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The experiences of mental health professionals providing services to persons who are dying: a phenomenological study

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University of Iowa

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THE EXPERIENCES OF MENTAL HEALTH PROFESSIONALS PROVIDING
SERVICES TO PERSONS WHO ARE DYING: A PHENOMENOLOGICAL STUDY

by

Jennifer Marie Hill

An Abstract

Of a thesis submitted in partial fulfillment
of the requirements for the Doctor of
Philosophy degree in Psychological and Quantitative
Foundations (Counseling Psychology)
in the Graduate College of
The University of Iowa

December 2009

Thesis Supervisor: Professor John Westefeld

ABSTRACT

Trends in lengthening life spans and population growth indicate that psychologists will be increasingly called upon to provide mental health services to persons who are dying. Some persons close to death have specialized needs that psychologists and other mental health professionals must learn to address appropriately. Psychologists need information from the wide variety of professionals who currently provide therapeutic interventions in order to be adequately prepared to do the same. The purpose of this study was to document the lived experience of mental health professionals who provide mental health services to persons who are dying in order to more fully establish the characteristics and nuances of what it is like to work with this population.

Moustakas' (1994) phenomenological methodology was used to analyze the interview data. Following analysis, six facets of the experience were identified. The phenomenon of providing mental health services to persons in the process of dying included experiencing:

- 1) Very positive and rewarding emotional aspects and very painful and distressing aspects;
- 2) Effective service provision involving making an invested and authentic connection, listening carefully and being "present", and carefully individualizing treatment; all while managing emotionality;
- 3) The otherworldly, either in religious or ethereal ways;
- 4) Learning from clients how to live and how to die;
- 5) End-of-life phenomena which were convincing, but anecdotal; and
- 6) Awareness of death and of personal mortality.

This study's findings generally supported by existing research were: 1) working with this population involves both positive and challenging emotional states and 2) individualized treatment based on client characteristics is paramount. Some of this study's findings were new contributions, such as identifying the importance of further individualizing service provision based on the setting and the presence of others. Other

unique findings included the many positive aspects of working with people who are dying, such as profound learning opportunities and experiencing religious/ethereal and other end-of-life phenomena.

Suggestions for psychologists' training to gain self-care skills were provided, both to avoid the negative emotional impact of providing services to this population and to desensitize themselves to death and personal mortality.

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CERTIFICATE OF APPROVAL

PH.D. THESIS

This is to certify that the Ph.D. thesis of

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To Bill and Marsha Hill, my remarkable parents who taught me to love life, to plan well for death, and to engage in life-long learning and growth

Live as if you were to die tomorrow. Learn as if you were to live forever.

Mahatma Gandhi

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CHAPTER I: INTRODUCTION

This initial chapter serves as an introduction to the current study. It includes a discussion of the context and background for the study, the need for and purpose of the study, the research questions, significance of and rationale for the study, and an explanation of key terminology.

Problem and Context

The American Psychological Association (APA) (2006) recently noted that psychologists are beginning to offer their professional services to people at the end of life. Although the APA noted that doctors, nurses, social workers, and the clergy have traditionally offered expertise to persons at the end of life, the organization now recognizes that psychologists have much to offer those who are dying, and much to learn from the professionals already providing service to the dying. Specifically, the APA noted that psychologists have training and expertise uniquely applicable to this population, and that psychologists are particularly suited to provide interventions after an illness is diagnosed, during advanced illness, and/or during the dying process. The APA stated, “The U.S. Supreme Court says Americans should expect palliative care, which combines active and compassionate therapies to comfort and support people and their families nearing the end of life. Psychologists can make significant contributions to improve the quality of end-of-life care and decision making” (<http://www.psychologymatters.org/endlife.html>). They add that psychologists are increasingly taking a more active role in the areas of clinical, education/training, and research, although doctors, nurses, social workers, and the clergy still provide the bulk of services to people who are dying (APA, 2006).

Kersting (2004) also states that establishing better mental health care for those approaching death is a priority for the APA. Since, according to the Robert Wood Johnson Foundation, 75 % of deaths in the United States occur in persons 65 or older, special attention and professional recommendations need to be made. Eighty percent of

persons over 65 have heart disease, cancer, and other chronic illness which can increase the complexity of the dying process (Kersting, 2004). William Haley, director of the School for Aging Studies at the University of South Florida, was quoted in Kersting's article as saying: "Psychologists who are trained to pay attention to the special needs of older adults at the end of life will be able to make a major impact in the quality of the death experience for both patients and their families" (p. 53). Although the dying process does not automatically demand mental health intervention, his statement implies both that psychologists should address the special needs of those approaching death and that more training and preparation in this area is needed. The movement in the APA toward better service provision for those who are dying and can benefit from mental health treatment adds impetus to research endeavors in this area.

