

## **INFORMATION TO USERS**

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

**The quality of this reproduction is dependent upon the quality of the copy submitted.** Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

# **UMI**

A Bell & Howell Information Company  
300 North Zeeb Road, Ann Arbor MI 48106-1346 USA  
313/761-4700 800/521-0600



**COMPARISON OF THE MEANING OF DEATH  
FOR PERSONS WITH CANCER AND PERSONS WITH AIDS  
AT THE END OF LIFE**

by

Michael Steven Ryan

---

A Thesis Submitted to the Faculty of the

**COLLEGE OF NURSING**

In Partial Fulfillment of the Requirements  
For the Degree of

**MASTER OF SCIENCE**

In the Graduate College

**THE UNIVERSITY OF ARIZONA**

1997

**UMI Number: 1385732**

---

**UMI Microform 1385732  
Copyright 1997, by UMI Company. All rights reserved.**

**This microform edition is protected against unauthorized  
copying under Title 17, United States Code.**

---

**UMI**  
300 North Zeeb Road  
Ann Arbor, MI 48103

**STATEMENT BY AUTHOR**

This thesis has been submitted in partial fulfillment of requirements for an advanced degree at The University of Arizona and is deposited in the University Library to be made available to borrowers under rules of the Library.

Brief quotations from this thesis are allowable without special permission, provided that accurate acknowledgment of source is made. Requests for permission for extended quotation from or reproduction of this manuscript in whole or in part may be granted by the head of the major department or the Dean of the Graduate College when in his or her judgment the proposed use of this material is in the interests of scholarship. In all other instances, however, permission must be obtained from the author.

SIGNED: Michael S. Ryan

**APPROVAL BY THESIS DIRECTOR**

This thesis has been approved on the date shown below:

Kathleen M. May  
Kathleen M. May  
Associate Professor of Nursing

4/21/97  
Date

## **ACKNOWLEDGMENTS**

I would like to express my deepest love and gratitude to my life partner, Terrance Long, for my continued existence in this world today. To me you embody beauty, humility, kindness, and patience in a world that is often overwhelming and frightening. I thank you for your presence in my life, the meaning you bring to my life, and the unending love you have so graciously bestowed upon our relationship. We are one.

Sincere appreciation and respect is extended to my advisor, mentor, and thesis chair, Dr. Kathleen May, for her seemingly limitless support and assistance throughout graduate school and the thesis process. You are a role model of academic excellence and scholarly integrity, and our collaboration was one of the highlights of my graduate education. Additional thanks to Dr. Cheryl McGaffic for her generosity and trust, and to Dr. Pamela Reed for helping us to recognize the importance of the human spirit in nursing care.

Lastly, I would like to thank the Sisters of Saint Joseph of Carondelet for renewing my faith by exemplifying spiritual beauty, unconditional love, and inexhaustible commitment to human values. I stand in awe of your devotion.

## **DEDICATION**

**This thesis is dedicated to my maternal grandmother**

**Cora May Church**

**who taught me kindness, compassion, empathy,**

**and the effects of sorrow on the human spirit.**

**The pains of your life have become the strengths of mine.**

## TABLE OF CONTENTS

LIST OF TABLES .....	8
ABSTRACT .....	9
CHAPTER ONE. INTRODUCTION .....	10
Background .....	11
Death and Dying .....	11
Hospice and Nursing Case Management .....	12
Cancer .....	15
AIDS .....	17
Statement of Problem .....	19
Statement of Purpose .....	20
Significance of the Study .....	20
Significance for Clients .....	20
Significance for Nursing .....	21
Significance for the Health Care System .....	22
Summary .....	23
CHAPTER TWO. CONCEPTUAL ORIENTATION AND REVIEW OF LITERATURE .....	24
Conceptual Orientation .....	24
Watson's Theory of Human Caring .....	24
Application of Watson's Theory .....	27
Review of Literature .....	28
Perceptions of Death and Dying .....	28
Summary .....	33
Spirituality .....	34
Summary .....	39
Nursing's Response to Death and Dying .....	39
Summary .....	44
Terminal Cancer .....	45
Summary .....	49
End-Stage AIDS .....	49
Summary .....	53

## TABLE OF CONTENTS -- continued

Hospice Care .....	53
Summary .....	60
Summary of Literature Review .....	61
Research Questions .....	62
Definition of Terms .....	62
Summary .....	63
<b>CHAPTER THREE. METHOD .....</b>	<b>64</b>
Design .....	64
Sample .....	65
Setting .....	65
Protection of Human Subjects .....	66
Data Collection Protocol .....	67
Instruments .....	68
Secondary Data Analysis .....	69
Plan for Data Analysis .....	71
Trustworthiness of the Research .....	74
Summary .....	77
<b>CHAPTER FOUR. RESULTS .....</b>	<b>78</b>
Description of the Sample .....	78
Persons with Cancer .....	78
Persons with AIDS .....	82
Results of Data Analysis .....	82
Research Question 1 .....	82
Persons with cancer .....	83
Persons with AIDS .....	85
Research Question 2 .....	88
Qualitative Analysis .....	88
Quantitative Analysis .....	93
Summary .....	95
<b>CHAPTER FIVE. DISCUSSION .....</b>	<b>97</b>
Relationship of Findings to Conceptual Orientation .....	97
Relationship of Results to Literature Reviewed .....	101
Limitations of the Study .....	105
Implications for Nursing .....	105

**TABLE OF CONTENTS--continued**

<b>Recommendations for Future Research</b> .....	110
<b>Summary</b> .....	111
<b>APPENDIX A-Approval Letters of Original Study</b> .....	112
<b>APPENDIX B-Approval Letters from Institutions     Participating in Original Study</b> .....	115
<b>APPENDIX C-Consent Form and Authorization Form of Original Study</b> .....	118
<b>APPENDIX D-Approval Letter for Secondary Analysis</b> .....	121
<b>APPENDIX E-Original Study Instruments</b> .....	124
<b>APPENDIX F-Death Construct Coding Dictionary Used in Original Study</b> .....	128
<b>APPENDIX G-Revised Death Construct Coding Dictionary from Original Study</b> ...	131
<b>REFERENCES</b> .....	135

**LIST OF TABLES**

Table 1	Demographic Composition of Subsamples .....	79
Table 2	Categories and Definitions for Research Question One for Persons with Cancer .....	84
Table 3	Categories and Definitions for Research Question One for Persons with AIDS .....	86
Table 4	Chi Square Analysis of Difference Between Subsamples in Thematic Units in Categories of Acceptance and Spiritual Awareness .....	94

## **ABSTRACT**

The purpose of this study was to describe and compare the perceptions of the meaning of death to persons diagnosed with terminal cancer and persons diagnosed with end-stage AIDS. The conceptual orientation for this study was Jean Watson's theory of human care, particularly the holistic individual.

This study used a descriptive design for secondary analysis of interview responses from an original study. The analysis explored the personal meaning of death to persons with cancer and persons with AIDS in the last six months of life. Content analysis was the method of data analysis used to address the research questions. Identified categories representing meaning of death to persons with cancer were: Acceptance, Release, Reluctance, and Spiritual Awareness. Categories representing meaning of death for persons with AIDS were: Uncertainty, Acceptance, Anticipatory Loss, Fear, Benefits, and Spiritual Awareness. Comparison revealed that the two subsamples shared the categories of Acceptance and Spiritual Awareness.

## **CHAPTER ONE**

### **INTRODUCTION**

Appropriate care of persons with terminal cancer and persons with end stage AIDS is an ongoing concern within the practice of nursing. With the advent of the Medicare Hospice Benefit in 1982, holistic approaches to care of persons with terminal illnesses living within the last six months of life incorporated multidisciplinary strategies to meet the needs of such persons and their families or significant others. As holistic approaches to the care of persons with cancer and AIDS continue to develop, exploration of the meaning of death is an integral consideration in end-of-life situations. Nursing interventions utilizing an holistic approach must incorporate understanding the meaning of death to ensure effective care. Such meaning may vary, depending on the physical, emotional, or spiritual domains of the person who is dying. Many factors may influence meaning and the interconnectedness of these three domains. Comparison of the meaning of death for individuals dying from cancer and individuals dying from AIDS offers additional insight into the dying experience, thereby strengthening nursing's preparation for offering differing approaches to care of individuals dying from cancer or AIDS. This study is a secondary analysis of the qualitative segment of a study entitled "Patterns of Spirituality and Health Among Aging Adults and Dying Adults Living in the Community" (McGaffic, 1995) in which participants dying from cancer and AIDS defined their meaning of death. The purpose of this study was to describe and compare the meaning of death for persons in the two subsamples, those dying from cancer and those dying from AIDS.

## **Background**

While anecdotal articles abound describing personal views of the experience of dying, few studies exist that capture the individual nature of the meaning of the dying experience. One aspect of this experience is the personal exploration of the meaning of death. The two sections that follow comprise an exploration of the concepts of death and dying and hospice. The third section of the background is a review of the current rates of cancer and AIDS, the conditions for which participants in this study received hospice care.

### **Death and Dying**

Dying is a natural, irreversible process wherein death is the ultimate goal or outcome (Backer, Hannon, & Russell, 1994). Consistent with current nursing theory, a holistic perspective of the dying process, either as a pattern of health or a component of humanism, emphasizes the physical, psychosocial, and spiritual dimensions of the dying process and the effects that each dimension has on the individual's perception of death (Newman, 1986; Watson, 1985). Within the physical domain, perceptual influences include such factors as pain or other symptoms associated with the terminal condition, relationship with physician, and continuation of health promotion activities such as dealing with stress or seeking alternate healing modalities (Fryback, 1993). The psychosocial domain consists of elements that directly affect a person's psychological and social health. Concepts common to the psychosocial domain include maintaining control, making choices that affect outcomes, hope, motivation towards achieving future-oriented goals, and love defined as caring for and by others (Fryback, 1993). The spiritual domain

pertains to perceptions of a relationship with a higher power, including spiritual beliefs and transcendence, recognition of one's mortality and an appreciation for living in the moment, and striving for self-actualization by finding meaning and purpose in either health or death (Fryback, 1993). While the concept of holism defines characteristics within the discrete categories of body, mind, and spirit, such characteristics may not be unique to a sole category. For example, hope is a characteristic reflecting both the spiritual and psychosocial domains. Additionally, the three domains may affect each other, such as physical characteristics influencing psychosocial issues (Hall, 1990).

Watson (1985) conceptualizes holism as harmony and unity of body, mind, and spirit. These aspects of holism are not discrete, but are in constant interaction with each other and both influence and are influenced by the person's concept of self. Achievement of balance through the interactions of body, mind, and spirit ultimately lead to actualization of the higher, holistic self. Programs, such as hospice care, exist to provide services and care to persons with terminal illness in order to achieve harmony among the domains that constitute holism.

### Hospice and Nursing Case Management

One program that addresses the holistic needs of persons with terminal illnesses is hospice care. The goal of hospice care is to address the physical, emotional, psychological, and spiritual needs of individuals with terminal illnesses and their families to maximize quality of life and prepare for the eventuality of death. Studies have shown that hospice provides cost effective care with high patient satisfaction (Office of Research and

Demonstrations, 1994). Initially, hospice services provided care for persons with terminal cancer, primarily due to the introduction of hospice services into the United States in the form of grants from the National Cancer Institute (Backer, Hannon, & Russell, 1994). Although cancer diagnoses represent the conditions most commonly found in persons enrolled in a hospice program, non-cancer diagnoses, particularly the diagnosis of human immunodeficiency virus (HIV) infection, also prevail with growing frequency in hospice programs (Christakis & Escarce, 1996). According to the National Hospice Organization (NHO), four percent of patients receiving hospice services have an admission diagnosis of acquired immunodeficiency syndrome (AIDS), making it the third most frequent hospice diagnosis in the United States (NHO, 1995). The diagnoses of carcinoma of the lung, breast, prostate, and colon-rectum continue to be the most frequent cancer diagnoses in the United States (American Cancer Society [ACS], 1996), as well as in hospice programs (NHO, 1995).

Within the hospice framework, coordination of services to patients with cancer and AIDS is an essential component. Nursing case management is a mechanism for coordination of services frequently seen in hospice programs (Kinzbrunner, 1995). Case management is defined as “a collaborative process which assesses, plans, implements, coordinates, monitors, and evaluates options and services to meet an individual’s health needs through communications and available resources to promote quality cost effective outcomes” (Case Management Society of America, 1994, p. 60). Case management provided by nurses is an effective care delivery system for persons diagnosed with AIDS

or persons dying from other terminal illnesses.

Nursing case management of persons enrolled in a hospice program focuses on coordinating the care needs of patients enrolled in a hospice program. In addition to addressing symptom control of complex terminal illnesses, hospice nurses also coordinate services within an interdisciplinary team of professionals, including social work, spiritual care, and bereavement follow-up. Kinzbrunner (1995) reports that hospice case management is effective in responding to challenges of providing and coordinating multiple services for individuals with terminal illnesses.

The Denver Nursing Project in Human Caring (Schroeder & Maeve, 1992) uses nursing case management with persons with HIV/AIDS. In that project, Jean Watson's theory of nursing as the art and science of human caring (Watson, 1985) guides a nurse-directed, outpatient facility providing nursing case management to persons in various stages of HIV/AIDS infection, including end-stage AIDS. The project bases its individualized, humanistic nursing on Watson's belief that health is defined as unity and harmony within body, mind, and soul. Shroeder and Maeve (1992) cite development, implementation, and evaluation data to support the effectiveness of nursing in providing case management services to individuals with HIV/AIDS.

In addition to services for persons with HIV/AIDS, hospice provides services to persons dying from various types of cancer. Carcinomas of varying kinds and sites are the most frequent diagnoses found in persons admitted to a hospice program of care (NHO, 1995). Frequency of cancer types in hospice programs are reflective of national statistics.

## Cancer

The American Cancer Society (1996) has reported that lung cancer is the leading cause of cancer-related deaths for both men and women in the United States. The incidence rate for lung cancer in men declined from a high of 87 per 100,000 in 1984 to 81 in 1992. However, the incidence rate for women increased to 43 per 100,00 in 1992. It was estimated that 98,900 new cases would be diagnosed in men in 1996 and 78,100 new cases diagnosed in women. The one-year relative survival rate for lung cancer rose from 32% in 1973 to 41% in the 1990's. However, the five-year survival rate for all stages combined is only 13%. A total of 158,700 deaths from lung cancer was estimated for the year 1996 with a higher estimated frequency of deaths in men (94,600) than women (64,300). Cigarette smoking, environmental exposures, and difficulty in early detection contribute to both the morbidity and mortality of this disease (ACS, 1996).

The second most common cancer-related death in women is carcinoma of the breast, not including in situ, and is the leading site of new cancer cases in women (ACS, 1996). Risks for developing breast cancer have been identified as strong personal or family history, early menarche or late menopause, and higher educational and socioeconomic status (ACS, 1996). Early detection is the best method of reducing mortality, as personal risk factors may not always be alterable. Mortality rates for white women are falling, due to earlier detection and improved treatments. Black women have lower death rates from breast cancer than white women in the United States (Barr, 1990). Survival rates for five years increased from 78% in the 1940's to 96% in 1996 (ACS,

1996). This rate drops dramatically with regional metastasis (75%) or distant metastasis (20%). It was estimated that 184,300 new invasive cases of breast cancer in women would be diagnosed in 1996, with 44,300 deaths estimated for the same year, according to the ACS. Breast cancer in men is rare. However, 1,400 new cases were estimated for men in 1996 (ACS, 1996).

However, prostate cancer is not rare in men. It is unclear what risk factors are most prevalent for prostate cancer, but international studies indicate that dietary fat may be contributory. The incidence rate for prostate cancer increases with age and 80% of cases are diagnosed in men over the age of 65 years. The ACS (1996) estimated that 317,100 new cases would be diagnosed in 1996, almost three times more than lung cancer. However, the five year survival rate is 98%, as most prostate cancer is diagnosed and treated while still localized. Survival rates decline after five years, with 61% surviving 10 years and 49% surviving 15 years. The ACS estimated that 41,400 men would die of prostate cancer in 1996, making it the second most common cause of cancer-related death (ACS, 1996). Black Americans have the highest incidence rate of prostate cancer in the world (Barr, 1990).

Colorectal cancer is the third most common cause of death from cancer for both men and women (ACS, 1996). Family or personal history of colorectal cancer and occurrence of polyps or inflammatory bowel disease are risks associated in developing colorectal cancer. While incidence rates for this disease have fallen over the last decade, the ACS estimated that 94,500 new cases of colon cancer and 39,00 new cases of rectum

cancer would be diagnosed in the year 1996 (ACS, 1996). Mortality rates for colorectal have fallen for both men (9%) and women (31%) over the last 30 years. Although the one-year survival rate (83%) and five-year survival rate (61%) for colorectal cancer is higher than lung cancer, the ACS estimated 46,400 deaths from colon cancer and 8,500 deaths from rectum cancer for the year 1996.

### AIDS

According to the Centers for Disease Control and Prevention (CDC) (1995) an individual infected with HIV is considered to have AIDS if diagnosed with one or more of the 26 CDC-defined AIDS-indicator conditions (AIDS-OI), and a CD4 T-lymphocyte count of less than 200 or a CD4 percentage of less than 14. The CDC (1995) reports that of the 513,486 cumulative AIDS cases, over 62% have resulted in death. HIV is the leading cause of death in men 24 to 44 years old and the third cause of death in women in this same age group. Since 1985, non-Hispanic white persons represented the largest cumulative death total for all age groups and both sexes (160,154); non-Hispanic black persons represented the second largest death total (102,361); and Hispanic persons constitute the third largest cumulative death total (54,041). For all three ethnic groups, ages 35 to 44 represented the largest cumulative death total for both men and women, with a total of 130,777 reported deaths for this age group since 1985. The average life expectancy from point of HIV infection to death from an AIDS-OI is 11.4 years (CDC, 1995). However, with the introduction of new antiretroviral therapies, including HIV

protease inhibitors, it is anticipated that the average life expectancy will increase (CDC, 1995).

According to the most recent information from the CDC (1995), men who have sex with men continue to represent the largest number and proportions of persons reported to have AIDS-OI's. There was an increased incidence of AIDS in the South (13%) and Northeast (11%) in 1995. Incidence by race/ethnicity, and sex increased among black persons (13%), Hispanic persons (13%), and men (5%). The largest increase in incidence (26%) was found among women from 1992 through 1994. AIDS-OI's are increasing most rapidly among persons infected heterosexually. For the first time since HIV surveillance began in 1985, black persons and Hispanic persons represented the majority of cases among men (54%) and women (76%). This indicates that the fastest growing population developing AIDS is women of a racial or ethnic minority. The reported AIDS incidence rates per 100,000 were six times higher for black persons (92.6) than for white persons (15.4), and two times higher than the incidence rates for Hispanic persons (46.2) (CDC, 1995).

According to the CDC (1995), male-to-male contact in 1995 represented the most predominant mode of transmission, at 51%. Injecting drug use was the second most common mode of transmission (24%). Both of these modes of transmission accounted for 76% of AIDS cases in men ages 20 to 24 years. Among females in this age group, 40% of reported AIDS cases were acquired through injecting drug use and 38% through

heterosexual contact, especially through contact with an injecting drug user. In children, 84% of reported cases of AIDS was in black or Hispanic persons. Incidence rates among children (per 100,00) were 16 times higher among blacks and six times higher among Hispanic than among white children. However, the reported number of cases of AIDS in children dropped from 1,034 in 1994 to 800 in 1995 (CDC, 1995).

Indeed, while new treatments and therapies offer hope to cancer and AIDS patients, morbidity and mortality rates demonstrate the probability of facing the terminal stages of any of the diagnoses discussed here. The inevitability of death is shared by all human beings. Yet, within populations with cancer or AIDS, the inevitable consequences of disease make confrontation with death a more immediate concern. While the health care community pays increasing attention to the holistic needs of persons with terminal cancer and end-stage AIDS, minimal information regarding the perceptions of the meaning of death for either group appears in the nursing literature.

