have then felt empowered and express a will to live. I do feel that suicide is a personal option - but many times the individuals who chose that option have not had adequate counselling, evaluation, and have not received the education, medical/psychiatric care available.	desire for death lessens with good pain control need to treat psychosocial issues lack of education/ counselling leads to requests for PAD	A1 A3 B1
#4: We seem to have the means to control physical pain except in very rare instances, and I feel that we should not hesitate to use it.	means to treat pain available	A3

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
#5: We are very concerned about this in our institution and as long as the patients are under the oncologists care they receive adequate pain relief.	<u>as long as</u> pts are under care of oncologist	B3
#4: Physical pain is not necessarily the worst problem. People who have terrible resp. compromise but wish to be alert to spend their last moments with their loved ones in a clear mind can be miserable for a long time before dying. This is the most painful situation I have had to witness several times - pt refused M.S. to be alert - and then watching them slowly drown in their secretions - lymphangitic spread to lungs.	problems in achieving balance between pain control and alertness	C2 C3
#5: I don't believe there is so much intractable pain as there are "intractable health care providers" most MD's and RN's are not very knowledgable ...I work in a cancer institute where a major effort is made to learn about each person's pain and deal with it. We are for the most part successful, yet when I worked with a local hospice and community (non-teaching) hospital for the most part pain control was poor.	lack of knowledge discrepancy in access to care	B1 B3 B4
#5: Because I work at a comprehensive cancer center - if I didn't my answer would probably be a 1 or 2 (gave 4 rating).	<u>because</u> works at a CCC	B4
#4: Each case is individual and depends on etiology of pain.	etiology of pain a factor	C3

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
#4: Pain may be controlled but often with subsequent side effects: mental clouding, lethargy, etc. that affect quality of life.	pain control at expense of SE - affects QOL	C1
#4: MS Contin and Roxanol have made a big difference.	drugs that work	A1
#5: Only because of nurse advocacy where I work - interns are unsophisticated and frightened about the doses and frequencies of the meds needed by our oncology patients - it's a constant battle and educational process to get my patients what they need.	Nurse advocacy makes a difference need to educate - constant battle	A2 B1
#5: Reasons in our hospice setting for inadequate pain control are due largely to 2 factors: 1) pt/family concern about narcotic use/or feel it is their "fate" to suffer, and 2) physician lack of cooperation in prescribing.	inadequate treatment due to pt/family fears - "fate" to suffer lack of MD cooperation	B1
#5: Depending on the physician - oncologists seem more likely to order meds and appropriate doses than do surgeons or internists.	<u>depends</u> on MD oncologists vs surgeons or internists	B3
#5: Depends on where the pt is, the expertise and value system of the medical and nursing staff.	<u>depends</u> on staff/values	B4 B3
#5: This is an important role for all members of the hospice team. We do it quite well.	hospice influence	A3
#5: Pts in hospitals probably fare worse than those dying at home with hospice care.	hospice care better - setting discrepancy	B4

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
#4: Can be is the key word. Seems like the major - or a major issue is the lack of knowledge on the part of many health care professionals - probably the majority - of how to effectively control pain - or willingness to learn and implement effective measures.	lack of knowledge willingness a factor	B1
#5: My own father died with lung cancer and bone mets. He was never free of or even close to being free of pain - no degree of comfort (and he was in the same boat as many patients I've been with too.) His physician told me that Dad would just have to learn to communicate better about his pain! My dad was a stoic, Red-Neck Iowan and the last thing he'd do is admit to pain to someone else. Besides - the MD was the one with the college education to know that this man had pain! Why should a dying man have to learn to communicate at this stage of his life?!!!	personal experience attitude of MD a barrier	B1
#4: In my practice with terminally ill patients I encourage the use of narcotics to relieve pain and teach families and patients to <u>not withhold</u> medication because of time or dosage.	pt/family education effective drug use	A1 B1
#5: We use the PCA pump and have obtained good results. To reiterate - my experience with terminally ill patients, which is extensive, shows that terminally ill people do not commit suicide despite the means at their command.	methods that work pts don't commit suicide despite access to means	A1 A3

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
#5: We (nurses) have to be aggressive in assessment/evaluation and prompting doctors for orders.	need for nursing persistence	A2
#4: Good pain control is based on trust, communication, and availability of experienced medical/nursing care - too few get this.	communication important-experienced caregiver needed	A3 B3
#5: I am working in a large university affiliated center now and feel that medical care is too fragmented to meet my patient's pain control needs. My prior position for 5 years at a community based C.T.C, allowed me to see good pain control. The medical oncologists there were experienced in pain control and it was a priority in our care.	care fragmented in large university setting - better in smaller community treatment center	B4 B3
#4: Research studies show inadequate knowledge or application of knowledge in caregivers. Is best option to terminate life because of our inadequacies?	lack of knowledge barrier-PAD the answer to our inadequacies?	B1
#5: Strong "pain team" and weekly multidisciplinary pain rounds as well as med conversion tables. Inappropriate/inadequate (deliberate) addressing of this issue is grounds for discipline at my institution.	multi-disciplinary team strong standards of pain treatment	A3
#5: We are getting better - non-relief of pain is iatrogenic - not lack of technology.	lack of implementing pain treatment	B1
#5: Because of patient advocacy by the caring nurse.	advocacy caring	A2