Significance of Need

The need for information on providing mental health services to the dying is two-fold: First, more persons are in need of these services and, secondly, psychologists will provide better services to the dying if they can access and apply the knowledge of those already working with persons who are dying. Both of these areas of need will be addressed below.

Due to fluctuation in the nation's population growth, more Americans per capita will be approaching death in the coming decades. According to the United States Census Bureau (2005), the number of Americans 55 years of age and older will almost double by the year 2030 – from 60 million in 2005 (21 percent of the total United States population) to 107.6 million (31 percent of the population) as the Baby Boomers reach retirement age. Similarly, by 2030, the number of Americans over 65 will more than double, from 34.8 million in 2000 (12 percent of the population) to 70.3 million in 2030 (20 percent of the total population). The next generation of retirees will be the healthiest, longest lived, best educated, most affluent in history (United States Census Bureau, 2005). These retirees, however, will likely live much longer than our health and mental health systems

are accustomed to, which will lead to a tremendous increase in demand for end-of-life services (Carbine, 2008). Americans reaching age 65 today have an average life expectancy of an additional 17.9 years (19.2 years for females and 16.3 years for males), compared to expectancies four decades ago. The likelihood that an American who reaches the age of 65 will survive to the age of 90 has nearly doubled over the past 40 years – from just 14 percent of 65-year-olds in 1960 to 25 percent at present. By 2050, 40 percent of 65-year-olds are likely to reach age 90 (United States Census Bureau, 2005). Many of these Americans will experience aging and dying processes that do not require psychological interventions. However, some Americans will require specific mental health intervention and will require it at a rate the mental health system is not currently prepared to provide.

In the coming decades, more Americans will need more mental health services in the end of life to address some of the special needs of this population. Those needs include depression, suicidal behavior, and the pain and disease associated with aging. The United States Census Bureau (2005) and the National Institutes of Mental Health (2003) have both identified a startling rate of suicide in American Caucasian men over 80 years of age. This group's suicide death rate is 59 deaths per 100,000 people, and is five times the national average. Among men 75 years or older, 12.5% of them are clinically depressed, whereas 18.7% of women 75 years or older are depressed (Health and Retirement Survey, 2002). In America, the demographic group growing most quickly is men and women over 85 years of age. The demand for end-of-life care, particularly around managing chronic pain, chronic disease, and the psychological distress of both, has grown exponentially and will continue to do so (Carbine, 2008).

Shernoff (1999) documents that persons approaching death are likely to participate in therapy at the end of life for two reasons: Persons are more likely to seek services if they have had an on-going therapeutic relationship and/or if their approaching death is particularly distressing to them. Archer (2006) agrees with Shernoff about the

two ways that people who are dying receive individual therapy. However, in her work as a psychoanalytic psychotherapist, Archer (2006) finds that many more clients continue in an already established therapeutic relationship throughout the dying process rather than seek therapy as death approaches. Stuych (2008) describes the trend of increasing numbers of professionals referring cancer patients to counseling. Typically, mental health professionals help these patients cope with feelings of anger, grief, and helplessness. Patients are often taught relaxation techniques and use mental health services to discuss topics such as end-of-life issues, advance directives, applying for disability benefits, and transitioning to hospice care. Counseling focuses on crisis intervention, overcoming helplessness, encouraging self-mastery, reframing meaning, and providing resource information and linkage (Stuych, 2008). Knight (2004) has found in his extensive work with older adults that older adults are most likely to seek mental health treatment independent of caregivers and that the older adults who seek therapy are very likely to have a chronic and progressive illness.

These statistics and projections into the future of the United States' health and mental health system establish that many more persons will be in need of end-of-life mental health services in the future which will change the demands on our healthcare system and the psychologists who work in it. This is one reason that explorations into mental health services with the dying are needed. A parallel reason for additional research is that psychologists will be better prepared to meet APA's directive to provide more services to persons approaching death (APA, 2006) if psychologists understand the experiences of professionals already providing services to persons who are dying. This second area of identified need will be explored below.

Researchers have indicated that as the population of the United States ages, the need for high-quality, empathetic, and holistic interventions at the end of life is becoming an urgent issue (Teno & Connor, 2009). The utilization of end-of-life services is growing as Americans live longer. More than 1.4 million Americans were served by the nation's

hospice providers last year, all receiving therapeutic interventions of various degrees (National Hospice and Palliative Care Organization, 2009). Lair (1996) has observed an increasing propensity for hospice patients to both request someone to talk with and build a trusting, supportive relationship with a mental health professional or hospice volunteer. Formal counseling and psychological interventions with persons approaching death are increasing in hospice and medical settings, although data about the quantity, quality, and outcomes of these interventions are not available (Vachon, 1988).