### **Statement of Problem**

Cancer and AIDS continue to represent a significant number of causes of yearly deaths in the United States. These diagnoses include a terminal stage occurring within the last six months of life. While there are holistic approaches to the care of persons with terminal cancer and end-stage AIDS, which include physical, emotional, and spiritual interventions, limited descriptions of the meaning of death to the two populations exist. Additionally, comparison of the meaning of death for persons with cancer and persons with AIDS is not found in the literature. Such comparison is necessary for nursing to

enrich its approach to providing holistic and individualized care to persons dying from cancer and AIDS.

### **Statement of Purpose**

Persons living in the final stages of terminal cancer or AIDS have an opportunity to explore the meaning of death to them personally. Identification of such meaning is useful in continuing efforts to provide and improve holistic care to people living within the last six months of life. Comparison of the meaning of death for persons with cancer and AIDS provides differing perspectives, which can be incorporated into the holistic and individualized nursing care of persons with terminal cancer and end-stage AIDS. Therefore, the purpose of this study was to describe and compare the perceptions of the meaning of death to persons diagnosed with terminal cancer and persons diagnosed with end-stage AIDS.

### **Significance of the Study**

Exploration of the personal meaning of death to people with cancer and AIDS is important on many levels. This study has significance for individual clients, nursing, and the health care system.

#### **Significance for Clients**

Exploring the meaning of death for individuals diagnosed with terminal illnesses provides them the opportunity for increasing self-awareness as end-of-life issues evolve. Identifying philosophical meaning assists the dying individual in resolving these issues. Personal recognition of the significance that the physical, psychosocial, and spiritual

domains have in defining meaning as death approaches assists the individual in the completion of life's journey. Additionally, interpretation of the meaning of death provides elucidation of the significance of the dying process and its effects on this completion.

Comparison of the meaning of death for individuals who are terminally ill with cancer and AIDS distinguishes the issues that may be directly related to the effects of the illness on the individual as a whole. The diagnosis of terminal illness has the potential to have an impact on not only the body, but the mind and spirit as well, thus influencing the meaning of death to the individual. Comparing perspectives of individuals with cancer and individuals with AIDS allows nursing to incorporate these varying aspects of the meaning of death in the delivery of care to the differing populations.

#### Significance for Nursing

There is potential for the emergence of many feelings that may form part of the individual's definition of the meaning of death. Nursing care of the dying individual assists with exploration of these feelings, thus assisting the individual to find meaning in the dying experience. As the potential for individual interpretation is unlimited, individualization of nursing care reflects the physical, psychosocial, and spiritual domains, based on an individual's interpreted need. For example, nursing strategies for the individual verbalizing a profound fear of pain may be directed towards symptom management of physical discomfort. Meaning of death may include anxiety over a family member's grief reaction, or anger about dying from a terminal disease after a strong faith in God had

provided joy and guidance throughout life. Nursing care then focuses on psychosocial or spiritual interventions. Conversely, the meaning of death may demonstrate a positive, hopeful philosophy by the individual, thereby providing the nurse with an opportunity to reinforce useful coping skills identified by the individual.

### Significance for the Health Care System

Potential implications for the health care system include providing appropriate community resources for the individual. While most terminal illnesses include a physical component, from onset of diagnosis to completion of treatment, the meaning of an individual's death may not focus on physical concerns. Appropriate identification of meaning leads to identification of appropriate resources to assist the individual. Within the health care system, this may mean hospice care for the individual who finds meaning in the natural progression of life, including illness, ultimately leading to death. For individuals who find meaning in battling the odds, continuation of acute hospitalization for aggressive medical interventions may be more appropriate. It is likely that the individual with a terminal illness will encounter the health care system at some point during the disease progression. Yet reliance solely on medical interventions may not address the focus of one's meaning of death. For example, finding meaning through spiritual support may mean providing nursing interventions which maximize coping based on spiritual beliefs, or referral to chaplain services or the individual's community network. Therefore, comparing the meaning of death for persons with terminal cancer and persons with end-

stage AIDS further elucidates potential and appropriate health care resources available to either population.

### **Summary**

This chapter provided an overview of the background for the study, including the morbidity and mortality of the most frequent cancer diagnoses and AIDS. While holistic approaches to care of the persons who are terminally ill continue to develop, little information on the meaning of death to individual's dying from cancer or AIDS is available. The purpose of this study was to describe and compare the perceptions of the meaning of death to persons diagnosed with terminal cancer and persons diagnosed with end-stage AIDS. The study was significant in its provision of knowledge useful for appropriate care of the individual client, enhanced nursing care, and improved services available through the health care system.

## **CHAPTER TWO**

### **CONCEPTUAL ORIENTATION AND REVIEW OF LITERATURE**

Chapter Two is a presentation of the conceptual orientation and the review of literature. The conceptual orientation reflects Watson's theory of human caring (1988). The review of literature addresses research related to the major conceptual areas of this study: perceptions of death and dying, spirituality, nursing's response to death and dying, terminal cancer, end-stage AIDS, and hospice care.

#### **Conceptual Orientation**

A conceptual orientation is an appropriate perspective for conducting qualitative research when there has been no, or little, previous research on the topic (Hinshaw, 1979). There has been no reported research on comparison of meaning of death for persons with cancer and persons with AIDS in the last six months of life.

Facets of Jean Watson's theory of human caring formed the conceptual orientation for this research. Watson's model addresses the four metaparadigm concepts of health, nursing, person, and environment. The component of Watson's theory most applicable for this study was the concept of the holistic individual.

#### **Watson's Theory of Human Caring**

Jean Watson describes her theory of human care as phenomenological-existential, and spiritual in nature, developed to address many of the philosophical, conceptual, and empirical problems that confront nursing (Watson, 1988). By incorporating the concept of the soul into human caring, Watson's theory invites the nurse to move beyond the

physical realities of human concerns and to examine the existential nature of the human experience in the provision of nursing care. Both the metaphysical and empirical influences in Watson's theory are evident in her definitions of the four metaparadigm concepts which comprise current nursing conceptual models: nursing, person, environment, and health (Fawcett, 1995).

Watson defines nursing as both a human science and an activity of art (Watson, 1988). Nursing activity is a human-to-human process of care that is held as a moral ideal. Watson delineates a set of nursing interventions referred to as carative factors. Nurses engaging in carative transactions with individuals or persons (Watson does not use the term patient) foster the human care process, which leads to a transpersonal caring relationship. By entering into this relationship, the nurse is able to assist the person in obtaining a higher level of harmony within the body, mind, and soul, which in turn generates self-reverence, self-healing, self-knowledge, and self-care within the person (Watson, 1988).

The metaparadigm concept of person within Watson's model is an experiencing and perceiving being-in-the-world who possesses three spheres of existence - body, mind, and soul. Conceptualization of the soul as a spiritual entity is an underlying assumption in Watson's definition of person. The soul is an ideal self, transcending time, space, and consciousness and reaching beyond the physical world of self-experiences. Actualization of this higher self and achievement of harmony within body, mind, and spirit are the goals towards which the person continuously strives (Watson, 1988). The nurse and person are

both conceptualized as described above and participate equally in a relationship to grow and learn from the encounter. Watson does not define the metaparadigm concept of environment in her model. However, inferences regarding environment are suggested as Watson does refer to a person's "world" as the immediate physical environment, such as nature or external reality, and the forces of the universe (Watson, 1988).

Consistent with her existential-phenomenological philosophy, Watson believes that health is not a feeling of good or bad, but rather the feeling of being at one with what is. Watson conceptualizes health as the unity and harmony within the mind, body, and soul. Harmony results from congruence between the perceived self and the self-as-actually-experienced. Therefore, the health a person experiences depends on the degree to which such congruence is attained (Watson, 1985).

A concept consistently present throughout Watson's theory of human caring is the establishment of nurse-client relationship. Human care begins when the nurse enters the phenomenal field, or frame of reference, of the person with an empathic ability that ultimately leads to the person's release of feelings regarding physical, emotional, and spiritual issues (Watson, 1988). A transpersonal caring relationship occurs when both the person and nurse mutually respect their presence in the world as whole beings. The essentials of a transpersonal relationship include a commitment to enhance and protect human dignity, the nurse's affirmation of the person's subjective significance, the nurse's ability to detect the inner condition and feelings of the person, the nurse's ability to feel and express union with another, the nurse's own life history, and the nurse's sensitivity

towards another individual (Watson, 1988).

Events of a human care interaction lead to an actual caring occasion under Watson's theory. The nurse brings the entire self to interact with the person, which leads to a coming together of their mutual phenomenal fields. Human care is then possible as the nurse detects, feels, and responds to the conditions of the person's body, mind, emotions, and soul. A transpersonal caring relationship develops based on the simultaneous, spiritual union of the nurse-patient feelings. This trusting relationship promotes the release of feelings of the lived experience by the patient. The human capacities of both nurse and person expand, thus allowing for new opportunities for greater knowledge of self and universe through the formation of an actual caring occasion (Watson, 1988).

#### Application of Watson's Theory

Of particular relevance to this study was the metaparadigm concept of the holistic individual Watson describes in her model. The individual is a being who embodies the metaparadigm concept of person with the three spheres of body, mind, and soul. Watson emphasizes these spheres not only in defining the individual, but as the core concepts from which nursing interventions, based on a transpersonal relationship with the individual, must arise. When addressing the needs of the individual who is dying, the three spheres of being are essential elements of care. Watson (1988) views the physical manifestation of the human body as confined in time and space. Death terminates the existence of the physical body within this measured realm. The mind and soul represent the individual's

higher senses. The higher senses transcend the perceived world of time and space and form beliefs surrounding the postulation of collective conscious, parapsychological phenomena, or mystical experiences. Watson suggests that such transcendent concepts are indications of the spiritual evolution of human beings (Watson, 1988). Therefore, personal meaning of death is a potential manifestation of the harmony of the three spheres of being described in Watson's conceptualization of person. Comparison of the meaning of death may include attitudes of transcendence of the physical realm for some, or an incorporation into the collective consciousness for others.

### **Review of Literature**

The review of the literature addresses: perceptions of death and dying, spirituality, nursing's response to death and dying, terminal cancer, end-stage AIDS, and hospice care.

#### **Perceptions of Death and Dying**

There is limited literature addressing the meaning of death and dying to specific populations. Existing qualitative and quantitative studies focus on meaning of death to individuals with terminal illnesses, healthy populations, and children.

McGaffic (1995) asked aging adults ( $n = 35$ ) living in the community and adults dying from a terminal illness ( $n = 35$ ) to describe what death meant to them personally. Using the Meaning of Death Coding Dictionary (Holcomb, Neimeyer, & Moore), McGaffic employed content analysis to identify six new constructs of the meaning of death: (a) Positive Evaluation of Death, (b) Positive Emotional State, (c) Acceptance, (d)

Realistic Appraisal of Death, (e) Religiosity, and (f) Self-Transcendence. Frequency of statements fitting into categories indicated the major death constructs. McGaffic's data revealed that death constructs reflecting meaning in death among aging adults were Self-Transcendence ( $n = 17, 48.6\%$ ), High Personal Involvement ( $n = 9, 25.7\%$ ) and Continued Existence ( $n = 9, 25.7\%$ ). Categories identified by aging participants six or more times included: Emotionally Positive Experience ( $n = 8, 22.9\%$ ), Positive Evaluation of Death ( $n = 7, 20\%$ ), Nonexistence After Death ( $n = 7, 20.0\%$ ), Religiosity ( $n = 7, 20.0\%$ ), Acceptance ( $n = 7, 20\%$ ), and Certainty of Death is High ( $n = 6, 17.1\%$ ). For the dying group, Positive Evaluation of Death ( $n = 15, 42.9\%$ ), Self-Transcendence ( $n = 13, 40.0\%$ ), and Religiosity ( $n = 11, 31.4\%$ ) were the most frequently mentioned death constructs. McGaffic concluded that fostering self-transcendent behaviors and assisting individuals to identify health-related patterns in both groups is an important aspect of nursing care.

Ross and Pollio (1991) used metaphors to describe some of the meanings death holds for healthy individuals. Participants ( $N = 26$ ) completed the Knapp metaphor inventory, then took part in interviews exploring the chosen metaphors most closely reflecting their views of death. The resulting dialogues and selected metaphors were analyzed quantitatively using frequency counts of the selected metaphors from the inventory, and qualitatively using a hermeneutic analysis technique. Quantitative results of responses to the Knapp metaphor inventory revealed that the three most frequently selected metaphors were: (a) An Infinite Ocean ( $f = 12$ ), (b) A Shadowed Doorway

( $f = 11$ ), and (c) The End of A Song ( $f=11$ ). Qualitative results yielded three major themes: (a) death viewed negatively, as a barrier or limit to life's meaning; (b) death viewed ambivalently due to a variety of mitigating factors perceived as making death more acceptable; and (c) death viewed positively, as a reinstatement or transformation of meaning. Additionally, Ross and Pollio found that church-going participants ( $n = 13$ ), yielded more Transformation themes than non-church participants ( $n = 13$ ) who viewed death more frequently as a barrier to life's meanings.

Jones (1993) studied one person's dying experience to describe the personal expression of the meaning of death. In a case study of a 67-year-old female dying from metastatic colon cancer, Jones used content analysis of taped interviews to identify themes from the situational context of the participant. The author identified themes of anger, reactions to dying, and sense of control in this case study. Implications for nurses providing care to individuals with terminal illnesses include paying ample attention to learning the meanings that individuals attach to certain life events, being fully present with the individual within the context defined by the individual, and honoring the integration of the individual's illness within the fullness of their life.

Reed (1986b) used the "Personal Death Perspective" scale, "Belief in Afterlife" index, and "Perceived Distance from Death" measure to describe differences in death perspectives among terminally ill adults ( $n = 57$ ) and healthy adults ( $n = 57$ ). Using a developmental conceptual framework, Reed matched the two groups on four variables postulated to have possible influence on death perspectives: age, gender, education, and

religious background. Results of the Personal Death Perspective scale showed that the Terminally Ill group ( $M = 4.20$ ,  $SD = .75$ ) did not differ significantly from the Healthy group ( $M = 4.13$ ,  $SD = .90$ ). Comparing the two groups on temporal variables, Reed found that the Terminally Ill group perceived that they had significantly less time left than the Healthy group. Temporal variables found to be statistically significant in the Terminally Ill group were Belief in Afterlife ( $r = .48$ ,  $p < .001$ ) and Time Since Diagnosis ( $r = -.23$ ,  $p < .05$ ). In the Healthy group, Belief in Afterlife ( $r = .70$ ,  $p < .001$ ) was a significant temporal variable. Reed concluded knowledge of death perspectives of dying individuals may be useful in promoting positive interactions between the dying individual, family members, friends and health care workers.

Researchers used the Intrinsic Religious Motivation Scale (IRM) and a death anxiety scale (DA) to measure relationships between elements of the fear of death and dying with a construct of intrinsic religiosity (Thorson & Powell, 1990) in participants ( $N = 346$ ) whose ages ranged from 18-88. Results indicated that older respondents ( $n = 180$ ), over the age of 50 years, had significantly lower mean scores on the DA ( $M = 40.50$ ,  $SD = 14.68$ ,  $p < .001$ ) and significantly higher scores on the IRM ( $M = 28.41$ ,  $SD = 7.35$ ,  $p < .001$ ) than younger participants ( $n = 165$ ). Those higher in intrinsic religiosity ( $M \geq 29$ ,  $n = 145$ ) were lower in fear of death ( $M \leq 39$ ,  $n = 136$ ). Respondents who were highest in death anxiety ( $M \leq 49$ ,  $n = 141$ ) were lower in religiosity ( $M \geq 24$ ,  $n = 137$ ). Separate factor analysis indicated that people higher in intrinsic religiosity do not construe death and dying much differently from those who score lower on the IRM scale. All participants

indicated major concerns with the process of dying, such as pain, helplessness, cancer, and a lingering death, rather than the prospect of being dead. The authors concluded that generally people, whether they are religious or not, seem to fear elements of dying more than they fear the state of being dead.

University students ( $N = 504$ ) participated in a study seeking personal views of death by providing written answers to the questions, “What is death? What does it mean to you?” and completing the Threat Index and Hoelter Multi-Dimensional Fear of Death Scale (Holcomb, Neimeyer, & Moore, 1993). Content analysis of the personal meaning of death paragraph, using a coding dictionary as a guide for classifying constructs, revealed death constructs of Purposeful (63.1%), Existence (61.9%), Negative Emotional State (39.5%), Nonexistence (37.5%), and Positive Understanding (28.2%) as the most frequent construct categories identified at least once. While researchers found no significant differences for age groups, females ( $F = 2.57$ ,  $df = 1,498$ ,  $p < .001$ ) were more likely to write about death as a form of continued existence, to describe it in both positive and negative terms, and to associate death with negative emotions and a high impact. Males expressed their views of death in more general terms, or as something that happens to everyone. Additionally, respondents demonstrating a “personal philosophy of death” ( $F = 1.81$ ,  $df = 1,488$ ,  $p = 0.1$ ) viewed death as more purposeful, expected, and involving some form of continued existence. Those reporting no personal philosophy wrote narratives indicating a negative evaluation, low acceptance, and low understanding of death. The researchers concluded that analyzing personal meaning of death was feasible

and provided new opportunities for understanding the ways in which individuals view death.

Tamm and Granqvist (1995) studied the qualitative differences and gender differences in children's concepts of death reflected in personal drawings. Participants in four age groups (9, 12, 15, and 18 years), male ( $n = 218$ ) and female ( $n = 213$ ), were asked to draw a depiction of the word "death" and attach a brief written commentary explaining and specifying their drawings. A phenomenological method of analysis revealed three major categories: (a) biological death concepts ( $n = 150$ ); (b) psychological death concepts ( $n = 75$ ); and (c) metaphysical death concepts ( $n = 196$ ). With regard to gender, significantly more boys than girls indicated the category of biological death ( $n = 154$ ,  $SD = 11.48$ ,  $p < .001$ ). Significantly more girls than boys had drawings that fit in the psychological death concept category ( $n = 73$ ,  $SD = 3.81$ ,  $p < .05$ ). The authors concluded that children's drawings about death can be reliably categorized by content-specific qualitative variations. They also suggest that the influences of age, gender, the representation of media, and sociocultural variables may influence a child's concept of death.

Summary. In summary, results of research on perceptions of death and dying revealed that analyzing personal meaning of death was feasible, and that such knowledge provided opportunities to promote positive interactions between dying individuals and significant others. Females were more likely to associate death with high-impact positive and negative emotions, while males expressed their views in more general terms of

inevitability. Common constructs of the meaning of death for individuals diagnosed with terminal illnesses were positive evaluation of death, religiosity, and self-transcendence. Having a personal philosophy of death assisted individuals in viewing death in more positive terms and with greater acceptance, compared to individuals who have no personal philosophy of death. Church-going individuals were more likely to describe personal meaning of death in terms of self-transcendence, and non-church going individuals saw death as a barrier to meaning in life. Additionally, people with less religious identification had higher degrees of death anxiety. However, it was also found that fear of the dying process was the primary concern of most individuals, regardless of religious identification. Children's perceptions of death vary with age, gender, media influences, and sociocultural variables.

### Spirituality

Both quantitative and qualitative studies contribute to a growing body of nursing literature surrounding spirituality. Studies pertaining to spirituality and terminal illness or end-of-life issues center on measures of self-transcendence, examination of spiritual perspectives of individuals who are healthy or terminally ill, and preferred spiritually-related nursing interventions.

McGaffic (1995) studied the difference between aging adults ( $n = 35$ ) and dying adults ( $n = 35$ ) for spiritual indicators of self-transcendence, spiritual perspective, and meaning and purpose in life and death. There was no difference in self-transcendence between the two groups ( $M = 52$ ) as measured by responses on the Self-Transcendence

Scale. Aging men had statistically significant lower scores ( $M = 32.86$ ,  $SD = 17.15$ ,  $p \leq .05$ ) on the Spiritual Perspective Scale than did aging women ( $M = 49.79$ ,  $SD = 6.00$ ), dying women ( $M = 50.50$ ,  $SD = 8.90$ ), or dying men ( $M = 50.53$ ,  $SD = 9.26$ ). However, dying women and dying men demonstrated essentially the same spiritual perspectives, indicating that dying has more influence on spiritual perspectives for men than age. The Purpose in Life Test indicated slightly greater purpose in life for the aging group ( $M = 112.60$ ,  $SD = 11.71$ ) than for the dying group ( $M = 109.23$ ,  $SD = 17.00$ ).