<u>Text</u>	<u>Comments</u>	<u>Codes</u>
#4: With the right combinations of drugs and support, patients can have good pain control more than when I first started to practice. The greatest problem is convincing physicians of the need to provide the <u>best</u> pain management for each patient. It then becomes the nurses delicate protocol to get orders for pain management - and <u>that</u> is the HARD PART.	nurse advocacy role and need for assertiveness	B1 A2
#4: I think we need to consider that there are many causes for discomfort in terminally ill cancer patients eg, nausea, fatigue, anorexia, bad taste in mouth, aversion to odors, weakness, hiccups, dizziness, constipation etc.	need to address other symptoms of discomfort	C3
#5: I work in an extremely sophisticated environment - I don't believe that most patients have access to this level of comprehensive pain control.	discrepancy between personal experience and knowledge of others	B4
#4: I feel that cancer pain can be controlled but very few physicians/nurses have adequate knowledge/clinical expertise to effectively treat pain. Nor is it viewed as a priority like cancer treatment is.	lack of knowledge - MD and RN pain control not a priority	B1 A3

APPENDIX H

Preliminary Categories for Questions #4
and #5 With Comment Excerpts

Preliminary Categories Identified for Questions #4 and #5
With Comment Excerpts

Specific Interventions Cited

PCA pumps/epidurals/nerve blocks

Morphine drips/narcotics/high doses/titration to effect

Tumor treatment (Chemotherapy, Radiotherapy)

Adjuvant medications (benzodiazepines to control anxiety/ NSAIDs)

Clinitron bed

If adequate analgesia given/adequate meds/appropriate dosage

Finding the correct combinations of medications/routes

Takes patience and time, gentle touch

Patient Education

Nursing Role Identification

Increased awareness of nurses about pain medications, comfort with unlimited dosage

Consultation/interdisciplinary effort

Reassessment/sustained efforts

Advocacy/persistence in getting what patient needs

Need for nurses to be aggressive in assessment and in prompting doctors for orders/encouraging doctors to increase dosage

It is not my duty to terminate life

Preliminary Categories for Questions #4 and #5

Philosophical Orientation/Factors Influencing Care

Patients cared for in cancer center or hospice are well controlled

Wisconsin Pain Initiative/state initiative influence
Every patient deserves expert pain management - use of multidisciplinary team if routine measures not effective

Requires total committment to patient comfort - takes work and patience with patients and families

Patients, families, MD's and nurses need to work together to accomplish pain control

Need for early intervention

If pain is a priority

Rarely if we work tirelessly to find the right approach

Patients experience adequate pain relief when there is excellent communication in the patient-nurse-physician triad

Our patients are told having pain controlled is a normal expectation and that it is our responsibility

Physicians allow nurses to keep patients comfortable - "the sky's the limit" on increased pain management

I don't feel - I know it can be done

Adequate pain control preferable to euthanasia

Relief of pain can give an entirely new outlook on living

Hospice alternative to aggressive treatment superior to PAD

Legal PAD would cause me to leave oncology nursing - possibly nursing profession because of the far reaching implications

Preliminary Categories for Questions #4 and #5

Knowledge and Attitudinal Barriers

Willingness to order or administer high doses/try different treatments

Poor attitude towards pain management (MD,RN)

Lack of cooperation (MD) in prescribing/unwilling to accept suggestions from nurses

Patient/family member perception that it is patient's "fate" to suffer, acceptance of pain as a part of the disease

Families may fight the dosage - they want family member alert

Fear of respiratory depression, addiction, sedation

Pain is not viewed as a priority like cancer treatment is

Depends on value system of medical/nursing staff

Physical pain could be controlled if we could overcome professional fears/reluctance to address pain control

If patients follow physician orders (compliance)

Depends on physician's knowledge, attitudes, and openness to suggestions

Failure due to fear/ignorance

Lack of public education - patients need to demand relief

Resistance to alternative/adjuvant treatments (Relaxation, imagery)

Lack of pain relief is iatrogenic - not lack of technology

Opiophobia among health care providers is very real - need more education

Preliminary Categories for Questions #4 and #5

In 1990 there is no reason for the terminally ill to suffer physical pain - however - there is a major knowledge deficit on the part of many MDs