The need for mental health intervention with persons who are dying is increasingly needed and requested. Psychologists will increasingly provide these services (APA, 2006; Weiser, 2006). As Weiser (2006) describes, providing therapy to persons who are dying is different than therapy with other populations. Weiser (2006), herself a psychologist, asserts that providing therapy with the dying involves “numerous therapeutic issues ... the likes of which I never dealt with in my graduate school training” (p. 12) and writes about her experiences working with persons who are dying in order to assist other professionals’ to be successful in similar work. The Encyclopedia of Death and Dying’s entry for “psychology” includes the statement, “Since 1956, psychology has moved from its original ostrich approach to death to a recognition of death studies as among the most important in the field” (<http://www.deathreference.com/Nu-Pu/Psychology.html>). The same entry discusses the need for psychology to continue to use the information provided by corollary fields (anthropology, education, medicine, nursing, philosophy, psychiatry, religion, social work, sociology, the arts, and the humanities) to advance the theory and research of psychology. This assertion, that psychology has and will develop most effectively by integrating the knowledge of other fields, is applicable to this study. Similarly, this Encyclopedia identifies that psychology needs to generate more studies on applied death and dying work, since most of the research in psychology on death and dying quantifies death attitudes and death anxiety. A study of the experiences of mental health professionals from various disciplines who

are currently providing services to the dying will assist psychologists' further transition into the field of therapy with the dying.

In summary, the need for the present study includes two facets. First, statistical projections establish that in the coming decade many more Americans will need end-of-life services. The aging of the Baby-Boomers will thoroughly change the demands on health and mental health care. A second and related reason for research on the experiences of professionals providing mental health services to people approaching death is that psychologists learning how to treat this population will benefit from the information in order to meet the increasing demand for mental health services at the end of life. Therefore, the current study attempts to address these needs.

Research Questions and Approach

For psychologists to most successfully provide services to persons who are dying, more information on the experiences of professionals doing this work is needed. This phenomenological study explores the lived experiences of ten mental health professionals using the method by Moustakas (1994). Moustakas (1994) stated that "the empirical phenomenological approach involves a return to experience in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the essences of the experience" (p.13). This study seeks to describe a phenomenon, what it is like to provide therapy to persons who are dying, by pooling the perceptions of those who have experienced the phenomena (Moustakas, 1994). This research approach is well suited to the identified need to understand the professional experiences of professionals already providing treatment to people who are dying. More detailed rationale for the specific methodology's use in this study is provided in Chapter II.

Research Questions

This study, based on the problem and the information needed to begin solving it are:

1. What is the lived experience of mental health professionals as they provide mental health services to people who are dying?
2. What situations and contexts influence the lived experience of providing mental health services to people who are dying?
3. What, based on the accounts of the experience, is a way to describe the overall, unifying experience of providing mental health service to persons who are dying?

Definition of Terms

There are three terms in this study which require clarification in order to understand the parameters of this study. These terms are “mental health professional”, “dying”, and “mental health services.” Each is discussed below.

Mental Health Professional

The World Health Organization (2001) defines mental health professional as a person who offers services for the purpose of improving an individual's mental health and/or researches in the field of mental health. Mental health professionals include psychiatrists, psychologists, social workers, psychiatric nurses, and “other” professionals including licensed marital and family therapists, marriage, family and child counselors, licensed professional counselors, and licensed mental health counselors. This study defines mental health professionals as persons from any of the above groups. All the participants in this study were licensed mental health professionals.

Dying

Death, in medical and legal terms, has been defined as the “1) irreversible cessation of circulatory and respiratory functions, or 2) irreversible cessation of all functions of the entire brain, including the brainstem, “(President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1981, p. 2) The Hastings Center has been studying the definition of death since 1970 and recently stated that “the controversies surrounding forgoing of life-support have sometimes turned out to be more easily resolved than those over the definition of death”

(Veatch, 2009, p.18). While the definition of death as the cessation of respiration and brain activity is actively in use, controversy over the definition abounds due to the ethical, moral, and legal implications of “physician-assisted suicide, active killing for mercy, conflicts among plausible surrogates, forgoing implanted devices such as pacemakers that would require active intervention to remove, tensions over which treatments are futile, and controversies involving resource allocation” (Veatch, 2009, p.18). In familiar terminology, dying is defined as passing from physical life or passing out of existence (Merriam-Webster’s Dictionary, 2009). In medical and hospice settings, dying is defined as having a terminal condition which will likely lead to death within six months (Marrelli, 2005; National Hospice and Palliative Care Organization, 1996). In this study, participants were asked to discuss their experiences providing therapeutic services to persons who had been medically determined to be within six months of physical death.