Coward (1990) conducted a phenomenological study of five women diagnosed with advanced breast cancer to identify themes of self-transcendence. Identified themes of self-transcendence through experiencing a sense of purpose and self-worth were:

(a) helping other women with breast cancer, (b) connectedness with the environment, and (c) accepting circumstances that could not be altered. The author concluded that nursing interventions should support patients in establishing or maintaining a sense of purpose or self-worth, which fosters self-transcendence.

Coward (1991) followed up with a cross-sectional correlational design to study self-transcendence and emotional well-being in women with advanced breast cancer. A convenience sample ( $N = 107$ ) of women diagnosed with advanced breast cancer completed questionnaires measuring self-transcendence, emotional well-being, cognitive well-being, symptom distress, and functional levels. Coward found that self-transcendence directly affected emotional well-being ( $B = -0.84$ ), and emotional well-being had a strong negative effect on illness distress ( $B = -0.84$ ). When controlling for emotional well-being,

a direct path from self-transcendence to illness distress ( $B = -0.31$ ) became nonsignificant ( $B = -0.08$ ). Coward concluded that women faced with terminal illness maintained the capacity for personal development, which included a sense of positive well-being, life satisfaction, and self-transcendence.

Researchers used a cross-sectional descriptive study to examine spiritual awareness, personal perspective on death, and psychosocial distress among persons with cancer (Smith et al., 1993). Study participants consisted of men ( $n = 57$ ) and women ( $n = 59$ ) diagnosed with cancer and receiving active treatment. Using the Brief Symptom Inventory and the Transpersonal Development Inventory, researchers determined that the higher the level of overall transpersonal development of the person with cancer, the lower the level of psychosocial distress. Conversely, persons who experienced high psychosocial distress tended to be less spiritually aware overall and have a more distressing personal perspective on death. The more the person with cancer was able to normalize death, the less psychosocial distress experienced. Researchers concluded that interventions that address a level of spiritual awareness and comfort with death perspectives may decrease psychosocial distress related to mortality issues for persons with cancer.

In an exploratory, descriptive study, the author used a phenomenological research approach to investigate the structure of self-transcendence in men ( $n = 10$ ) and women ( $n = 10$ ) with AIDS (Coward, 1994). Participants described transcendence situations as they remembered them, including their thoughts, feelings, and perceptions at the time. Using Colaizzi's phenomenological analysis technique, men revealed nine themes: (a)

experiencing fear, (b) taking care of themselves, (c) seeking out challenge, (d) creating a legacy, (e) accepting that which cannot be changed, (f) connecting with others, (g) letting go, (h) accepting help, and (i) having hope. Eight women's themes emerged: (a) experiencing fear and aloneness, (b) experiencing uncertainty, (c) using others as role models, (d) finding inner strength, (e) reaching out, (f) having purpose/making a difference, (g) viewing AIDS as an opportunity, and (h) having hope. The author concluded that nurses may want to focus on interventions that help men to reach out for assistance and support, while interventions for women may focus on ensuring confidentiality when women do reach out. Additionally, nursing interventions that encourage both men and women to share their experiences may assist them in finding new meaning and purpose in life, as well as an increased sense of self-worth.

Reed (1986a) compared religious perspectives between healthy adults ( $n = 57$ ) and terminally ill ambulatory adults ( $n = 57$ ) matched for age, gender, religion, and education. Using the Religious Perspective Scale, the terminally ill group indicated significantly greater religiousness than the healthy adults group ( $t [112] = 3.12, p < .001$ ). However, the Index of Well-Being, used to measure life satisfaction, did not demonstrate a statistically significant difference between the two groups. For the healthy group, well-being was significantly related to religious perspective ( $r = .43, p < .001$ ). The same was not true for the terminally ill group.

Reed (1987) examined differences in spiritual perspective and well-being among terminally ill hospitalized adults ( $n = 100$ ), nonterminally ill hospitalized adults ( $n = 100$ ),

and healthy nonhospitalized adults ( $n = 100$ ) matched on age, gender, education, and religious background. The findings revealed a statistically significant greater spiritual perspective for the terminally ill group ( $F [1,297] = 5.16, p = .02$ ) than for either of the other two groups. The Index of Well-Being demonstrated a statistically significant positive relationship between spiritual perspective and well-being for the terminally ill group ( $r = .32, p < .001$ ). For the nonterminally ill hospitalized adults and the healthy adults, this relationship was not significant. Additionally, Reed found that being both female and terminally ill contributed significantly to greater religiousness.

Reed (1991) studied nonterminally ill hospitalized adults ( $n = 100$ ), healthy adults ( $n = 100$ ), and a hospitalized terminally ill group ( $n = 100$ ) to determine preferences for spiritually related nursing interventions and to identify differences between the groups in a secondary analysis of her previous study (Reed, 1987). Participants responded to structured and open-ended questions about specific nursing interventions that they thought would help meet their spiritual needs. The category "arrange a visit with clergy" was the most frequently obtained response both within and across the three groups (27%), followed by "allow time for personal prayer" (17%), and "provide time for family involvement in spiritual activities" (15%). Comparatively, the nonterminally ill group found it helpful for nurses to assist them to attend chapel or discuss spiritual beliefs, while the terminally ill group responded more to nursing interventions that facilitated an environment conducive to personal spiritual expression. Reed concluded that spiritually related nursing interventions for nonterminal hospitalized persons focus on individualized

nursing interactions. Individuals with terminal illnesses may require more creative nursing interventions to establish an environment that promotes expression of spiritual beliefs.

Summary. In summary, results of research on spirituality related to end-of-life issues demonstrated healthy adults as having a greater purpose in life than adults with terminal illnesses. Self-transcendence in women with breast cancer revealed themes reflecting a sense of purpose and self-worth. Additionally, high self-transcendence directly affected emotional well-being, including decreasing psychosocial distress. Experiencing fear, hope, and reaching out were common themes of self-transcendence among men and women with end-stage AIDS. However, men sought to accept the inevitable while women experienced uncertainty. Compared to healthy adults, individuals with terminal illnesses report greater spiritual perspectives. Greater spirituality was also associated with a higher sense of well-being in individuals who were terminally ill. Spiritually-related nursing interventions for persons with terminal illness include fostering an environment for the individual's spiritual expression, and exploration of feelings to foster meaning, purpose, and self-transcendence.

#### Nursing's Response to Death and Dying

Research addressing nursing's response to death and dying deals with identification of appropriate nursing behaviors and interventions. Researchers have also studied nurses' attitudes toward dying persons and their holistic needs. Additionally, studies address the impact of death education on changing nursing behaviors and attitudes.

Ryan (1992) used Jean Watson's theory of human caring as a conceptual

framework to study the nursing behaviors perceived as most helpful and as least helpful by primary caregivers and by hospice nurses in a hospice homecare setting. Caregiver participants ( $n = 20$ ) and hospice nurse participants ( $n = 5$ ) ranked a Q-sort of 60 nursing behaviors from most helpful to least helpful in three categories of care: patient's physical needs, patient's psychosocial needs, and caregiver's psychosocial needs. Primary caregivers ranked "Listen to the patient/listen to what the patient wants" (Ryan, 1992, p. 25) ( $M = 5.65$ ,  $SD = .93$ ) as the most helpful and "Talk with me about my guilt" (Ryan, 1992, p. 26) ( $M = 2.50$ ,  $SD = 1.24$ ) as the least helpful. Categorically, caregivers attributed the highest mean score to patient's psychosocial needs ( $M = 4.21$ ,  $SD = .247$ ,  $p = .001$ ) while caregiver's psychosocial needs was the lowest ( $M = 3.74$ ,  $SD = .482$ ,  $p = .001$ ). Hospice nurses ranked "Assure the caregiver that nursing services will be available 24 hours a day, 7 days a week" (Ryan, 1992, p. 27) as the most helpful nursing behavior ( $M = 6.20$ ,  $SD = .45$ ) and "Describe how to keep the patient well-groomed" (Ryan, 1992, p. 27) as least helpful ( $M = 1.80$ ,  $SD = 1.30$ ). Nurses also ranked the category of patients' psychosocial needs highest ( $M = 4.46$ ,  $SD = .171$ ,  $p < .05$ ) and patients physical needs lowest ( $M = 3.58$ ,  $SD = .299$ ,  $p < .05$ ). Thus, both caregivers and hospice nurses ranked meeting patient's psychosocial needs highest. Ryan concluded that, consistent with Watson's carative factors, nurses should focus on the importance of involving both the person who is terminally ill and their families in the identification of needs and how they can best be met.

A naturalistic study described the development of the relationship between nurses

and persons diagnosed with a terminal illness in a hospice setting (Raudonis, 1995).

Content analysis and constant comparative analysis were analytical methods used for data from broad, open-ended interviews with 10 adults with terminal illnesses who reported experiencing an empathetic relationship with at least one hospice nurse. Results indicated the development of the empathetic relationship occurred in three sequential phases: (a) initiating, (b) building, and (c) sustaining. The author concluded that the therapeutic relationship develops over time, and that the relationship emphasizes the importance of a nurse's self-knowledge in dealing with a person diagnosed with a terminal illness. For a nurse to relate to another human being, there is a need for personal knowing.

Waltman and Zimmerman (1991) performed secondary analysis of data from a larger study to describe nurses' behavioral intentions toward dying persons. A convenience sample of registered nurses ( $N = 372$ ) working in a variety of settings in a Midwestern state completed a 12-item questionnaire, entitled "Behavioral Intentions of Nurses Toward the Dying", which addressed categories of General Nursing Measures, Open Communication, and Continuing Care for the Family. The category of General Nursing Measures ranked highest ( $M = 5.51$ ,  $SD = .79$ ), with the item "allow family to remain past visiting hours" (Waltman & Zimmerman, 1991, p. 43) scoring highest ( $M = 5.69$ ,  $SD = .79$ ). Continuing care for the family ranked lowest ( $M = 2.99$ ,  $SD = 1.97$ ) in category, with "attend the patient's funeral" (Waltman & Zimmerman, 1991, p. 43) the lowest item ( $M = 2.95$ ,  $SD = 1.97$ ). Researchers concluded that nurses are not meeting the continuing care needs of bereaved families in traditional health care settings, and that

different groups of nurses have different approaches to care of the dying, as well as different learning needs.

Using a descriptive design, one researcher examined relationships among nurses' spirituality, perceived social support, death anxiety, and nurses' willingness to care for persons diagnosed with AIDS (Sherman, 1996). A convenience sample of female RN's ( $N = 220$ ) who cared for persons with AIDS either on AIDS specialty units ( $n = 88$ ) or medical-surgical scatter bed units ( $n = 132$ ) completed the Spiritual Orientation Inventory, the Personal Resource Questionnaire-85, the Templer Death Anxiety Scale, and the Willingness to Care for AIDS Patients instruments. Results indicated that willingness to care for persons with AIDS was positively correlated with spirituality ( $r = .24, p < .001$ ) and perceived social support ( $r = .25, p < .001$ ), and negatively correlated with death anxiety ( $r = .23, p < .00$ ). This supported the hypothesis that the greater the nurse's death anxiety, the less willingness there was to care for persons with AIDS. Differences in location of nursing practice of the two groups was not statistically significant.

Researchers used an exploratory design to investigate possible relationships among measures of death anxiety, communication apprehension with dying persons, and empathy (Servaty, Krejci, & Hayslip, 1996). Volunteer participants ( $N = 129$ ) from a Midwestern university consisted of a freshmen nursing group ( $n = 13$ ), a freshmen premed group ( $n = 31$ ), a freshmen control group ( $n = 31$ ), a senior nursing group ( $n = 11$ ), senior premed group, ( $n = 23$ ), and senior control group ( $n = 28$ ). Researchers used demographic information, including previous experiences with the death of a significant other, the

Mehrabian and Epstein Empathy Scale, the Death Anxiety Scale, and the Communication Apprehension with the Dying Scale to measure the relationships. Significant moderate positive correlations were found between death anxiety and communication apprehension ( $r = .42, p < .01$ ) with dying persons. There was a weak significant positive correlation between death anxiety and empathy ( $r = .20, p < .05$ ). There was a weak significant positive correlation also between communication apprehension and empathy ( $r = .12, p < .05$ ). Additionally, researchers found a significant difference in communication apprehension with dying persons between freshmen and seniors, with seniors scoring lower than the freshmen ( $F = 4.47, p < .01$ ). Nursing participants and premed participants scored similarly. However, communication apprehension with dying persons was significantly lower for both nursing groups ( $F = 4.47, p < .01$ ) than controls. Researchers concluded that experience, either personal or professional/academic, may influence the degree of apprehension an individual has with communication with dying persons.

Hainsworth (1996) studied the effect of death education on attitudes of hospital nurses toward care of dying persons. The research design divided 28 randomly-selected registered nurses from medical-surgical hospital units into experimental ( $n = 14$ ) and control ( $n = 14$ ) groups. Twenty-five of the participants had previous experience with the death of a loved one. Measurement instruments included a demographic questionnaire, and the Attitudes, Subjective Norms, and Behavior Intentions of Nurses Toward Care of Dying Persons and Their Families (ASBID) questionnaire to measure the variables of interest. The educational intervention for the experimental group consisted of personal

death awareness, communication with dying persons and their families, and care for the caregiver. Researchers administered the ASBID and demographic survey to participant groups two weeks before the educational intervention, and to the experimental group one week after the intervention, and one year later. Results indicated that while the educational program resulted in a statistically significant ( $p < .010$ ) effect on the subjective norms subcategory of the ASBID, no significant difference resulted for effects of the intervention at either two weeks or one year post-testing. Hainsworth speculated that previous experience with the death of a loved one could have significantly shaped participants' attitudes toward death and dying. Therefore, death education may have been less likely to change these attitudes. She also concluded that hospital nurses must continue to find appropriate means to improve their interventions with persons with terminal illnesses and their families.

Summary. Both hospice nurses and caregivers thought meeting psychosocial needs to be the most helpful nursing behaviors when dealing with persons who are dying. Both groups ranked meeting the dying person's physical needs as lowest. Relationships between persons who are terminally ill and nurses progress over time through phases of initiating, building, and sustaining. Nursing intentions towards addressing the holistic needs of dying persons, particularly bereavement follow-up with family members, were not adequate in traditional hospital settings. Nurses who reported an expanded spiritual orientation demonstrated a greater willingness to work with persons with AIDS, while nurses with greater death anxiety demonstrated less willingness to work with persons with

AIDS. While senior nursing students demonstrated less anxiety and apprehension than freshmen nursing students when dealing with dying persons, both nursing groups demonstrated less communication apprehension with dying persons than premed students or control groups. Death education was not effective in changing attitudes or behaviors of medical-surgical nurses toward dying persons, but was effective in changing subjective norms. Previous personal experience with death and dying may be more influential in attitude formation than professional/academic experience for nurses caring for people who are dying.

#### Terminal Cancer

There are few studies addressing end-of-life issues for cancer patients. Focus of the existing quantitative and qualitative literature deals with identification of meaning and quality of life.

O'Connor, Wicker, and Germino (1990) used qualitative methods to study the experience of finding meaning in life, illness, and death for participants ( $N = 30$ ) diagnosed with breast, lung, and colorectal cancer. Secondary analysis data collected from a larger study (Germino & Funk, 1989) revealed six major themes: (a) seeking an understanding of the personal significance of the diagnosis; (b) looking at the consequences of the diagnosis; (c) reviewing life; (d) change in an outlook toward self, life, and others; (e) living with the cancer; and (f) hope. Researchers concluded that nurses can facilitate the process by which persons diagnosed with cancer may explore what cancer means for their lives, as well as assisting family members in understanding the significance of finding

meaning in the cancer experience

Loveys and Klaich (1991) studied women ( $N = 79$ ) diagnosed with varying stages of breast cancer in the Seattle, Washington area to identify the demands of illness.

Structured interviews included four questions on identification of changes in life since diagnosis, particular difficulties, preparedness, and open comments. Content analysis yielded 14 domains of illness demands: (a) treatment issues, (b) change in life context or perspective, (c) acceptance of the illness, (d) social interaction or support, (e) physical changes, (f) reconstructing the self, (g) uncertainty, (h) loss, (i) making comparisons, (j) acquiring new knowledge, (k) making choices, (l) financial or occupational concerns, (m) making a contribution, and (n) mortality issues. Implications for nursing include that knowledge of the demands of illness on women with breast cancer can serve to assist nurses with maximizing coping skills of women in various stages of breast cancer: newly diagnosed, actively treated, and terminal phases.

Padilla, Ferrell, Grant, and Reiner (1990) studied persons with cancer ( $N = 41$ ) to define content domain of quality of life. The sample population answered four questions to measure existential attributes of quality of life, pertinent attributes used by persons with cancer to evaluate quality of life, and quality of life attributes related to pain. Content analysis of responses revealed three categories of attributes that embrace the quality-of-life domain: (a) general functioning and disease-specific attributes, (b) psychological well-being, and (c) interpersonal well-being. Researchers concluded that identification of content domain of quality of life measures has application in evaluation of quality of life

related to disease-specific symptoms, including the terminal phases of the disease process.

McMillan (1996) measured quality of life for persons with terminal cancer ( $N = 118$ ) from point of admission to a hospice program to week four, in a descriptive study using the Hospice Quality of Life Index (HQLI) and demographic information. HQLI scores could range from a low of 25 to a high of 250. Mean HQLI scores ranged from 168 to 173.7 and were not significantly different from point of admission ( $M = 171.4$ ) to week four ( $M = 173.7$ ). Factor analysis confirmed that the HQLI consists of four subscales: (a) social/spiritual, (b) psychological/emotional, (c) physical/functional, and (d) financial. Participants were least satisfied with physical/functional aspects of quality of life. With a possible range of 9 to 90, physical/functional aspects remained significantly low at point of admission ( $M = 23.9$ ,  $SD = 9.3$ ) and at week four ( $M = 25.3$ ,  $SD = 8.5$ ) compared to the other three subscales. McMillan concluded that while the persons with terminal cancer studied had a reasonably good quality of life which was maintained over the course of the three week study, nursing interventions that address the physical/functional aspects of quality of life must continue to develop in order to provide comprehensive care to persons enrolled in a hospice program.

The Sendra Quality of Life Index (SQLI) measured quality of life in a study of persons with terminal cancer ( $N = 45$ ) and their caregivers enrolled in a hospice program of care (McMillan & Mahon, 1994). The mean score for the group on admission ( $M = 49.2$ ) was not significantly different three weeks later ( $M = 49.7$ ). However, caregiver perceptions of patient quality of life improved from point of admission ( $M = 48.2$ ) to week

three ( $M = 53.3$ ,  $t = 2.06$ ,  $p > 0.05$ ). Results showed a moderately weak to weak relationship between quality of life as perceived by the person with terminal cancer and as perceived by the caregiver, with correlations decreasing slightly from admission ( $r = 0.45$ ) to week three ( $r = 0.39$ ). Researchers concluded that persons with terminal cancer felt increasingly supported by nurses from admission ( $M = 57.9$ ,  $SD = 27.8$ ) to week three ( $M = 72.3$ ,  $SD = 12.8$ ), worried less about cost of medical care from admission ( $M = 42.7$ ,  $SD = 27.1$ ) to week three ( $M = 50.9$ ,  $SD = 26.7$ ), and reported an increase in sexual activity from point of admission ( $M = 9.4$ ,  $SD = 15.7$ ) to week three ( $M = 17.3$ ,  $SD = 27.2$ ).