Legal/Regulatory Issues

Nurses need to be able to adjust doses

Need for legislation/laws to force doctors to become educated

Nurses/physicians fear breaking the rules

Many MD's do not obtain triplicates to be able to order MS etc

Difficult to obtain appropriate Class II and III narcotics from local pharmacies

Agree with laws allowing PAD with concern for potential abuse

Concern about insurance companies refusing to pay benefits for suicide

Provider Discrepancies

Depends on physician's knowledge, attitudes, and openness to suggestions

Medical doctors better able to manage pain than surgeons

Older physician more conservative - younger physician more likely to keep patient comfortable

Depends on the physician - oncologists more likely to order appropriately than internist or surgeon

Setting/Access Discrepancies

Most patients not in a setting to receive adequate treatment

Small rural setting often means lack of willingness/lack of knowledge of MD's and nurses

Preliminary Categories for Questions #4 and #5

The poor, uninsured, veterans - may be a different story (lack of access to care)

Care fragmented in a large university setting - better in a smaller community cancer treatment center

Patients cared for in cancer center or hospice are well controlled - however others are not because of inadequate care by nurses and MD's who are not well prepared to manage pain

In my institution most patients receive adequate relief -this is not true elsewhere

Discrepancy between personal experience and knowledge of other situations

Patients in hospitals probably fare worse than those at home with hospice care

Some MD's provide adequate control but some refuse to use narcotics in the home and not all patients can get into hospitals

98% possible, unfortunately not near there yet

If attention is paid - alas attention is not always paid so some people suffer needlessly

Difficulties Achieving Balance/Compromise with Side Effects

Achieving balance between pain control and maintaining alertness/may require total sedation

Pain control at expense of side effects that affect QOL

Death promoted by overdosing to keep pain free

Large doses needed - in some cases causes death due to respiratory arrest

It is almost impossible to relieve all physical pain without giving lethal doses

Exceptional situations - nothing short of anesthesia helps

Preliminary Categories for Questions #4 and #5

Double effect - increasing narcotics acceptable even if it shortens life

Lack of attention to side effect management - eg laxatives

Need to address other symptoms/causes of discomfort (nausea, fatigue, anorexia, hiccups etc)

Suffering Issues

Other factors affecting pain (guilt, anxiety, mental anguish)

Emotional and spiritual pain are different

Pain is not always the greatest concern - psychic pain is some times the harder burden

Physical pain difficult to isolate from emotional stress

It's not the physical pain that can't be controlled - rather the wasting, emotional suffering, loss of money etc.

Pain and suffering are different - pain can be controlled and patient can still suffer

Difficulty in some cases even with high doses - becomes a hardship when death is inevitable - hard for family to be so helpless

No matter what medications are used or how much, pain is never under good control

Physical pain is easy to control and must be done first - then deal with the spiritual and psychosocial dimensions - provided these are not the overwhelming cause of pain

Unfortunately pain is not the only symptom causing suffering -indifference to psychological needs is just as cruel

Preliminary Categories for Questions #4 and #5

Variability/Individual Patient Factors

Success depends upon the etiology of the pain - bone pain difficult to control

Much variance between people

Controlled does not mean eliminated - for some types of pain we have limited resources

APPENDIX I

Comparison of Responses Between Comment and Original Samples

Situation #4

Mrs. W is a competent, terminally ill cancer patient who requests physician assisted death. She tells you repeatedly that she has "suffered too much, too long" and requests you be present when medications are administered to assist her dying.

	COMMENT		ORIGINAL	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
1 (Justified/Would Cooperate)	213	(43.8)	578	(48)
2 (Not Justified/Would Cooperate)	76	(15.6)	190	(16)
3 (Justified/Would Not Cooperate)	45	(9.3)	107	(9)
4 (Not Justified/Not Cooperate)	124	(25.5)	295	(24)
Missing	28	(5.8)	40	(3)

Question #4

To what degree do you feel that the physical pain of terminally ill cancer patients can be controlled?

	COMMENTS		ORIGINAL	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
<u>Rating</u>				
Poorly Controlled	1	2 (.4)	8	(.7)
	2	10 (2.1)	49	(4)
	3	178 (36.6)	539	(44.5)
Effectively Controlled	4	295 (60.7)	608	(50.2)
Missing		1 (.2)	6	(.5)

Question #5

Do you believe that cancer patients you know of receive adequate physical pain relief?

	<u>Rating</u>	COMMENTS		ORIGINAL	
		<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
Almost Never	1	13	(2.7)	25	(2.1)
	2	87	(17.9)	213	(17.6)
	3	164	(33.7)	453	(37.4)
Most of Time	4	221	(45.5)	511	(42.2)
Missing		1	(.2)	8	(.7)