An international research group studied quality of life (QL) for persons with terminal cancer in the last weeks of life (Morris, Suissa, Sherwood, Wright, & Greer, 1986). Using the Karnofsky Performance Index, the Spitzer QL Index, the Hebrew Rehabilitation Center for Aged (HRCA)-QL Index, the Spitzer Uniscale QL Index, an integrated Pain and Discomfort Index, a scale measuring Emotional QL, a scale measuring awareness, and an overall score measuring Social QL, researchers studied 25 persons diagnosed with terminal cancer in palliative care units in Montreal, Canada, and 1121 persons with terminal cancer from 26 hospice programs throughout the United States. General findings indicated accelerated deterioration reported in quality of life scales between three weeks prior to death and last week of life in both Montreal (68.0%) and the United States (64.2%). However, the authors limited the definition of quality of life was limited almost exclusively to the physical realm. Pain reports followed a different pattern

from the other measures. More persons studied were in either of the extreme categories, worst (25%) or best (40%), at an earlier point in time than found for the other measures. This did not change as death approached.

Summary. In summary, results of research on quality of life and meaning for persons with terminal cancer focused on physical, psychological, emotional, financial, and spiritual components. The demands of illness for women with breast cancer centered on acceptance of the illness and ensuing changes, uncertainty, hope and loss. Nursing can assist people to maximize coping with terminal stages of cancer by acknowledging the physical, emotional, and spiritual demands of the illness, and by helping persons who are ill and families to find meaning in the illness experience. For individuals with terminal cancer, as death neared, general quality of life declined and pain surveys were a definitive measure. Initiation of hospice services helped persons with terminal cancer improve their quality of life with increased nursing support, decreased financial worries, and decreased fear of sexual activity. Quality of life was poorest in the physical/functional aspects of life for persons with terminal cancer in a hospice program from point of admission to death.

### End-Stage AIDS

Research addressing end-stage AIDS addresses anxiety related to terminal diagnosis, identification of psychosocial needs, and coping patterns. Both quantitative and qualitative studies have implications for nurses dealing with people with end-stage AIDS.

Baker and Seager (1991) compared the psychosocial needs of persons with AIDS ( $N = 11$ ) with persons who did not have AIDS ( $N = 36$ ), both enrolled in a hospice

program. Nurses and members of a psychosocial team ( $N = 13$ ) of a Midwestern hospice completed a seven item questionnaire probing staff perceptions about the time and stress associated with persons diagnosed with AIDS versus persons who had diagnoses other than AIDS. The mean age of the two groups was 55. Researchers found that there was a significant difference in the number of psychosocial staff contacts made to persons with AIDS per week ( $M = 2.8$ ,  $SD = 0.6$ ,  $p = <.026$ ) compared with persons with other diagnoses ( $M = 1.2$ ,  $SD = 0.2$ ). Persons with AIDS required contact over 2 ½ times more often by telephone and twice as often in person. Nursing staff estimated spending fifteen minutes to an hour more per visit with the persons diagnosed with AIDS. Most respondents (92%) felt that extra time was needed because the persons with AIDS had more physical and emotional needs. Respondents (64%) felt that working with persons with AIDS was more stressful than working with persons with other diagnoses of similar ages due to their unique needs and social stigmatization. Researchers identified the greater psychosocial needs of persons with AIDS as being grief over multiple losses to AIDS, lack of health insurance, and inadequate financial resources.

A descriptive study identified and categorized major physical and psychological concerns of persons with AIDS (Longo, Spross, & Locke, 1990). Using a convenience sample ( $N=34$ ), researchers conducted semistructured interviews which consisted of 40 open-ended questions aimed at eliciting the individual participant's perceived psychological and physiological concerns. Analysis of objective data used means and frequencies. Qualitative data were subject to content analysis. Five major themes

emerged: (a) uncertainty of the future, (b) desire to maintain physical and/or psychological health, (c) social unacceptability, (d) fatigue, and (e) weight loss. Respondents stated that empathy (24%) and acceptance (18%) were the characteristics they felt were most helpful for nurses to incorporate when caring for persons with AIDS. The authors concluded that for the respondents life was short-term, with all creative energies being channeled into coping with the illness, staying in control, and adjusting to the uncertain changes in their lives. Recommended nursing interventions were: assessment for depression, identification of support networks, and evaluation of the experience of stigmatization due to the diagnosis.

Hayslip, Luhr, and Beyerlein (1991) used the Templer Death Anxiety Scale (DAS) to measure overt fear of death and the Incomplete Sentence Blank (ISB) task to measure covert fear of death in men who were terminally ill. Participants ( $N = 25$ ) had a diagnosis of end-stage AIDS ( $n = 13$ ) or were healthy ( $n = 12$ ). Results indicated that while both groups did not differ in Templer DAS scores ( $F = 1.56, p > .05$ ), descriptively those with AIDS ( $M = 2.0$ ) were more likely to disagree with the statement "There is such a thing as life after death" (Hayslip, Luhr, & Beyerlein, 1991, p. 15) than their healthy counterparts ( $M = 1.54$ ). Additionally, those with AIDS ( $M = 2.83$ ) were more likely to disagree with the statement "Sharing in someone's death is a wonderful experience" (Hayslip, Luhr, & Beyerlein, 1991, p. 16) than were healthy men ( $M = 2.3$ ). The ISB revealed that the group with AIDS ( $M = 8.30, SD = 3.32$ ) had a more covert fear of dying than the healthy group ( $M = 6.75, SD = 2.63$ ). Researchers conclude that diagnosis of a terminal illness

evokes defenses to deal with anxiety.

A phenomenological study addressed the lived experience of 36 persons with AIDS (McCain & Gramling, 1992). Researchers attempted to capture the structure of experiences of living with HIV diseases, and employed content analysis to identify stress and coping themes. Both male ( $n = 32$ ) and female ( $n = 4$ ) participants responded to questions regarding the most stressful experience they had encountered since time of diagnosis and methods they had employed to cope with the experience. Nine selected transcripts were coded according to phenomenological methods. Content analysis identified three stress and coping themes: (a) living with dying, (b) fighting the sickness, and (c) getting worn out. McCain and Gramling (1992) concluded that the structure of the lived experience of coping with HIV disease unfolds from the initial diagnosis of HIV, through the diagnosis of AIDS, to impending death. They recommended that nurses consider the stage of the illness when using interventions that address maximizing coping skills of the individual.

The heuristic research method was used to examine the theory of health as expanding consciousness in persons with HIV/AIDS (Lamendola & Newman, 1994). Lamendola asked gay men diagnosed with AIDS ( $N = 9$ ) to tell him "about the most meaningful persons or events in your life" (Lamendola & Newman, 1994, p. 15). Patterns identified were: (a) alienation, (b) breaking away, (c) cycles of aloneness and searching, and (d) turning points. Researchers concluded that the life stories of the participants revealed an evolving pattern of the whole. Acknowledgment of the influences of living

with AIDS within those patterns, including acceptance of their own mortality, led to recognition of the unfolding pattern of expanding consciousness in their lives. The nurse's understanding of the phenomenon of health as expanding consciousness is integral to the mutual interaction with persons with AIDS.

Summary. In summary, results of research on end-stage AIDS demonstrate that psychosocial needs of persons with AIDS were identified as dealing with depression, social stigmatization, grief, and inadequate insurance or financial resources. Men with end-stage AIDS have a greater covert fear of death, but anxiety about death in general is similar in healthy men. Coping themes for people with end-stage AIDS included living with the probability of death, illness demands, and final debility. Empathy and acceptance were the two characteristics most helpful in nurses caring for individuals with end-stage AIDS. Recommended nursing actions include acknowledgment of the physical, emotional, and spiritual demands of living with AIDS when entering into a nurse-client relationship, thereby expanding the effectiveness of interventions that maximize coping skills of persons with end-stage AIDS.

### Hospice Care

Available studies about hospice reflect the holistic approach to care rendered under the hospice philosophy. Research on spiritual, psychosocial, and physical topics within a hospice framework yielded implications for care of the people with terminal illnesses.

In a survey of physician ( $N = 966$ ) attitudes towards hospice care (Von Gunten, Von Roenn, Neely, Martinez, & Weitzman, 1995), 69% of faculty physicians of a

Midwestern teaching hospital reported that symptom control was “excellent” and 26% reported symptom control as “good.” Respondents rated psychosocial support of the family as “excellent” (66%) or “good” (23%). Seventy percent of respondents reported “excellent” family satisfaction, with 22% reporting “good.” Researchers concluded that when a hospice program is integrated into an academic medical center, physician acceptance is broad and that hospice should be integrated into general physician practice settings.

In a study measuring consumer perceptions of preferred characteristics of a care setting for individuals who were terminally ill, results indicated that “trustworthy/ethical” and “affordable” were the two top distinguishing characteristics of a preferred setting, followed by “professional/experienced” and “high technology” (McCracken, Colburn, & Pastorik, 1994). A perceptual mapping technique compared preferred characteristics between hospital, nursing home, home health care, and hospice care settings. Hospice care received the highest rating along a dimensional scale that distinguished between the alternatives. Authors concluded that hospice, compared with hospital, nursing home, or home health services, is perceived as providing the support assistance needed to enable the family to physically and emotionally care for a person with a terminal illness.

Literature addressing the spiritual component of hospice care focuses primarily on anecdotal or observational accounts, but some studies do address hospice nurses as spiritual care providers. In an effort to identify the requisite hospice competencies of caring spiritually and guiding letting go, Zerwekh (1993) interviewed hospice nurses

(N=32) working with people nearing death. Using a process of constant comparative analysis, Zerwekh identified and described ten competencies of providing spiritual care by hospice nurses: (a) personal grounding, (b) identifying spiritual issues, (c) being there and dialoguing, (d) dialoguing, (e) fostering reconciliation, (f) sharing nearing death mystical experiences, (g) letting go of life itself, and (h) nurse presence at death. The author concluded that by identifying core competencies of spiritual care provided by hospice nurses, a foundation for interpretation of spiritual care and letting go is established.

Taylor and Amenta (1994) studied hospice nurses' attitudes and beliefs about the provision of spiritual care. Data were obtained from Hospice Nurses Association members (N = 641) who completed the Spiritual Care Perspectives Survey. The hospice nurses' attitudes and beliefs about spiritual care reflected personal religiosity and education of the nurse respondent. Results indicated that belief that spiritual care is an important part of nursing increased with higher educational levels, with recognition of patient's spiritual need more strongly held by Masters-educated nurses than those with associate degrees. However, attitudes about how a nurse should relate to an individual's spirituality were variable.

Herth (1995) studied hope as a component of spiritual care interventions provided to individuals with chronic illnesses or terminal illnesses by home health nurses and hospice home care nurses. In a descriptive survey design, 62 hospice nurses and 96 home health nurses completed the Hope Intervention Questionnaire. While all subjects identified hope as highly important (M = 4.56), hospice nurses' mean score on importance of hope

( $M = 4.35$ ) was lower than that of home health nurses ( $M = 4.78$ ). However, the differences were not statistically significant. Provision of comfort and pain relief emerged as the most effective and most frequently used hope intervention by both hospice nurses ( $M = 4.762$ ) and home health nurses ( $M = 4.692$ ). Results indicate interventions that foster hope were effective for individuals with chronic or terminal illnesses.

Grief and bereavement are common topics of study in the hospice literature on emotional and psychological aspects of care. Assessing the support needs of paid and unpaid caregivers of individuals with terminal illnesses in New South Wales, Australia, researchers used qualitative and quantitative analysis (Pincomb & Tooth, 1996). Researchers performed content analysis of taped interviews in which 20 palliative care nurses and 20 non-paid caregivers discussed the impact and experience of caring for individuals with terminal illnesses. The quantitative technique employed the Inventory of Socially Supportive Behaviors (ISSB). Results indicated that unpaid and paid caregivers were older, required increased respite-care facilities, and lacked personal support. The authors concluded that an expansion of palliative care services would provide increased social support for caregivers, provide greater opportunities for persons with terminal illnesses to die at home, and lessen the burden on unpaid caregivers and family members.

Using a qualitative framework, Marquis (1996) assessed bereavement services in a palliative care program in Australia. Fifty in-depth interviews were conducted with bereaved caregivers, nurses, and volunteers over a five-month period of time in an effort to identify valued aspects of the bereavement program. Using a phenomenological

approach, the eight major themes identified were: (a) mutuality - partnership for a purpose; (b) continuity - bridging life and death in partnership; (c) collaboration - decisions in partnership; (d) concluding care - bridging life and death in partnership; (e) resolving loss - letting go and reinvesting; (f) developing confidence - belief and knowledge in skills; (g) connecting - contact for a purpose; and (h) finding meaning - personal growth through helping. By comparing and contrasting common experiences, the author identified valued elements of the bereavement program for future planning and safeguarding.

The author of a mini-ethnographic study used observation and participation procedures to identify what interventions children (N=16) in weekly hospice bereavement group found helpful during their bereavement (Lehna, 1994). Verbal and artistic descriptions of the children's bereavement findings portrayed patterns of affective distress, somatic complaints, and disruptive behaviors. Interventions helpful for the children included verbalization of feelings, art therapy, and life review through viewing photographs of the deceased. Lehna concluded that hospice nurses caring for families experiencing a death may see children's grief reactions in the form anger, sadness, loneliness, happiness, and disruptive behavior and that interventions to address these feelings may be reflective of those expressed by the children of this study.

Research addressing the physical aspects of hospice care center on effective assessment and control of pain. In a descriptive study of pain assessments and patterns of analgesic use in persons enrolled in a hospice program, researchers performed

retrospective chart reviews of 76 randomly selected deceased persons at a Florida hospice (Morgan, Lindley, & Berry, 1994). Hospice policy dictated that personnel perform pain assessments upon entry into the hospice, at one month intervals, or whenever a change in pain status occurred. Results indicated that pain assessments were performed an average of 2.7 times per patient, with pain intensity scores increasing as the number of pain assessments increased. Researchers found that 25.2% described their pain as occasional, 26.6% frequent, and 24.1% constant. Long-acting morphine sulfate (25.4%), acetaminophen and hydroxy/oxycodone combinations (20.1%), and NSAIDS (17.1%) were the most commonly used analgesics. Researchers concluded that pain management at the studied hospice was consistent with accepted pain management standards. The authors attributed this, in part, to the effectiveness of the pain assessment guidelines and tool of the hospice studied.

Researchers addressed the implications of pain assessment on the development and psychometric testing of the Pain Inventory and the Pain Coping Tool (Arathuzik, 1994). The Pain Inventory measured cognitive factors believed to influence the pain experience, and the Pain Coping Tool measured coping behaviors and strategies believed to be effective in dealing with pain. Forty nursing doctoral students, head nurses, and clinical nurse experts established content validity of the Pain Inventory (.92 CVI) and Pain Coping Tool (.94 CVI). Significant moderate to strong correlations (.37,  $p < .001$ ) found between these instruments and the Pain Intensity and Pain Distress Scales (.61,  $p < .001$ ) established construct validity. Arathuzik concluded that results are preliminary due to the small

sample ( $N=20$ ) of persons with metastatic breast cancer who participated in the study. However, the author believed these instruments could be effective in determining interventions to promote effective coping, particularly with persons with cancer who may mask their pain.

Crane (1994) determined that the use of intermittent subcutaneous infusion of opioids in hospice home care was an effective, economical, and manageable option of pain control for persons with terminal illnesses. A random, retrospective chart review ( $N=50$ ) addressed variables such as indication of subcutaneous route, opiate use, dose requirements, pain rating prior to and after subcutaneous injections, days of hospitalization, person administering opiates, and experienced side effects. Crane concluded that for persons no longer able to swallow due to imminent death, intermittent subcutaneous infusions of morphine were most cost effective, easier for lay caretakers to manage, had less side effects, and provided effective pain relief, compared with intravenous (IV) or epidural routes of administration. Crane emphasized the use of the hospice interdisciplinary team for a comprehensive assessment of the appropriate time to implement intermittent subcutaneous infusions.

Other aspects of physical care addressed in the hospice literature include the administration of IV hydration to persons who are dying. Waller, Hershkowitz, and Adunsky (1994) conducted a prospective study of persons enrolled in a hospice program ( $N = 68$ ) who had blood and urine samples collected 48 hours or less before death, and were also assessed for levels of responsiveness. Fifty five of the 68 persons had been

hydrated orally and 13 had received IV hydration. Using indicators of serum sodium and urine osmolality, the researchers found that persons receiving IV fluids were not better hydrated than those without IV therapy, nor was their state of consciousness improved from initial baseline assessment. The authors concluded that IV fluids contributed nothing to the medical well-being of the person who was dying. The authors further argued that the equipment and attention required when providing IV hydration inhibited physical contact between the dying individual and family, and distracted hospice staff from providing optimal emotional and spiritual support.

Summary. In summary, results of research on hospice care focused on spiritual, psychosocial, and physical aspects of care for persons with terminal illnesses. Physicians, patients, and caregivers viewed hospice as a program that provided excellent symptom control and emotional support for individuals with terminal illnesses and their families. Hospice, compared with hospitals, nursing homes, or home health services, was better able to provide both physical and emotional support to persons with terminal illnesses. Most studies emphasized the use of the hospice interdisciplinary team in pain management for persons with terminal illnesses. Masters-educated nurses, more than those with associate degrees, recognized the need for spiritual nursing interventions; however nurses differed on how they felt spiritual care should be provided to who were terminally ill. Most commonly used spiritual interventions fostered hope and included provision of comfort and pain relief for dying persons. Core competencies necessary for the provision of spiritual care by hospice nurses focused on dialoguing, sharing experiences with

individuals, and guiding letting go. Psychosocial aspects of hospice care included identification of caregivers of persons enrolled in a hospice program as older, lacking in personal support, and in need of additional respite services. Effective elements of bereavement programs for both adults and children were partnership and collaboration, verbalization of feelings, and finding meaning in the death experience. Pain assessment and management in hospices were consistent with accepted standards in the community.

### **Summary of Literature Review**

While measures of death anxiety and perceptions of death in healthy populations are available, there is limited reported research that explores meaning of death. Additionally, formulation of instruments that measure constructs of the meaning of death may help to quantify meaning to particular groups of individuals with terminal illnesses, thus serving to validate current interventions which are largely based on nursing tradition. Research is also needed to explore the experience of persons with cancer in the terminal stages. The majority of this research is in the hospice literature and focuses on the effectiveness of hospice on the holistic domains of individuals who are terminally ill. Little information is available on the effects of advanced cancer on the individual's meaning of death. This is also true for the current research with persons with AIDS. Numerous qualitative studies address the experience of living with HIV/AIDS, including the inevitability of death. However, few studies address the end-stages of AIDS, particularly the meaning of death as experienced by the individual who is dying. While studies exist that compare healthy populations with individuals with terminal illnesses, no studies exist

which compare the meaning of death among populations with differing terminal diagnoses.

### **Research Questions**

Based on the literature, there is limited information on the perception of the meaning of death to people with cancer or AIDS in the terminal stages. The investigator of the original study asked the question “ What are the death constructs reflecting meaning in death among dying adults?” (McGaffic, 1995, p. 132). The research questions asked in this study reflect the aims and research question of the original study. The research questions for this study were:

(1) What is the meaning of death to persons with cancer and persons with AIDS in the last six months of physical life?

(2) What are the similarities or differences in the meaning of death between persons with cancer and persons with AIDS in the last six months of physical life?

### **Definition of Terms**

**Meaning:** significance, intention, conveyance by language, connotation, denotation, or purpose as described by the participant.

**Death:** a permanent cessation of all vital functions of the physical body; end or cessation of life.

**Cancer:** the diagnosis, known to the client, of a malignant tumor of potentially unlimited growth that expands locally by invasion, and systemically by metastasis.

**AIDS:** the diagnosis, known to the client, of acquired immunodeficiency syndrome.

Currently believed to be caused by the human immunodeficiency virus (HIV). To

be diagnosed with AIDS, the affected individual must be HIV seropositive, CD4 T-lymphocyte count of less than 200 cells/uL or a CD4 percentage of less than 14, and have been diagnosed with one of 26 clinical conditions specified by the Centers for Disease Control and Prevention.

Persons living in the last six months of life: those individuals diagnosed with a terminal cancer or end-stage AIDS, and admitted to a hospice program which requires a prognosis of six months or less to live.

### **Summary**

Chapter Two was an overview of the conceptual framework and review of literature for this study. The conceptual orientation for this study was Jean Watson's theory of human care (Watson, 1988). The conceptual orientation provided a context for examining and comparing the meaning of death for persons with cancer and persons with AIDS living in the last six months of life. The component of particular relevance to this study was Watson's conceptualization of the holistic individual, consisting of the three spheres of body, mind, and spirit.

Review of research on perceptions of death and dying, spirituality, nursing's response to death and dying, terminal cancer, end-stage AIDS, and hospice care indicates the need for further research on identification of the meaning of death to terminal populations. Chapter Two also included the research questions and definition of terms.

## **CHAPTER THREE**

### **METHOD**

In Chapter Three the design, sample, setting, protection of human subjects, data collection protocol, instruments, secondary data analysis, plan for data analysis, and trustworthiness of the research are presented.

#### **Design**

This research employed a descriptive, qualitative design, and was a secondary analysis of a larger research project (McGaffic, 1995). The original study used a non-experimental, descriptive cross-sectional design. A cross-sectional design allows for observation of all variables at one point in time (Polit & Hungler, 1995). The intent of the original study was to “describe the magnitude and significance of relationships between patterns of spirituality and health in two groups of adults living in the community” (McGaffic, 1995, p. 107). One group consisted of Aging adults ( $n = 35$ ) and the other group consisted of Dying adults ( $n = 35$ ). This study uses a descriptive design to study the perceptions of the meaning of death by the subsample constituting the Dying group with a diagnosis of terminal cancer ( $n = 13$ ) or AIDS ( $n = 13$ ) from the original study. Participants from the original study with diagnoses other than cancer or AIDS were not included in this secondary analysis as the purpose of this study was to compare the meaning of death to persons with cancer and persons with AIDS.

### **Sample**

The convenience sample ( $N = 26$ ) for this study were members of the Dying group with cancer ( $n = 13$ ) or AIDS ( $n = 13$ ) who were interviewed during the original study (McGaffic, 1995). A convenience sample is used to study a population consisting of people with specific traits (Polit & Hungler, 1995). The sample selection criteria for the original study required that participants were: (a) able to understand English, (b) able to verbalize answers to interview questions, (c) 60 years of age or older for the Aging group, and (d) 21 years of age or older for the Dying group whose members had been told by their physician that they had 12 months or less time to live (McGaffic, 1995). For this study, the same sample selection criteria, with the exception of (c), are applicable.

Participants from the Aging group were not included as this study focused on the meaning of death to persons who were dying. The participants in the Dying group for the original study were enrolled in a hospice program of care or other community support program for individuals with terminal illnesses in Tucson, Arizona. Admission to a hospice program licensed by the State of Arizona requires a prognosis of six months or less to live.

Therefore, this study identifies the participants of the Dying group as living in the last six months of life

### **Setting**

In the original study, the researcher recruited participants comprising the Dying group through referrals from three sources in Tucson, Arizona: (a) the director of nurses

from the Carondelet Hospice Services homecare program, (b) referrals from a support group coordinator for cancer patients at Tucson Medical Center, and (c) the Tucson AIDS Project case manager. All interviews took place in the participants' homes at a time convenient to them (McGaffic, 1995).

### **Protection of Human Subjects**

The Human Subjects Committee at the University of Arizona (Appendix A) and the office of Nursing Research at The University of Arizona College of Nursing (Appendix A) granted approval for the original study. Formal approval from the institutions providing sample participants was also obtained (Appendix B). For the original study, the interviewer read the consent form (Appendix C) to the potential participant, who then signed an authorization form upon agreement (Appendix C). The consent form consisted of an explanation of the purpose of the study, eligibility requirements, nature of the questions, estimated length of time to complete the interview, right to withdraw from the study at any time with no negative consequences, and assurance of confidentiality. The researchers maintained the confidentiality of the participants through use of numerical codes on the questionnaires, which were then locked in a cabinet at The University of Arizona. To further ensure confidentiality of the participants of the original study, the numeric codes of the participants from the two subsamples were changed to alphabetical codes for this research. The original researcher and the Human Subjects Review Committee of the College of Nursing granted approval

for this secondary analysis (Appendix D).

### **Data Collection Protocol**

For the original study, the researcher collected data between September, 1994 and June, 1995. After obtaining referrals from the three sources for participants, the researcher contacted participants of the Dying group at home by telephone to set up an appointment to obtain informed consent as described above (McGaffic, 1995). For this group, it was often necessary to contact the participant's primary caregiver or family member. During the initial telephone contact, the researcher described the questions to be asked and the amount of time it would take to complete the interview, which was approximately 45 to 90 minutes. Responses to the question regarding personal meaning of death took from 2 to 10 minutes to complete (C. McGaffic, personal communication, March 31, 1997). The investigator and a graduate student in the geriatric nurse practitioner program at The University of Arizona College of Nursing, who received two hours of training to assure consistency, conducted the interviews (McGaffic, 1995).

Participants provided informed consent and signed authorization forms. Most interviews were conducted privately. However, for some participants, the primary caregiver or family member was present during the interview if requested by the participant. Due to the sensitive nature of the topic, the presence of family members for data collection purposes was a deviation felt necessary by the original investigator, and provided comfort for the requesting participant. Both interviewers believed the

participants answered questions honestly. Interviewers wrote responses verbatim on paper to capture answers to the question related to personal meaning of death. The question related to personal meaning of death was asked at mid-interview prior to administration of a structured questionnaire about death to prevent bias potentially introduced by previous questions.

At the end of the interview, interviewers debriefed the participants as is recommended when performing research on sensitive topics (McGaffic, 1995). Interviewers asked the question: "How are you feeling now that we're finished with the interview?" (McGaffic, 1995, p. 115). Responses included descriptions of feeling fine or fatigued, but most participants found the questions thought provoking.

### **Instruments**

This study is part of a larger study in which several instruments were used to measure four indices of health and three indices of spirituality (McGaffic, 1995). All instruments used a self-report design in order to capture the subjective experience of the respondents. The instrument (Appendix E) used for this study was the Personal Meaning of Death Paragraph (Holcomb, Neimeyer, & Moore, 1993). This consisted of the interviewer asking participants for a response to the following: "In one or two sentences, could you please describe what death means to you personally" (McGaffic, 1995, p. 267).

The original investigator also used a manual and coding dictionary (McGaffic, 1995) to analyze responses specifically related to meaning in death (Appendix F).

Development of the manual was based on constructs generated from content analysis of narrative responses from 542 college students of varying ages in two earlier studies exploring the personal meaning of death ( Holcomb, Neimeyer, & Moore, 1993; Neimeyer, Fontana, & Gold, 1984). The manual and coding dictionary provided guidelines for analysis of data in McGaffic's original study. However, McGaffic expanded the original manual and coding dictionary by adding six new constructs identified in her study (Appendix G).

Interviewers for the original study obtained demographic information from the participants using a descriptive information questionnaire (Appendix E) presented at the beginning of the interview (McGaffic, 1995). Descriptive information consisted of: (a) age, (b) gender, (c) education, (d) ethnicity, (e) relationship with significant other, (f) present living arrangement, (g) present medical diagnosis, (h) present health, (i) religious or spiritual affiliation, (j) major source of support, (k) attendance at a support group, and (l) financial status.

### **Secondary Data Analysis**

Secondary data analysis involves using previously gathered data from an original research project to test new hypotheses, explore new relationships among variables, or apply a different theoretical framework (Polit & Hungler, 1995). Often the data are examined by researchers who did not collect the original data, but wish to analyze them from a different perspective.

The expansion of knowledge obtained from the original study is an advantage of performing secondary analysis of the gathered data (Polit & Hungler, 1995). The purpose of secondary analysis for this study was to examine the responses obtained from individuals with cancer or AIDS regarding personal meaning of death using content analysis. The original investigator used content analysis to analyze those same responses from all participants in the Dying group (McGaffic, 1995). This secondary analysis differs from the original study in that the focus of this study is the analysis of responses from the subsample with cancer and the subsample with AIDS separately. The researcher of this study also compared the results obtained through content analysis of data from the two subsamples. This differed from the original study in that this researcher examined the meaning of death for individuals with the same diagnosis, contrasted with the meaning of death for persons with a different diagnosis.

This study also examined the application of a conceptual orientation different from the theoretical framework for the original study. In this study, Jean Watson's theory of human care provided the conceptual orientation, with particular emphasis on Watson's conceptualization of the holistic individual (Watson, 1988). In the original study, the theoretical framework used "seven developmental patterns (concepts) believed to be correlates of two unitary phenomena (constructs) important to aging and dying in the life process" (McGaffic, 1995, p. 48). Therefore, by distinguishing subsamples, comparing responses of the two groups, and applying a different conceptual orientation, this study

provided a different perspective of the meaning of death and expanded the scientific knowledge base established by the original study.

There are potential disadvantages to the use of secondary data analysis, including the fact that the researcher performing secondary analysis did not participate in data collection, which limits this researcher's knowledge of deficiencies or problems that may arise that limit the reliability of the results of the secondary analysis (Polit & Hungler, 1995). The researcher for this study did not gather the data from the original participants. Therefore, controls on data collection procedures relied solely on the original interviewers. Given the qualitative nature of this research, factors occurring during data collection which may have provided additional insight into the analysis of the original data are not present in this secondary analysis. However, availability of the original interviewers for consultation minimized the importance of this limitation.

#### **Plan for Data Analysis**

Data analysis methods corresponded with the two research questions asked in this study. Central tendency measures (mean, median, mode) described the demographic characteristics of the subsamples, including age, gender, number of years of education, ethnicity, present medical diagnosis, religious or spiritual affiliation, and importance of spirituality.

Research Question 1 was: What is the meaning of death to persons with cancer and persons with AIDS in the last six months of physical life? Data analysis of the open-

ended, narrative responses for Research Question 1 consisted of content analysis of recorded responses to the data-generating interview from the original study, “In one or two sentences, could you please describe what death means to you personally” (McGaffic, 1995, p. 267). Content analysis is a form of qualitative analysis which uses recorded words as the source of data, and provides a “systematic means of measuring the frequency, order, or intensity of occurrence of words, phrases or sentences” (Burns & Grove, 1987, p. 203). Content analysis is a form of quantifying narrative qualitative material and is applied to oral and written communications (Krippendorff, 1980; Polit & Hungler, 1995).

Coding begins with identification of thematic units or words from narrative responses. These phrases or words having meaning are termed thematic units (Krippendorff, 1980). The researcher performed the content analysis by taking the raw data from the responses received from each of the two subsamples, to identify thematic units. Each thematic unit was assigned a label to identify its theme. The next step was the grouping of thematic units according to commonalities, or themes, into categories. Definitions for the categories were developed as themes emerged. The researcher concurrently developed definitions for categories and used the definitions for sorting thematic units by themes into categories. These categories reflected the meaning of death for the two subsamples, those dying from cancer and those dying from AIDS.

One aspect of performing data analysis using content analysis is the need for

consistency in classifying the data into categories, which can be established through interrater or intercoder reliability (Burns & Grove, 1987; Krippendorff, 1980). This refers to the extent to which content classification produces the same results when the same text is coded by different individuals (Weber, 1990). Differences in coding can result from random coding errors, unclear coding instructions, or cognitive differences between the coders. In content analysis, it is unrealistic to insist on accuracy as the strongest test of reliability (Weber, 1990). However, at a minimum, data should be “highly reproducible by independent researchers, at different locations, and at different times, using the same instructions for coding the same set of data” (Weber, 1990, p. 132). For this study, the researcher randomly selected 10 percent of thematic units for independent coding by the thesis chair and a thesis committee member. The researcher provided each independent coder with: (a) a list of thematic units, (b) a list of category names and definitions, and (c) directions for recording results of coding. The researcher determined the percent of agreement of the coders’ results with the researcher’s results. The level of acceptable agreement of independent coders’ results with those of the researcher for this study was .80, which is the usual acceptable level of reliability (Nunnally, 1978).

The first time intercoder reliability was checked for research question number one, there was .60 agreement, which did not meet the established level of acceptance.

Category names and definitions were revised for each subsample and additional thematic units added. While an acceptable level of intercoder reliability was achieved with the new

category names and definitions at .80, a third revision was made in an attempt to increase agreement between the researcher and the coders. Intercoder reliability for the third revision was established at .90 agreement.

Research Question 2 was: What are the similarities or differences in the meaning of death between persons with cancer and persons with AIDS in the last six months of life? Data analysis consisted of qualitative analysis of selected content-analyzed data, and chi square analysis of results from the two groups. The alpha level for statistical significance in this study was set at  $p < .05$ .

### **Trustworthiness of the Research**

According to Lincoln and Guba (1989), the established criteria for assuring trustworthiness in qualitative research are: credibility, transferability, dependability, confirmability. The technique of bracketing was also used to maintain integrity in data analysis (Streubert & Carpenter, 1995). Trustworthiness of this study was assured using these five criteria.

The first criterion, credibility, assures confidence in the truth of the findings through the use of various methods, including persistent observation, peer debriefing, and triangulation (Lincoln & Guba, 1989). Persistent observation is a method of establishing credibility by being present in a context enough to be able to identify the most relevant characteristics and elements in a situation and focus upon them in detail. In the original study, the detailed focus was on the characteristics and elements that defined meaning in

death to a terminal sample. The investigator for the original study had many years of experience in the context of communication with persons dying of cancer and AIDS. The researcher for this study has extensive experience of communication with persons dying of cancer and AIDS. Peer debriefing is a technique useful in establishing credibility by exposing oneself to a disinterested peer for the purpose of exploring aspects of the inquiry that might otherwise be overlooked by the investigator. In the original study, peer debriefing was useful in providing a catharsis for the investigator, thus clearing her mind of emotions and feelings that may have been clouding insights as well as providing closure to a sensitive topic (McGaffic, 1995). For this research, peer debriefing occurred through sharing of insights about the research process and product with a colleague familiar with qualitative data analysis. Triangulation establishes credibility by use of different sources, different methods, and different investigators to interpret results. In the original study, the use of seven descriptive instruments and an open ended question about the personal meaning of death provided triangulation. Only one source, the open ended question, provided data for this secondary analysis, so triangulation did establish credibility of the original study but was not assured further in this study.

Transferability confirms that results of a study are not bound to the conditions of the study (Lincoln & Guba, 1985). Transferability is established through the use of a thick description of the study, which enables potential appliers of the results to transfer these results to other contexts. The researcher for this study provided a thick description of the

process and product of data analysis, and it is the responsibility of other researchers and clinicians to determine the applicability of the study to their context.

Dependability refers to both the stability and the traceability of variance over time (Lincoln & Guba, 1985). An inquiry audit was used to examine both the process and the results of this study. The thesis chair assisted in establishing dependability through the inquiry audit by examining the data from the two subsamples, the thematic units obtained from the narratives, the derived themes and categories established through content analysis, and the results of comparison of the two subsamples. The thesis chair and a member of the thesis committee participated in establishing intercoder reliability, which supports dependability of the study.

Confirmability attests that the data support the findings of the research and that it is internally coherent (Lincoln & Guba, 1985). Confirmability is closely linked to dependability in that it attempts to validate the end product of the research through use of the audit trail. In this research, confirmability was established through the audit process by the thesis chair as described above. Notes reflecting the researcher's personal thoughts and potential biases served as signals to maintaining objectivity when interpreting data.

Bracketing is a methodological device used in qualitative research in which the researcher identifies all judgements and ideas related to the subject or phenomena under investigation and suspends these judgements and ideas during data interpretation (Streubert & Carpenter, 1995). For this research, the researcher acknowledged

identifiable preconceived ideas or judgements about analysis outcomes by discussing them with the thesis chair. These ideas included the possibility of age influencing the meaning of death, the possibility of each domain of being affecting an individual's interpretation of the meaning of death, and the possible influences of the results of studies described in the review of literature. Throughout the secondary analysis the researcher maintained objectivity through use of the content analysis process by recognizing these preconceived possibilities and not anticipating outcomes.

### **Summary**

A descriptive design was used to investigate the perceptions of the meaning of death for patients with cancer and AIDS in the last six months of life. The sample selection criteria and setting were reviewed. The Human Subjects Committee of the University of Arizona and the Office of Nursing Research of the College of Nursing granted approval for both the original study and this study.

A secondary analysis of data from responses to an interview question on the meaning of death guided analysis for this study. Demographic characteristics were analyzed using descriptive statistics. Content analysis and chi square were methods used to analyze interview data. Trustworthiness of the research was established through five methods: credibility, transferability, dependability, confirmability, and bracketing.

## CHAPTER FOUR

### RESULTS

Chapter Four provides descriptions of the two subsamples studied and results of data analysis in relation to each of the research questions.

#### Description of the Sample

The total convenience sample ( $N = 26$ ) for this study consisted of participants from the Dying group of the original study (McGaffic, 1995) diagnosed with some form of cancer ( $n = 13$ ) or end-stage AIDS ( $n = 13$ ). Demographic categories for both subsamples relevant to this study are age, gender, number of years of education, ethnicity, description of present health, type of cancer, total number of symptoms, religious or spiritual affiliation, and importance of spirituality. The demographic data are derived from information obtained from each participant at the time of the original interview.

#### Persons with Cancer

For the subsample of persons with cancer ( $n = 13$ ), ages ranged from 42 to 87 years ( $M=68.79$ ,  $SD=12.676$ ). Six of the participants were male and seven were female. Number of years of education ranged from 10 to 20 years ( $M=13.846$ ,  $SD=2.968$ ). Of this subsample, 11 were Caucasian and two were Latino. All participants of this subsample had a diagnosis of some form of cancer. Table 1 lists demographic information for both subsamples.

Table 1

**Demographic Composition of Subsamples (N = 26)**

	Persons with Cancer (n = 13)	Persons with AIDS (n = 13)
Mean Age	68.79	40.00
Gender		
Male	46.2% (6)	69.2% (9)
Female	53.8% (7)	30.8% (4)
Mean Education Years	13.846	12.692
Ethnicity		
Caucasian	84.6% (11)	84.6% (11)
Latino	15.4% (2)	15.4% (2)
Description of Health		
Poor	30.8% (4)	0.0% (0)
Fair	23.1% (3)	38.5% (5)
Average	7.7% (1)	7.7% (1)
Good	38.5% (5)	53.8% (7)

Table 1 - Continued

	Persons with Cancer ( $n = 13$ )	Persons with AIDS ( $n = 13$ )
<b>Types of Cancer</b>		
Prostate	23.1% (3)	0.0% (0)
Breast	23.1% (3)	0.0% (0)
Lung	15.4% (2)	0.0% (0)
Lymphoma	15.4% (2)	0.0% (0)
Colon	7.7% (1)	0.0% (0)
Throat	7.7% (1)	0.0% (0)
Carcinoid	7.7% (1)	0.0% (0)
<b>Total Number of Symptoms</b>		
One	23.1% (3)	7.7% (1)
Two	7.7% (1)	23.1% (3)
Three	7.7% (1)	7.7% (1)
Four	23.1% (3)	15.4% (2)
Five	30.8% (4)	7.7% (1)
Six	7.7% (1)	38.5% (5)

Table 1 - Continued

	Persons with Cancer ( <u>n</u> = 13)	Persons with AIDS ( <u>n</u> = 13)
<b>Religious or Spiritual Affiliation</b>		
Protestant	7.7% (1)	15.4% (2)
Catholic	53.8% (7)	38.5% (5)
Jewish	15.4% (2)	0.0% (0)
New Age	7.7% (1)	0.0% (0)
Episcopalian	15.4% (2)	0.0% (0)
Other	0.0% (0)	46.2% (6)
<b>Importance of Spirituality</b>		
Somewhat Important	7.7% (1)	30.8% (4)
Very important	92.3% (12)	69.2% (9)

### Persons with AIDS

For the subsample of persons with AIDS ( $n = 13$ ), ages ranged from 26 to 58 years ( $M=40.00$ ,  $SD=9.992$ ). Nine of the participants were male and four were female. Years of education ranged from 7 to 17 years ( $M=12.692$ ,  $SD=2.926$ ). Eleven participants of this subsample were Caucasian and two were Latino. All participants had a diagnosis of AIDS. See Table 1 for additional demographic information.

### **Results of Data Analysis**

Data analysis occurred in three stages. For Research Question 1, content analysis of data for each subsample was used. For Research Question 2, methods used were qualitative analysis of selected content-analyzed data, and quantitative analysis of categorical data for the two subsamples. Results are presented for each research question.

#### Research Question 1

Research Question 1 was: What is the meaning of death to persons with cancer and persons with AIDS in the last six months of physical life? Content analysis of all ( $N = 26$ ) responses to the interview question regarding personal meaning of death to persons with cancer and persons with AIDS generated one hundred fifteen thematic units (Krippendorff, 1980) or phrases with identifiable meanings. In this research, thematic units were identified, assigned themes to reflect the meaning of the thematic unit, then grouped according to common themes into categories. As commonalities among themes emerged, the researcher developed definitions and names of categories that guided the

sorting of thematic units and themes into categories. The categories represent the meaning of death to each of the two subsamples.

Persons with cancer. Four categories reflect the meaning of death to persons with cancer ( $n = 13$ ) participating in this study: Acceptance, Release, Reluctance, and Spiritual Awareness. Table 2 lists the categories and definitions of categories for Research Question 1 for the subsample of persons with cancer.

The category of Acceptance is defined as the perception that death is an inevitable, normal process shared by all living beings, indicating the end of physical life, and demonstrated through feelings of completion, or state of preparedness for death. Six themes of Acceptance reflected feelings of death as a shared experience, preparedness, fulfillment, no fear, finality, and fate. Examples of thematic units reflecting Acceptance are: "I'm ready to go whether or not it's today or in two weeks" (Participant E), and "I accept it because we all do it" (Participant A).

The category of Release is defined as relief from physical, emotional, or spiritual suffering experienced in the living physical realm. Two themes emerged: deliverance and potential benefits. An example of a thematic unit represented in the category of Release is, "It means release from trouble" (Participant E).

Reluctance is defined as a sense of hesitation about death or the dying experience. Four themes emerged: unwillingness, concern for survivors, regret, and uncertainty. An example of a thematic unit reflecting Reluctance is, "I don't like the thought of leaving my

Table 2

**Categories and Definitions for Research Question One for Persons with Cancer (n=13)**

---

Category Name	Definition
Acceptance	Perception that death is an inevitable, normal process shared by all living beings indicating the end of physical life, and demonstrated through feelings of completion, or state of preparedness for the event of death.
Release	Relief from physical, emotional, or spiritual suffering experienced in the living physical realm.
Reluctance	A sense of hesitation about death or dying experience.
Spiritual Awareness	A belief in the existence of a dimension that is purposeful, a God or power greater than the self, or the continuation of the soul or spirit.

---

wife or other people and the suffering it would cause them” (Participant F).

The category of Spiritual Awareness is defined as a belief in the existence of a dimension that is purposeful, a God or power greater than the self, or the continuation of the soul or spirit. Five themes emerged: place, explanation, reunion, afterlife, and greater power. Examples of thematic units in the category of Spiritual Awareness are: “It’s the pleasure of seeing Christ” (Participant K), and “You will see your loved ones someday” (Participant L).

Persons with AIDS. Six categories reflect the meaning of death to persons with AIDS ( $n = 13$ ) participating in this study: Uncertainty, Acceptance, Anticipatory Loss, Fear, Benefits, and Spiritual Awareness. Table 3 lists the categories and definitions for Research Question 1 for persons with AIDS.

The category of Uncertainty is defined as a sense of doubt or speculation about the meaning of death. Within the group of participants with AIDS, two themes emerged: indecision and speculation. An example of Uncertainty is, “I don’t have any idea what’s next” (Participant R).

The category of Acceptance is defined as the perception that death is an inevitable, normal process shared by all living beings indicating the end of physical life, and demonstrated through feelings of completion, or state of preparedness for death. Seven themes emerged: normal experience, fate, preparedness, no fear, finality, process, and fulfillment. One person with AIDS expressed Acceptance by stating, “Life and death is

Table 3

Categories and Definitions for Research Question One for Persons with AIDS (n=13)

Category Name	Definition
Uncertainty	Doubt or speculation about the meaning of death.
Acceptance	Perception that death is an inevitable, normal process shared by all living beings indicating the end of physical life, and demonstrated through feelings of completion, or state of preparedness for the event of death.
Anticipatory Loss	A sense of grief, sorrow, or regret over the consequences of death or the dying experience on self or others.
Fear	Feelings of apprehension about potential effects of death or dying experience on self or others.
Benefits	Positive physical, emotional, or spiritual advantages of death or dying experience.
Spiritual Awareness	A belief in the existence of a dimension that is purposeful, a God or power greater than the self, or the continuation of the soul, spirit, or energy.

like a normal experience/process” (Participant X).

The category of Anticipatory Loss is defined as a sense of grief, sorrow, or regret over the consequences of death or the dying experience on self or others. Three themes emerged: separation from survivors, unfinished business, and empathy. An example of a thematic unit in the category of Anticipatory Loss is, “Not being able to finish things I started. Goals and stuff” (Participant Q).

The category of Fear is defined as feelings of apprehension about the potential effects of death or the dying experience on self or others. Four themes emerged: illness concerns, unknown consequences, trepidation, and shared caution. An example of a thematic unit in the category of Fear is, “I just fear it because I don’t know the outcome” (Participant N).

The category of Benefits is defined as positive physical, emotional, or spiritual advantages of death or dying experience. Four themes emerged: harmony, physical comfort, bonding, and spiritual support. An example of a thematic unit in the category of Benefits is, “Death means to me peace, worrylessness, no pain” (Participant U).

The category of Spiritual Awareness is defined as a belief in the existence of a dimension that is purposeful, a God or power greater than the self, or the continuation of the soul, spirit, or energy. Seven themes emerged: transition, placement, reunion, God, continuation of energy, the greater beyond, and reincarnation. Examples of thematic units in the category of Spiritual Awareness are: “Death means a path between what’s here and

what's beyond" (Participant W), and "I know I'll be moving on to a better understanding of God and the light" (Participant V).

### Research Question 2

Research Question 2 was: What are similarities or differences in the meaning of death between persons with cancer and persons with AIDS in the last six months of physical life? The researcher used a descriptive comparison of selected content-analyzed data, and quantitative analysis of results of categorical data for the subsamples to address this research question.

Qualitative analysis. The researcher examined the similarities and differences between the responses regarding meaning of death to persons with cancer and persons with AIDS, producing a descriptive comparison of content-analyzed results for the two subsamples.

The categories of Release and Spiritual Awareness were identified as categories for the subsample of persons with cancer, indicative of a sense of transformation within the definition of personal meaning of death for persons with cancer. This can be interpreted from the definitions of both categories, viewing death as a providing relief from the physical, emotional, or spiritual suffering in the physical realm, to a dimension that includes a reunion, a continuation of the soul or spirit, or an encounter with a greater power. This sense of transformation may also be related to the category of Acceptance, as described in the definition which includes death as the end of physical life. Citing the

physical relief and actualization of spiritual beliefs to be gained by death, strong indications of Acceptance as a category in meaning of death by persons with cancer can be appreciated. Yet, the presence of themes reflective of the fourth category, Reluctance, introduces a sense of hesitation or uncertainty about death, which stands in contrast to the previously mentioned perception of transformation. Thus the meaning of death for persons with cancer, based on this study, can be viewed as paradoxical in nature.

The paradoxical nature of the meaning of death identified for persons with cancer is also evident for persons with AIDS, although far more apparent. While the categories of Acceptance, Benefits, and Spiritual Awareness demonstrate the nature of transformation with which death is associated for this subsample, sharply contrasting categories were also identified. This is seen in the remaining categories of Uncertainty, Anticipatory Loss, and Fear, which reflect patterns of doubt, speculation, grief, sorrow, regret, and apprehension in relation to personal meaning of death. Therefore, while categories which define the meaning of death for persons with AIDS were extracted from content analysis, variations and diversity among these categories is reflective of a paradox in the meaning of death for persons with AIDS in this study.

The meaning of death is also seen within the categories of Acceptance and Spiritual Awareness shared by both subsamples. A theme found in both subsamples in the category of Acceptance was that of no fear. Persons with cancer had three thematic units indicating no fear, and persons with AIDS had four. However, for persons with cancer,

their lack of fear was more closely associated with effective symptom management, such as pain control, as exemplified by Participant E who stated “These extensions and the absence of pain (receiving M. S. Contin) are a big factor in not having fear.” For persons with AIDS, thematic units with the theme of no fear about death were more general or unconditional, without reference to physical well-being: “I’m not looking at death with fear at all” (Participant O).

Paradoxically, for the subsample of persons with AIDS, themes indicating fear were prevalent enough to warrant a completely separate category of Fear. This is notable in that for the subsample of persons with cancer no themes nor categories of fear were identified.

Also in the category of Acceptance, the theme of preparedness was present in both subsamples. Preparedness for persons with cancer was expressed in general terms of readiness for death. However, for persons with AIDS, preparedness was reflected in one thematic unit that included a deity, “When Jesus is ready for me, I’ll be ready for him” (Participant P).

Fate was a theme also seen in both subsamples in the category of Acceptance, however, persons with cancer referred to the fate of the illness experience, as in this thematic unit, “I feel I could have recovered (malignant melanoma) if I hadn’t had pneumonia” (Participant E). For persons with AIDS the theme of fate was not associated directly with the illness experience, “If this is the end, that’s the way it is” (Participant X).

Fulfillment was a theme shared by both subsamples under the category of Acceptance. For persons with cancer, fulfillment was associated with fulfilling responsibilities or societal expectations. For persons with AIDS, fulfillment was expressed in terms of the illness experience, "Because of my disease, death will be fulfilling when I get real sick" (Participant Q).

Both subsamples shared the theme of death as a normal or shared experience, which would be expected, given they share the same definition of the category of Acceptance. This was also true of the shared theme of finality for which there was no noted difference in meaning between the two subsamples.

While the subsample of persons with AIDS had fewer thematic units representing Acceptance, there was one additional theme not seen in persons with cancer, termed process. Within this theme, thematic units reflected a specific goal or desire that gave meaning to the actual dying process or experience not seen in the subsample of persons with cancer: "My job now is to die with dignity" (Participant O).

Spiritual Awareness was the second category identified for both persons with cancer and persons with AIDS. While the subsample of persons with AIDS had more thematic units and themes reflecting the category of Spiritual Awareness, the quality or content of the thematic units also differed from those of the subsample of persons with cancer. For persons with AIDS, there were 16 thematic units in the category of Spiritual Awareness, indicating a sense of continuation, transition, or movement. This finding is

illuminating due to the reported importance of spirituality for this subsample, which was comparatively lower than for the subsample of persons with cancer.

Additionally, persons with AIDS had fewer participants reporting association with organized religions compared to persons with cancer, with 46.2% of participants with AIDS responding with “other” for religious or spiritual affiliation. This may be a relevant factor in the paradoxical finding of more thematic units representing indecision about what occurs after death in this same subsample with the higher number of thematic units representing Spiritual Awareness and the previously mentioned themes. Participants, in five thematic units, referred to ideas such as “something else out there” (Participant Z). Five thematic units indicating beliefs in reincarnation were identified for persons with AIDS. Reincarnation was not mentioned by any of the persons with cancer.

Persons with cancer had fewer thematic units reflecting the category of Spiritual Awareness, but these represented more specific beliefs, compared with the subsample of persons with AIDS. This may be consistent with the demographic information in which persons with cancer had a higher number of participants affiliated with organized religion, compared with the subsample of persons with AIDS. Participants from the subsample of persons with cancer were more explicit in reference to a purposeful afterlife, “A spicity world that can reach the living” (Participant H). Thematic units reflecting a reunion with loved ones or religious entities were also greater in number and more definitive in content for the subsample of persons with cancer. Furthermore, this subsample referred to a

religious Deity twice as often as persons with AIDS who referred more often to spirit, soul, or energy. For persons with cancer, there were no thematic units representing indecision in the category of Spiritual Awareness. Additionally, two thematic units emerged for persons with cancer, indicating meaning of death as a reason or “an explanation of life” (Participant C), which were not seen in the subsample of persons with AIDS.

Two shared themes for both subsamples in the category of Spiritual Awareness were those of reunion and placement. For persons with cancer, more thematic units reflecting reunion were identified, while persons with AIDS had more thematic units reflecting placement. There were no differences in meaning of the two themes for the two subsamples

Quantitative analysis. The statistical method used to address this research question was chi square. Content analysis of data revealed that both subsamples shared two categories: Acceptance and Spiritual Awareness. Chi square analysis determined the degree of difference between the results for the two subsamples in frequency of occurrence of thematic units in these two categories. The number of times responses from each subsample produced a thematic unit reflecting Acceptance or Spiritual Awareness was compared. A comparison table of the results between the categories of the two subsamples assisted in identifying similarities and differences in the data (see Table 4). The table is organized to reflect the number of times participants from each subsample

Table 4

Chi Square Analysis of Difference Between Subsamples in Thematic Units in Categories of Acceptance and Spiritual Awareness (N=26).

	Person with Cancer (n=13)			Person with AIDS (n=13)			Chi Square	Significance
Number of times partici- pant responds with thema- tic unit in category	0	1	2+	0	1	2+		
Acceptance	5	5	3	7	3	2	0.61905	0.43140
Spiritual Awareness	6	3	4	3	3	7	1.52941	0.21620

p<0.05 is statistically significant

responded with thematic units representing the category of Acceptance and the category of Spiritual Awareness.

There was no statistically significant difference between participants with cancer and participants with AIDS in number of thematic units representing the category of Acceptance. There was no statistically significant difference between participants with cancer and participants with AIDS in number of thematic units representing the category of Spiritual Awareness. Results for both categories must be interpreted in light of the fact that only 41.7% of the cells contained the expected frequency of five or more per cell, and may reflect the small sample size.

Summary. Comparison and contrast of the similarities and differences in themes and categories reflected the paradoxical nature of the meaning of death to persons with cancer and persons with AIDS in this study. Both subsamples shared the categories of Acceptance and Spiritual Awareness. There were more thematic units and themes in the category of Acceptance for persons with cancer. There were more thematic units and themes in the category of Spiritual Awareness for persons with AIDS. While both subsamples had themes representing no fear, for the subsample of persons with AIDS, the category of Fear was identified. However, the category of Fear was not found in the subsample of persons with cancer. The illness experience was present in both subsamples in the category of Acceptance, but through differing themes. Persons with cancer associated comfortable symptom management and the inevitability of illness complications

under themes of no fear and fate, while illness in relation to meaning of death for persons with AIDS was reflected in the theme of fulfillment.

Both subsamples had themes reflecting reunion and placement in the category of Spiritual Awareness. However, persons with AIDS had themes reflecting both concrete and indecisive beliefs about the afterlife in the category of Spiritual Awareness. Persons with cancer referred to a religious Deity twice as often as persons with AIDS.

Reincarnation was a theme seen in the category of Spiritual Awareness for persons with AIDS, but this theme was not seen in the subsample of persons with cancer. Chi square analysis revealed no statistically significant difference between the two subsamples on number of thematic units in the categories of Acceptance and Spiritual Awareness.

## **CHAPTER FIVE**

### **DISCUSSION**

In this chapter, the relationship of findings to the conceptual orientation and the literature reviewed, limitations of the study, implications for nursing, and recommendations for further research are presented.

#### **Relationship of Findings to Conceptual Orientation**

The conceptual orientation for this research was based on Jean Watson's theory of human caring (Watson, 1988). The component of Watson's theory most applicable for this study was the concept of the holistic individual. The conceptual orientation guided the interpretation of the major findings of the meaning of death to persons with cancer and persons with AIDS reflected in the identified categories and corresponding definitions.

Watson (1988) conceptualizes the individual as the embodiment of the three spheres of body, mind, and spirit. These three spheres correspond with essential elements of care when addressing the needs of the dying individual. Watson acknowledges that death is the termination of the physical body in the measured realm. However, the mind and soul are representative of the individual's higher senses that transcend the perceived world of time and space, which Watson maintains is indicative of the spiritual evolution of human beings. Personal meaning of death is a manifestation of harmony among the three spheres of being as conceptualized by Watson.

Findings of this study are reflective of Watson's conceptualization of the

individual. While it must be noted that Watson does not conceptualize the three spheres of being as discrete parts that can be separated, findings of this study in relation to the conceptual orientation are presented here to reflect the body, mind, and spirit.

The influence of the physical sphere in the meaning of death was noted in both subsamples in categories of Acceptance, Release, Fear, and Benefit. In the category of Acceptance, participants acknowledged death as being the end of physical life. Themes of finality, preparedness, and shared or normal experience reflected this acknowledgment in both subsamples. Additionally, the meaning of death in relation to the physical realm was seen in the category of Release for the subsample of persons with cancer, and the categories of Fear and Benefits for the subsample of persons with AIDS. The definitions of these categories are reflective of themes that also refer to a physical aspect in relation to meaning of death, such as release from pain, fear of extended illness, or the benefit of the perceived discontinuation of physical suffering upon death of the body.

The influence of the sphere of the mind was also reflected in both persons with cancer and persons with AIDS in categories of Acceptance, Release, Reluctance, Uncertainty, Anticipatory Loss, Fear, and Benefits. The category of Acceptance, shared by both subsamples, was also defined by perceptual acknowledgment, feelings of completion, or state of preparedness for death. For the subsample of persons with cancer, the category definition of Release included reference to relief from emotional suffering. Also for persons with cancer, the category of Reluctance was defined as hesitation about

death or the dying experience reflected in themes of unwillingness, concern, regret, and uncertainty. For the subsample of persons with AIDS, the influence of the sphere of the mind in meaning of death was reflected in the category of Uncertainty, in which doubt and speculation about death comprised its definition, and in the category of Anticipatory Loss, in which feelings of grief, sorrow, or regret influenced the meaning of death. Also for persons with AIDS, the category of Fear included feelings of apprehension in its definition, and the category of Benefits included in its definition the positive emotional advantages of dying.

The third sphere of Watson's holistic individual, the spirit, is reflected by both subsamples in categories of Spiritual Awareness, Release, and Benefits. Here, the category definition of Spiritual Awareness may be reflective of Watson's belief in the spiritual evolution of human beings as they transcend the perceived world of time and space and form the collective conscious. Thematic units and themes of both subsamples led to a definition of Spiritual Awareness that included the existence of another dimension, a God or greater power, or the continuation of the soul, spirit, or energy. Other category definitions reflect the sphere of the spirit as well. The category of Release for the subsample of persons with cancer is partially defined as relief from spiritual suffering, and the category of Benefits for persons with AIDS includes reference to positive spiritual advantages in its definition.

Thus, the three spheres of body, mind, and spirit representing the holistic

individual as conceptualized by Watson (1988) are demonstrated in categories reflecting the meaning of death for persons with cancer and persons with AIDS for this study. Just as Watson conceptualized the interaction of the three spheres to represent the holistic individual, the categories reflecting the meaning of death here represent an interaction of body, mind, and spirit and are not mutually exclusive. As demonstrated here, personal meaning of death is a potential manifestation of the harmony of the three spheres.

Although all of the aspects of the meaning of death identified in this study are consistent with Watson's conceptualization of the holistic individual, the findings of this study also provide for expansion of her theory of human care. The paradoxical nature of the meaning of death for each subsample revealed in this study is reflective of the paradox inherent in the interactions of the three spheres upon the death of the individual. While Watson views death as the termination of the physical body in the measured realm, she also believes in the continuation of the higher senses of the mind and spirit that form the collective consciousness. Therefore, only the mind and body continue after death. This same paradox was demonstrated in this study wherein participants with cancer acknowledged meaning of death in categories that reflected the continuation of the mind and spirit: Acceptance, Release, and Spiritual Awareness. Yet, themes in the category of Reluctance also revealed the hesitation associated with the meaning of death for some participants, such as concerns for survivors after the termination of the physical body in the measured realm. This paradox was also seen in the subsample of persons with AIDS

as previously described. Therefore the paradox identified in Watson's theory was reflected in the meaning of death for the two subsamples of this study.

### **Relationship of Results to Literature Reviewed**

There is no literature that compares the meaning of death for persons with cancer and persons with AIDS living in the last six months of life. Therefore, there is limited context in which to compare the results of this research. The relationship of this study for either the subsample of persons with cancer or the subsample of persons with AIDS will be compared with results of relevant studies reviewed in Chapter Two.

Previous qualitative research that analyzed the meaning of death for an aging population and a dying population living in the community (McGaffic, 1995) revealed constructs of Self-Transcendence and Continued Existence for the Dying Group. Although the secondary analysis for this study was on only the data from the Dying group from the McGaffic study, results were similar in that the theme of reunion and afterlife were identified under the category of Spiritual Awareness for the subsample of persons with cancer, and themes of transition, reunion, and continuation of energy under the category Spiritual Awareness were identified for the subsample of persons with AIDS.

From a qualitative study by Ross and Pollio (1991) results indicated that for a sample of healthy adults three major themes reflecting meaning of death were death viewed either negatively, ambivalently, or positively. This is similar to results in this study in which the subsample of persons with cancer demonstrated categories of Reluctance,

Uncertainty, and Acceptance in relation to personal meaning of death. For the subsample of persons with AIDS, categories of Fear, Acceptance, and Benefits are similar to the results reflecting death negatively, ambivalently, or positively. However, comparison of results is limited due to differences in samples for the two studies.

Results from this study are similar to the results of a study which described one person's personal expression of the meaning of death (Jones, 1993). The author identified a theme of reaction to dying that echoes results from both subsamples in this study, in that all categories reflect a reaction to dying in response to the focus of the interview question. Honoring the integration of illness within the fullness of the person's life was recommended by Jones. This was reflected as a theme of fulfillment for both subsamples under the category of Acceptance in this study.

Reed (1986b) identified Belief in Afterlife as a statistically significant temporal variable in a Terminally Ill group and a healthy group. This compares with results from this study in which afterlife was a theme under the category of Spiritual Awareness for the subsample of persons with cancer. Within the subsample of persons with AIDS, themes reflecting a belief in afterlife found under the category of Spiritual Awareness were transition, placement, reunion, continuation of energy, and the greater beyond.

In a study that measured relationships between elements of the fear of death and dying with a construct of intrinsic religiosity (Thomson & Powell, 1990), the authors concluded that generally people seem to fear elements of dying more than they fear the

state of being dead. The category of Fear was identified for the subsample of persons with AIDS for this study. Reflective of Thomson and Powell's results, the theme of illness concerns in this study was identified as expressed in fear of the process of dying from AIDS.

Using a phenomenological method, Tamm and Granquist (1995) identified three major categories representing the meaning of death to children: biological, psychological, and metaphysical death concepts. This is similar to the findings identified through the conceptual orientation of this study, the holistic individual, but limited comparisons can be made due to the age differences in the populations studied in each group.

Coward (1994) also used a phenomenological method to investigate the structure of self-transcendence in men and women with AIDS. Of the nine themes revealed, for male participants, the themes of experiencing fear and accepting that which cannot be changed, and for female participants, the theme of experiencing uncertainty most closely corresponded to the categories of Fear, Acceptance, and Uncertainty found in the AIDS subsample of this study. However, participants of the sample studied by Coward were not in the end-stages of AIDS, so comparability of the results of the two studies is limited.

In a qualitative study in which participants with cancer were asked to define meaning in life, illness, and death, six major themes emerged (O'Connor, Wicker, & Germino, 1990). Of the six themes of personal significance, consequences, life review, change in outlook, living with cancer, and hope identified by the researchers, two compare

with themes and categories of the subsample of persons with cancer in this study.

Personal significance is reflective of the all themes and categories in this study in that for persons with cancer meaning of death reflects personal significance to the participants.

Consequences is reflective of the themes of concern for survivors and regret in the category of Reluctance for persons with cancer for this study.

Results from a study in which content analysis was used to define quality of life for persons with cancer (Padilla, Ferrell, Grant, & Reiner, 1990) included the categories of general functioning and disease specific attributes and psychological well-being. This is similar to results in this study that identified themes relating to meaning of death reflecting concern over illness in both subsamples. Additionally, psychological well-being is similar to the sphere of the mind addressed in categories in both subsamples for this study. Comparison of results is limited in that the studies addressed two differing aspects of the disease trajectory.

Qualitative data from a study exploring the major physical and psychological concerns for persons with AIDS (Longo, Spross, & Locke, 1990) revealed that out of five major themes, one theme of uncertainty of the future was similar to the category of Uncertainty for the subsample of persons with AIDS for this study. The other four themes reflected themes not comparable to those of this study, therefore comparison of results is limited.

Quantitative results measuring overt fear of death in a sample of men diagnosed

with end-stage AIDS (Hayslip, Luhr, & Beyerlein, 1991) revealed that the sample did not believe in the idea of an afterlife. Results of the current study sharply contrasted the former study as the category of Spiritual Awareness was strongly identified by the subsample of persons with AIDS, including six themes reflecting themes of an afterlife. However, research methods of the two studies differed.

### **Limitations of the Study**

By using data from interviews that were not conducted by this researcher, limited access to any additional cues or information that might have provided more in depth insight into the participants' meaning of death were not present for this secondary analysis. Another limitation of the study was the grouping of the two subsamples by broad category. There are many types of cancer that affect individuals in many and differing ways physically, emotionally, and spiritually. Similarly, persons with AIDS are susceptible to a myriad of opportunistic infections and complications. Thus, the influence of the specific illness experience in either subsample was not incorporated into the research design of this study. Another limitation of this study was the small sample of participants, particularly in application of chi square to measure difference between the two subsamples.

### **Implications for Nursing**

While new modalities in the treatment of cancer and AIDS provide hope for cure or life extension for afflicted individuals and their families, both illnesses continue to be

two of the most prevalent causes of illness-related deaths in the United States. Care delivery systems for individuals with terminal illnesses, particularly hospice programs or other palliative care services, have focused on holistic approaches to meeting the physical, emotional, and spiritual needs of the dying individual. Yet, few, if any, of these interventions have incorporated individual meaning of death in approach to care for persons diagnosed in the end-stages of cancer or AIDS. As demonstrated through application of Watson's concept of the holistic individual, meaning of death for persons with cancer and persons with AIDS studied in this research reveals the influences of the three spheres of body, mind, and spirit, thus reinforcing the need for nursing to examine its provision of holistic care.

Implications for nursing include the potential value of nurses' exploration of the meaning of death with a person diagnosed with end-stage cancer or AIDS. By so doing, the nurse assists the dying individual in self discovery as the completion of life's physical journey approaches. Identification of meaning of death assists the individual in becoming cognizant of philosophical beliefs that reflect aspects of body, mind, or spirit in relation to life, family, the illness experience, or the dying process. The nurse is then better able to individualize nursing care based on identified meaning. This is similar to recommendations for nursing by Jones (1993) and other researchers (Coward, 1994; Holcomb, Neimeyer, & Moore, 1993; O'Connor, Wicker, & Germino, 1990; Reed, 1986b; Ryan, 1992; Smith, et.

al., 1993) who encourage nurses to assist persons in finding personal meaning in death or the illness experience.

Based on this researcher's clinical and academic experience in the care of persons with terminal illnesses, exploration of personal meaning of death yields a multitude of responses reflective of the many influences in the individual's life. The findings of this study correspond with clinical observations that have not been previously studied. This is particularly evident in the findings of the meaning of death for the subsample of persons with AIDS. The diversity in categories representing meaning of death may be indicative of the diverse and variable disease trajectory which accompanies a diagnosis of AIDS, as seen in this researcher's clinical practice. Historically, AIDS is a new disease with limited information regarding opportunistic disease processes, treatment or prevention, or manner of death. Accompanying the limits of medical knowledge are the psychosocial ramifications of being diagnosed with AIDS, including social stigmatization, isolation, multiple losses, and premature death, as identified in the review of literature. Therefore, while there is sufficient knowledge to inform the individual with AIDS about the eventual certainty of death, the process that the illness will follow to that death is unknown.

Comparing this with the cancer experience, in which treatment options and disease trajectories are better established, it can be understood that for persons with AIDS, based on this study, the meaning of death encompasses more divergence in categories than does the view of persons with cancer. Here it may also be important to consider the possible

influence of age in the meaning of death for the subsample of persons with AIDS whose mean age was 40 years.

However, it is important for nurses to realize that age may not be a significant factor in the meaning of death for either subsample. Age ranged from 42 to 87 years for participants with cancer, and from 26 to 58 years for participants with AIDS. Yet, both groups shared categories indicating meaning of death not only within each subsample, but across the two subsamples. Therefore, based on the results of this study, people of different ages may have similar perspectives associated with the dying experience. Conversely, people with terminal illnesses do not necessarily share the same view, as noted in the categories that differed between the two subsamples.

The themes and categories identified in this research can be used by nurses caring for persons with terminal cancer or end-stage AIDS. Nurses are encouraged to recognize that both groups share indications of Acceptance and Spiritual Awareness in their personal meaning of death. Identification of either or both of these categories during the nursing assessment of a person with cancer or a person with AIDS can be useful in planning care. By building upon the strengths identified by the individual through meaning of death reflected in categories of Acceptance or Spiritual Awareness, the nurse can provide more comprehensive care as the end of physical life approaches.

Similarly, exploration of categories of meaning of death not shared by the two populations can be included in the nursing assessment. For persons with cancer, this

exploration may lead to identification of themes reflecting Release or Reluctance. For persons with AIDS, the nursing assessment may reveal indications of Uncertainty, Anticipatory Loss, Fear, or Benefits. Identification of these categories assists the nurse in planning care that incorporates meaning for the individual diagnosed with either terminal cancer or end-stage AIDS. This in turn may lead, for example, to interventions which address issues of fear for the individual with AIDS, such as appropriate symptom management to alleviate the individual's fear of the potential physical effects of the illness. However, it should be noted that the differences in categories between the two subsamples for this study should not be interpreted to negate the likelihood that these same categories may be shared by either persons with cancer or persons with AIDS in other circumstances or study designs. Clearly, assessment for Fear is not limited to persons with AIDS exclusively.

Yet nursing care for individuals who are terminally ill may not take the form of traditional interventions or tasks when incorporating meaning of death. Indeed, given the personal and paradoxical nature of the meaning of death, an appropriate nursing intervention may focus on validation of the individual's response, versus an intervention that is aimed at "fixing" what some might see as a problem. For example, based on the findings of this research, when caring for a person with cancer, the nurse may focus aspects of care with an understanding that regret or concern for survivors may be prevalent constructs in the individual's meaning of death. Interventions that foster self-

disclosure, processing of feelings, spiritual support, assurance of physical comfort, or other needs identified through individual meaning of death may serve to optimize the experience for both the individual and the nurse. As both the individual and the nurse enter what Watson (1988) describes as a transpersonal caring relationship, the nurse assists the individual with cancer in achieving self-reverence, self-healing, and self knowledge. Thus, incorporation of the meaning of death into nursing care can assist the individual in establishing harmony.

### **Recommendations for Future Research**

There is little known about the meaning of death to persons with differing terminal illnesses. Based on results of this study, recommendations for future research include studying the meaning of death to persons with specific types of cancer, or persons with AIDS who have specific opportunistic infections. Further study into the identified categories of Fear, Uncertainty, and Anticipatory Loss for persons with end-stage AIDS in relation to age and gender is recommended as these were three of the four categories not identified for persons with cancer. Cultural differences in the meaning of death would be captured by studying a particular ethnic group. Research into the two shared categories of Acceptance and Spiritual Awareness might help to further elucidate distinctions between the two subsamples by comparing spiritual perspectives of participants prior to diagnosis of a terminal illness. Additionally, replication of this study with a larger sample size might assist in generalization of results. Finally, development of

an instrument that measures the meaning of death for persons with terminal illnesses may help quantify results and identify patterns that are amenable to interventions by health care providers.

### **Summary**

Chapter Five was a presentation of the discussion of relationship of findings to the conceptual orientation, relationship of findings to the literature reviewed, implications for nursing, limitations of the study, and recommendations for further research.

The meaning of death for persons with cancer and persons with AIDS living in the last six month of life had not been previously studied. The categories derived for the meaning of death for the two subsamples revealed influences of body, mind, and spirit. Content analysis yielded four categories reflecting meaning of death for persons with cancer and six categories reflecting meaning of death for persons with AIDS. The two categories shared by both persons with cancer and persons with AIDS were Acceptance and Spiritual Awareness. The findings provide nursing with an opportunity to enrich the provision of holistic care to persons with cancer and persons with AIDS living in the last six months of physical life.

**APPENDIX A**

**Approval Letters of Original Study**

Human Subjects Committee

1422 E. McDowell St.  
Tucson, Arizona 85724  
(602) 426-4271

July 20, 1994

Cheryl N. McGaffie, BSN, RN  
 c/o Leanna Crosby, D.N.Sc.  
 College of Nursing  
 Arizona Health Sciences Center

RE: A COMPARISON OF PERSPECTIVES ABOUT LIFE AND DEATH AMONG OLDER  
 ADULTS AND ADULTS EXPERIENCING A LIFE-THREATENING ILLNESS

Dear Ms. McGaffie:

We have received documents concerning your above cited project. Regulations published by the U.S. Department of Health and Human Services [45 CFR Part 46.101(b) (2)] exempt this type of research from review by our Committee.

Thank you for informing us of your work. If you have any questions concerning the above, please contact this office.

Sincerely yours,

  
 William F. Denny, M.D.  
 Chairman  
 Human Subjects Committee

WFD:ja

cc: Departmental/College Review Committee

College of Nursing

The University of  
**ARIZONA.**  
HEALTH SCIENCES CENTER

Tucson, Arizona 85724  
(520) 624-4134

## MEMORANDUM

TO: Cheryl M. McGuffic, BSN, RN

FROM: Leanna Crosby, D.N.Sc., R.N. Director of Intramural Research *10/24/84*

DATE: July 21, 1984

SUBJECT: Human Subjects Review: "A Comparison of Perspectives about Life and Death Among Older Adults and Adults Experiencing a Life-Threatening Illness"

Your research project has been reviewed and approved by William Denny, M.D., Chairman of the University of Arizona Human Subjects Committee, and deemed to be exempt from review by their full committee. You will be receiving a confirmation letter from Dr. Denny. In addition, your project has been reviewed and approved by the College of Nursing Human Subjects Review Committee.

We wish you a valuable and stimulating experience with your research.

LC/ms

**APPENDIX B**

**Approval Letters from Institutions**

**Participating in Original Study**

# CARONDELET

HEALTHCARE

April 3, 1995

Cheryl McGaffie, RN  
University of Arizona  
College of Nursing  
Tucson, Arizona 85721

The Healthy  
Society Program

Sponsored by the  
Community  
Nursing  
Organization

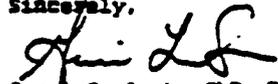
Dear Ms. McGaffie:

Your request for access to Carondelet Hospice Home Health Program for the purpose of conducting your research on "Developmental Patterns and End of Life Experiences" has been approved.

Michael Ryan, RN will be your contact person. Please make an appointment with Michael to make any necessary arrangements to begin data collection. You can reach him at 622-5833, extension 5742.

Please inform Michael any time when you have completed data collection. We will assist you in scheduling a time to share your findings with the Hospice staff. Please do not hesitate to call me with any questions. Good luck with your research.

Sincerely,



Gerri S. Lamb, PhD, RN, FAAN  
Clinical Director for Research

1601 West  
St. Mary's Rd.

Tucson, AZ  
85745-2682

602 749-4136

1-800-883-4532

Member of  
Carondelet Health  
System

Sponsored by the  
State of St. Joseph  
of Carondelet



**Tucson Medical Center**  
Team • Technology • Tucson

May 2, 1995

Cheryl McGaffie, PhD-C, RN  
College of Nursing  
1501 N. Campbell Ave.  
Tucson, Arizona 85721

**RE: Developmental Patterns and End of Life Experiences: A Comparison of Perceptives About Life and Death Among Community-Dwelling Adults**

Dear Dr. McGaffie:

Thank you for presenting this study at the Human Research Committee this morning. Based on your presentation the committee approved your study. You may begin data collection.

It is understood that no changes will be made to the study without the knowledge and permission of the Human Research Committee. Please be aware that a copy of the consent form must be placed in the patient's medical record. Review has been set at six months.

Please contact me at 324-5332 if you have any questions. You may also contact Chris Arslanian RN, PhD at 324-5512.

Sincerely,

Ronald P. Spark, M.D., Chair  
TMC Human Research Committee

**APPENDIX C**

**Consent Form and Authorization Form of Original Study**

**Patterns of Spirituality and Health in Persons Facing Death****Consent form**

**I AM BEING ASKED TO READ THE FOLLOWING MATERIAL TO ENSURE THAT I AM INFORMED OF THE NATURE OF THIS RESEARCH STUDY AND OF HOW I WILL PARTICIPATE IN IT, IF I CONSENT TO DO SO. SIGNING THIS FORM WILL INDICATE THAT I HAVE BEEN SO INFORMED AND THAT I GIVE MY CONSENT. FEDERAL REGULATIONS REQUIRE WRITTEN INFORMED CONSENT PRIOR TO PARTICIPATION IN THIS RESEARCH STUDY SO THAT I CAN KNOW THE NATURE AND RISKS OF MY PARTICIPATION AND CAN DECIDE TO PARTICIPATE OR NOT PARTICIPATE IN A FREE AND INFORMED MANNER.**

I am being asked to voluntarily participate in the above-titled study. The purpose of this study is to explore factors that relate to spirituality and health. I am being invited to participate in this study because I: a) am over the age of 60; or b) have been diagnosed with a life-threatening illness. Eighty people are being asked to participate in this pilot study.

If I agree to participate, I will be asked to answer questions that will be recorded by the investigator. I will be asked some questions about my health and my views about my perspective about issues surrounding life and death. The entire interview will take about 90 minutes at a place and time convenient to me. If I feel uncomfortable during the interview I will let the investigator know and the interview will be terminated.

There are no known risks or benefits to me as a result of participation in this study.

I am free to withdraw from this study at any time without incurring any ill will. My name will not be used on the paper and pencil forms that have my answers to the investigator's questions. I will let the investigator know if I would like to receive a summary of the results of this study. The investigator, Cheryl McGaffic may be contacted at the address below or at (602)-884-7119.

Cheryl McGaffic, RN  
Doctoral Candidate  
College of Nursing  
University of Arizona  
Tucson, AZ 85721

## AUTHORIZATION

"BEFORE GIVING MY CONSENT BY SIGNING THIS FORM, THE METHODS, INCONVENIENCES, RISKS, AND BENEFITS HAVE BEEN EXPLAINED TO ME AND MY QUESTIONS HAVE BEEN ANSWERED. I UNDERSTAND THAT I MAY ASK QUESTIONS AT ANY TIME AND THAT I AM FREE TO WITHDRAW FROM THE PROJECT AT ANY TIME WITHOUT CAUSING BAD FEELINGS OR AFFECTING MY MEDICAL CARE. MY PARTICIPATION IN THIS PROJECT MAY BE ENDED BY THE INVESTIGATOR OR BY THE SPONSOR FOR REASONS THAT WOULD BE EXPLAINED. NEW INFORMATION DEVELOPED DURING THE COURSE OF THIS STUDY WHICH MAY AFFECT MY WILLINGNESS TO CONTINUE IN THIS RESEARCH PROJECT WILL BE GIVEN TO ME AS IT BECOMES AVAILABLE. I UNDERSTAND THAT THIS CONSENT FORM WILL BE FILED IN AN AREA DESIGNATED BY THE HUMAN SUBJECTS COMMITTEE WITH ACCESS RESTRICTED TO THE PRINCIPAL INVESTIGATOR, CHERYL MCGAFFIC, OR AUTHORIZED REPRESENTATIVE OF THE NURSING DEPARTMENT. I UNDERSTAND THAT I DO NOT GIVE UP ANY OF MY LEGAL RIGHTS BY SIGNING THIS FORM. A COPY OF THIS SIGNED CONSENT FORM WILL BE GIVEN TO ME."

\_\_\_\_\_  
Subject's signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Parent/Legal Guardian (If necessary)

\_\_\_\_\_  
Date

## INVESTIGATOR

I have carefully explained to the subject the nature of the above project. I hereby certify that to the best of my knowledge the person who is signing the consent form understands clearly the nature, demands, benefits, and risks involved in his/her participation and his/her signature is legally valid. A medical problem or language or educational barrier has not precluded this understanding.

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

**APPENDIX D**

**Approval Letters for Secondary Analysis**

9034 E. Lee St.  
Tucson, AZ 85715  
(520) 298-9600

122

March 28, 1996

Cheryl McGaffic, RN, Ph.D.  
College of Nursing  
University of Arizona  
Tucson, Arizona

Dear Dr. McGaffic,

I am a graduate student in the College of Nursing at the University of Arizona and I would like to conduct a content analysis of the qualitative data from your recently completed dissertation. The purpose of the conduction of this content analysis is for completion of my Master's Thesis. I plan to study the perception of the meaning of death to terminally ill patients.

I have been instructed by my thesis chairperson, Dr. Kathleen May, that should you consent to this analysis, I would need copies of the following documents from your original study: human subjects approval letter, consent form or disclaimer used in your study to obtain data, and a copy of the instrument which includes the qualitative question of your study.

If you are in agreement with the above request, please return this letter with your signature marked "approved" and the date.

Thank you for your assistance and cooperation.

Sincerely,



Michael S. Ryan, BSN, RN, CRNH

4/15/96

Approved

Cheryl M McGaffic RN PhD

**April 15, 1996**

**Mr. Michael S. Ryan  
9034 East Lee Street  
Tucson, AZ 85715**

**Dear Mr. Ryan:**

**Your request to complete a secondary analysis of the data collected by Dr. Cheryl McGaffic has been approved by the Office of Nursing Research.**

**We wish you success with your research.**

**Sincerely,**



**Carolyn Murdaugh, PhD, RN, FAAN  
Director of Clinical Research**

**CM/sl**

**APPENDIX E**

**Original Study Instruments**

Code \_\_\_\_\_

**PERSONAL MEANING OF DEATH PARAGRAPH**

In one or two sentences, could you please describe what death means to you personally.

---

---

---

---

---

---

---

---

---

---

Code \_\_\_\_\_

**Descriptive Information Questionnaire**

1. Age: \_\_\_\_\_
2. Gender: \_\_\_\_\_  
1=Male  
2=Female
3. Number of years of education: \_\_\_\_\_ (High School Diploma=12)
4. Ethnicity: \_\_\_\_\_  
1=African-American  
2=Asian-American  
3=American-Indian  
4=Caucasian  
5=Mexican-American
5. Relationship with significant other: \_\_\_\_\_  
1=Married  
2=Living together  
3=Widowed  
4=No relationship  
5=Divorced
6. Present living arrangement: \_\_\_\_\_  
1=Alone  
2=Spouse/partner  
3=Family member  
4=Friends  
5=Other (please describe) \_\_\_\_\_
7. Present medical diagnosis: \_\_\_\_\_  
1=Aging Adult  
2=Dying Adult

8. How would you describe your present health? \_\_\_\_\_  
1=Poor  
2=Fair  
3=Average  
4=Good  
5=Excellent
9. Religious or Spiritual Affiliation: \_\_\_\_\_  
1=Protestant  
2=Catholic  
3=Jewish  
4=Eastern Religion  
5=12 Step Program  
6=New Age  
7=Other (Please describe) \_\_\_\_\_
10. What is your major source of support \_\_\_\_\_  
1=family  
2=friends  
3=support group  
4=other
11. Do you attend a support group?  
1=yes \_\_\_\_\_ Type of Support group \_\_\_\_\_  
2=no \_\_\_\_\_
12. What do you consider your financial status?  
1= Not at all secure  
2= Somewhat secure  
3= Secure  
4= Very Secure

**APPENDIX F**

**Death Construct Coding Dictionary Used in Original Study**

Death Construct Dictionary and Coding Manual  
(Neimeyer, Fontana, & Gold, 1984; Holcomb,  
Neimeyer, & Moore, 1993).

Definitions of Death Constructs

---

1. Purposefulness
  - a. purposeful: constructs dealing with meaningfulness of the death, its having some justification ethically, psychologically, or naturally.
  - b. purposeless: constructs suggesting the meaninglessness of the death, its being unjustified or unnecessary.
2. Evaluation
  - a. positive: constructs expressing an evaluation of death as "good" or valued.
  - b. negative: constructs having to do with an evaluation of the death as nonvalued or "bad."
3. Emotional state
  - b. negative: constructs suggesting negative emotional state.
4. Acceptance
  - b. low: constructs depicting the death as something to be rejected or resisted.
5. Understanding
  - a. high: constructs indicating achievement of some understanding of the death.
  - b. low: constructs expressing lack of understanding of the death.
6. Suffering
  - a. high: constructs suggesting that the death is painful or induces suffering.
  - b. low: constructs implying that death is painless or produces minimal suffering.
7. Personal involvement
  - a. high: constructs connoting personal involvement in the death.
  - b. low: constructs depicting the death as remote or not pertaining to the self.
8. Temporal expectation

- a. long range: constructs suggesting that death is anticipated.
  - b. short range: constructs implying that death is unanticipated.
9. Certainty
- a. high: constructs having to do with certain death.
10. Existence
- a. existence: constructs having to do with continued life.
  - b. nonexistence: constructs having to do with finality of the death.
11. Choice
- a. high: constructs emphasizing a degree of personal choice involved in the death.
  - b. low: constructs stressing absence of personal choice.
12. Specificity
- a. specific: constructs pertaining to the uniqueness of death.
  - b. general: constructs suggesting the generality of death.
13. Impact
- a. high: constructs dealing with the impact of death.
  - b. low: constructs implying that death has minimal impact.
14. Causality
- a. known: constructs suggesting that the physical cause of death is known or explained.
  - b. unknown: constructs implying that the physical cause of death is nonspecific or unknown.
15. Wishful Thinking
- a. constructs suggesting an optimal portrayal of death, but one that is qualified in such a way that this positive portrayal seems to be at odds with the subject's true beliefs, feelings, or fears

**APPENDIX G**

**Revised Death Construct Coding Dictionary from Original Study**

## Revised Death Construct Coding Dictionary

(Holcomb, Neimeyer, & Moore, 1993; McGaffic, 1995; Neimeyer, Fontana, & Gold, 1984)

### Definitions of Death Constructs

---

1. Purposefulness
  - a. purposeful: constructs dealing with meaningfulness of the death, its having some justification ethically, psychologically, or naturally.
  - b. purposeless: constructs suggesting the meaninglessness of the death, its being unjustified or unnecessary.
  
2. Evaluation
  - \* a. positive: constructs expressing an evaluation of death as valued or "good."
  - b. negative: constructs having to do with an evaluation of the death as nonvalued or "bad."
  
3. Emotional state
  - \* a. positive: constructs suggesting positive emotional state.
  - b. negative: constructs suggesting negative emotional state.
  
4. Acceptance
  - \* a. high: constructs depicting the death as something to be accepted or embraced
  - b. low: constructs depicting the death as something to be rejected or resisted.
  
5. Understanding
  - a. high: constructs indicating achievement of some understanding of the death.
  - b. low: constructs expressing lack of understanding of the death.

6. **Suffering**
  - a. high: constructs suggesting that the death is painful or induces suffering.
  - b. low: constructs implying that death is painless or produces minimal suffering.
  
7. **Personal involvement**
  - a. high: constructs connoting personal involvement in the death.
  - b. low: constructs depicting the death as remote or not pertaining to the self.
  
8. **Temporal expectation**
  - a. long range: constructs suggesting that death is anticipated.
  - b. short range: constructs implying that death is unanticipated
  
9. **Certainty**
  - a. high: constructs having to do with certain death.
  - \* b. low: constructs having to do with uncertain death.
  
10. **Existence**
  - a. existence: constructs having to do with continued life.
  - b. nonexistence: constructs having to do with finality of the death.
  
11. **Choice**
  - a. high: constructs emphasizing a degree of personal choice involved in the death.
  - b. low: constructs stressing absence of personal choice.
  
12. **Specificity**
  - a. specific: constructs pertaining to the uniqueness of death.
  - b. general: constructs suggesting the generality of death.

13. **Impact**
  - a. high: constructs dealing with the impact of death.
  - b. low: constructs implying that death has minimal impact.
  
14. **Causality**
  - a. known: constructs suggesting that the physical cause of death is known or explained.
  - b. unknown: constructs implying that the physical cause of death is nonspecific or unknown.
  
15. **Wishful Thinking**
  - a. constructs suggesting an optimal portrayal of death, but one that is qualified in such a way that this positive portrayal seems to be at odds with the subject's true beliefs, feelings, or fears
  - \* b. constructs suggesting a realistic appraisal of death, either positive or negative: an appraisal which seems to be consistent with subject's true beliefs, feelings, or fears
  
16. \* **Spirituality**
  - a. **Religiosity:** constructs suggesting that death or the process of dying involves one's connection to God, prayer, or beliefs connected to a particular religion
  - b. **Self-transcendence:** constructs implying that death or the process of dying involves one's connectedness with others, Nature, or other spiritual realm of existence

### References

- American Cancer Society. (1996). Cancer facts and figures - 1996. Atlanta, GA: American Cancer Society, Inc.
- Arathuzik, D. (1994). Preliminary assessment: The Pain Inventory and the Pain Coping Tool. The American Journal of Hospice and Palliative Care, 11(5), 25-29.
- Backer, B.A., Hannon, N. R., & Russell, N.A. (1994). Death and dying: Understanding and care. Albany, NY: Delmar Publishers Inc.
- Baker, N. T., & Seager, R. D. (1991). A comparison of the psychosocial needs of hospice patients with AIDS and those with other diagnoses. Hospice Journal, 7(1-2), 61-69.
- Barr, F. E. (Ed.). (1990). Cancer source book (Vol. 1). Detroit, MI: Omnigraphics, Inc.
- Burns, N., & Grove, S. K. (1987). The practice of nursing research: Conduct, critique, and utilization. Philadelphia: W. B. Saunders Company.
- Case Management Society of America (CSMA). (1994). CMSA proposes standards of practice. The Case Manager, 5(1), 59-70.
- Centers for Disease Control and Prevention (CDC). (1995). HIV/AIDS surveillance report, 7(2). Atlanta, GA: National Center for Prevention Services, Centers for Disease Control and Prevention (CDC).
- Christakis, N. A., & Escarce, J. J. (1996). Survival of Medicare patients after

enrollment in hospice programs. The New England Journal of Medicine, 335(3), 172-178.

Coward, D. D. (1990). The lived experience of self-transcendence in women with advanced breast cancer. Nursing Science Quarterly, 3(4), 162-169.

Coward, D. D. (1991). Self-transcendence and emotional well-being in women with advanced breast cancer. Oncology Nursing Forum, 18(5), 857-863.

Coward, D. D. (1994). Meaning and purpose in the lives of persons with AIDS. Public Health Nursing, 11(5), 331-336.

Crane, R. A. (1994). Intermittent subcutaneous infusion of opioids in hospice home care: An effective, economical, manageable option. The American Journal of Hospice and Palliative Care, 11(1), 8-12.

Fawcett, J. (1985). Analysis and evaluation of conceptual models of nursing (3rd ed.). Philadelphia: F. A. Davis Company.

Fryback, P.B. (1993). Health for people with a terminal diagnosis. Nursing Science Quarterly, 6(3), 147-159.

Germino, B. B., & Funk, S. G. (1989). Development of the family concerns inventory. Unpublished grant (NIH # ROINRO1331). Washington, DC: National Center for Nursing Research.

Hainsworth, D. S. (1996). The effect of death education on attitudes of hospital nurses toward care of the dying. Oncology Nursing Forum, 23(6), 963-967.

Hall, B.A. (1990). The struggle of the diagnosed terminally ill person to maintain

hope. Nursing Science Quarterly, 3, 177-184.

Hayslip, B., Luhr, D. D., & Beyerlein, M. M. (1991). Levels of death anxiety in terminally ill men: A pilot study. Omega, 24(1), 13-19.

Herth, K. (1995). Engendering hope in the chronically and terminally ill: Nursing interventions. The American Journal of Hospice and Palliative Care, 12(5), 31-39.

Hinshaw, A. S. (1979). Problems in doing research. Western Journal of Research, 1, 250-253.

Holcomb, L. E., Neimeyer, R. A., & Moore, M. K. (1993). Personal meaning of death: Content analysis of free response narratives. Death Studies, 17, 299-318.

Jones, S. A. (1993). Personal unity in dying: Alternative conceptions of the meaning of health. Journal of Advanced Nursing, 18, 89-94.

Kinzabrunner, B. M. (1995). Hospice: Case management for terminally ill patients. The Case Manager, 6(1), 57-66.

Krippendorff, K. (1980). Content analysis: An introduction to its methodology. Beverly Hills, CA: Sage Publications.

Lamendola, F. P., & Newman, M. A. (1994). The paradox of HIV/AIDS as expanding consciousness. Advances in Nursing Science, 16(3), 13-21.

Lehna, C. (1994). Children's descriptions of their feelings and what they found helpful during bereavement. The American Journal of Hospice and Palliative Care, 11(5), 24-30.

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage.

Longo, M. B., Spross, J. A., & Locke, A. M. (1990). Identifying major concerns of persons with acquired immunodeficiency syndrome: A replication. Clinical Nurse Specialist, 4(1), 21-26.

Loveys, B. J., & Klaich, K. (1991). Breast cancer: Demands of illness. Oncology Nursing Forum 18(1), 75-80.

Marquis, R. (1996). A qualitative evaluation of a bereavement service: An analysis of the experiences of consumers and providers of services in Australia. The American Journal of Hospice and Palliative Care, 13(4), 38-43.

McCain, N. L., & Gramling, L. F. (1992). Living with dying: Coping with HIV disease. Issues in Mental Health Nursing, 13, 271-284.

McCracken, S., Colburn, K., & Pastorik, L. (1994). Hospice care: Mapping the message. The American Journal of Hospice and Palliative Care, 11(3), 30-35.

McGaffic, C. M. (1995). Patterns of spirituality and health among aging adults and dying adults living in the community. Unpublished doctoral dissertation, University of Arizona, Tucson.

McMillan, S. C. (1996). The quality of life of patients with cancer receiving hospice care. Oncology Nursing Forum, 23(8), 1221-1228.

McMillan, S. C., & Mahon, M. (1994). A study of quality of life of hospice

patients on admission and at week 3. Cancer Nursing, 17(1), 52-60.

Morgan, A. E., Lindley, C. M., & Berry, J. I. (1994). Assessment of pain and patterns of analgesic use in hospice patients. The American Journal of Hospice and Palliative Care, 11(1), 13-25.

Morris, J. N., Suissa, S., Sherwood, S., Wright, S. M., & Greer, D. (1986). Last days: A study of the quality of life of terminally ill cancer patients. Journal of Chronic Disease, 39(1), 47-62.

National Hospice Organization (NHO) (1995). Hospice fact sheet: October 10, 1995. Arlington, VA: Author.

Neimeyer, R. A., Fontana, D. J., & Gold, K. (1984). Personal constructs in thanatology: An introduction and research bibliography. Death Education, 2(3), 87-94.

Newman, M.A. (1986). Health as expanding consciousness. St. Louis: Mosby.

Nunnally, J. C. (1978). Psychometric theory (2nd ed.). New York: McGraw-Hill.

O'Connor, A. P., Wicker, C. A., & Germino, B. B. (1990). Understanding the cancer patient's search for meaning. Cancer Nursing, 13(3), 167-175.

Office of Research and Demonstrations. (1994). Report to Congress: High-cost hospice care (HCFA publication no. 03360). Baltimore, MD: Health Care Financing Administration.

Padilla, G. V., Ferrell, B., Grant, M. M., & Rhiner, M. (1990). Defining the

content domain of quality of life for cancer patients with pain. Cancer Nursing, 13(2), 108-115.

Pincombe, J., & Tooth, B. (1996). Carers of the terminally ill: An Australian study. The American Journal of hospice and Palliative Care, 13(4), 44-55.

Polit, D. F., & Hungler, B. P. (1995). Nursing research: Principles and methods. Philadelphia: J. B. Lippincott.

Raudonis, B. M. (1995). Empathetic nurse-patient relationships in hospice nursing. The Hospice Journal, 10(1), 59-74.

Reed, P. G. (1986a). Religiousness among terminally ill and healthy adults. Research in Nursing and Health, 9, 35-42.

Reed, P. G. (1986b). Death perspectives and temporal variables in terminally ill and healthy individuals. Death Studies 10, 467-478.

Reed, P. G. (1987). Spirituality and well-being in terminally ill hospitalized adults. Research in Nursing and Health, 10(5), 335-344.

Reed, P. G. (1991). Preferences for spiritually related nursing interventions among terminally ill and nonterminally ill hospitalized adults and well adults. Applied Nursing Research, 4(3), 122-128.

Ross, L. M., & Pollio, H. R. (1991). Metaphors of Death: A thematic analysis of personal meanings. Omega, 23(4), 291-307.

Ryan, P. Y. (1992). Perceptions of the most helpful nursing behaviors in a home-

care hospice setting: Caregivers and nurses. The American Journal of Hospice and Palliative Care, 9(5), 22-31.

Schroeder, C., & Maeve, M. K. (1992). Nursing care partnerships at the Denver Nursing Project in Human Caring: An application and extension of caring theory in practice. Advances in Nursing Science, 15(2), 25-38.

Servaty, H. L., Krejci, M. J., & Hayslip Jr., B. (1996). Relationships among death anxiety, communication apprehension with the dying, and empathy in those seeking occupations as nurses and physicians. Death Studies, 20, 149-161.

Sherman, D. W. (1996). Nurses' willingness to care for AIDS patients and spirituality, social support, and death anxiety. Image, 28(3), 205-213.

Smith, E. D., Stefanek, M. E., Joseph, J. V., Verdieck, M. J., Zabora, J. R., & Fetting, J. H. (1993). Spiritual awareness, personal perspective on death, and psychosocial distress among cancer patients: An initial investigation. Journal of Psychosocial Oncology, 11(3), 89-103.

Streubert, H. J., & Carpenter, D. R. (1995). Qualitative research in nursing. Philadelphia: J. B. Lippincott.

Tamm, M. E., & Granqvist, A. (1995). The meaning of death for children and adolescents: A phenomenologic study of drawings. Death Studies, 19, 203-222.

Taylor, E. J., & Amenta, M. (1994). Midwifery to the soul while the body dies: Spiritual care among hospice nurse. The American Journal of Hospice and Palliative Care,

11(6), 28-35.

Thorson, J. A., & Powell, F. C. (1990). Meanings of death and intrinsic religiosity. Journal of Clinical Psychology, 46(4), 379-391.

Von Gunten, C. F., Von Roenn, J. H., Neely, K. J., Martinez, J., & Weitzman, S. (1995). Hospice and palliative care: Attitudes and practices of the physician faculty of an academic hospital. The American Journal of Hospice and Palliative Care, 12(4), 38-42.

Waller, W., Hershkowitz, M., & Adunsky, A. (1994). The effect of intravenous fluid infusion on blood and urine parameters of hydration and on state of consciousness in terminal cancer patients. The American Journal of Hospice and Palliative Care, 11(6), 22-27.

Waltman, N. L., & Zimmerman, L. (1991). Variations among nurses in behavioral intentions toward the dying. The Hospice Journal, 7(4), 37-49.

Watson, J. (1985). Nursing: The philosophy and science of caring. Boulder, CO: Colorado Associated University Press.

Watson, J. (1988). Nursing: Human science and human care. Norwalk, CT: Appleton-Century-Crofts.

Weber, R. P. (1990). Basic content analysis. Newbury Park: Sage.

Zerwekh, J. (1993). Transcending life: The practice wisdom of hospice nurse experts. The American Journal of Hospice and Palliative Care, 10(5), 26-31.