Mental Health Services

Gazzaniga and Heatherton (2006) define mental health services as psychiatric medication, psychotherapy, physical treatments, lifestyle adjustments, and/or supportive measures. Participants in this study, as a group, provided all of these mental health services.

Summary

This introduction has discussed the context for this study which, in the most basic terms, is that psychologists are joining the other professional groups that routinely provide mental health services to persons who are dying. It also describes that there is a significant need for this to occur, since population changes of the United States will bring many more persons who are in the dying process and many more persons who will experience mental health symptoms that psychologists can become well-prepared to treat. This introduction also asserts that since knowing what it is like to provide services to the dying is paramount to quality service provision to this population, a phenomenological

study is best suited to this problem and inquiry. The research questions, in general, inquire about the lived experience of providing professional therapeutic services to persons who are dying and what situational or contextual factors influence the experience of the work. Key terms in this study, given the questions, are “mental health professional”, “dying”, and “mental health services”, all of which have been defined.

CHAPTER II: REVIEW OF THE LITERATURE

This chapter will review literature pertinent to this study. This review is provided in order to summarize what is already established in professional literature about providing mental health services to persons who are dying and to provide a framework for the current qualitative, phenomenological study. The review is in four primary areas: 1) information on the professionals currently providing mental health services to persons approaching death and the settings in which they practice, 2) the mental health treatments currently available specifically for persons who are dying, 3) the nature of phenomenological studies and, 4) examples from extant literature of phenomenological studies which have advanced the mental health services provided to persons who are dying. These bodies of literature informed the construction of this study and remain relevant for understanding the study and its results.

Mental Health Professionals Currently Providing Service to Persons Who are Dying

As previously mentioned, the majority of mental health services to the dying are provided by doctors, nurses, social workers, and the clergy (APA, 2006), although the rapidly expanding demand for psychological intervention with this population is necessitating that more professionals from various disciplines provide services (Carbine, 2008; Knight, 2004). Although specific data and details are not available (Vachon, 1988), it is possible to make some generalizations about how mental health services are provided to persons who are dying by examining the settings in which such services are delivered. These settings are discussed below and details about the professionals and the mental health services provided in each setting are provided.

Hospices

Hospice is an organized method of providing care directed toward comfort and support for patients with a terminal illness and a life expectancy medically assumed to be six months or less (Marrelli, 2005). There are currently more than 4700 hospice

programs in the United States (Teno & Connor, 2009). Virnig, Kind, McBean, and Fisher (2000) reported that the majority of people in the United States have access to hospice services, the only exceptions being of a small number of people in rural settings. Ninety-three percent of hospice programs are now Medicare certified; certified programs are required to have an interdisciplinary team of physicians, nurses, and other health care professionals; use volunteers; provide bereavement services; provide speech, physical, and occupational therapies as appropriate; and offer short-term inpatient care and home health aides (National Hospice and Palliative Care Organization, 2008).

Patients move to hospice care upon referral from their physician when the physician assesses that the patient can no longer benefit from “curative measures” such as chemotherapy, radiation, surgeries, and/or multiple curative medication regimens (Marrelli, 2005). Hospice care focuses on palliative care (relief from pain and uncomfortable symptoms) rather than curative care, optimizes quality of life, and helps patients, partners, and loved ones focus on the time the patient has left to live (Marrelli, 2005). Hospice’s aim is to provide as many services as is feasible in the patient’s home. However, hospice services are also provided in hospitals, skilled nursing facilities, and home health agencies (Marrelli, 2005).

According to the Centers for Medicare and Medicaid Services (2008), hospices provide a package of services that include physician, nursing, social work, home health aide, volunteer, physical therapy, occupational therapy, speech therapy, counseling, dietary, and spiritual professionals; medications related to the terminal illness; medical supplies and equipment; short general inpatient and respite care; 12 months of bereavement follow-up; and any other services reasonable and necessary for palliation of the terminal illness. More than 1.4 million Americans were served by hospice in 2008, each one receiving mental health interventions to various degrees (National Hospice and Palliative Care Organization, 2008). For hospice patients, most mental health services are provided by social workers, who are usually master’s prepared (Marrelli, 2005).

Bereavement services for hospice patients' families are provided for up to thirteen months after the death and are provided by social workers or, more often, trained volunteers (Marrelli, 2005).

Mental health workers in hospice come from a variety of training backgrounds including medicine, psychology, nursing, and social work (Marrelli, 2005; Woodson, 1987). Mental health services are provided with the guiding principles of patient-centered listening and communication and prioritizing the patient's values. For example, if the patient wishes to prioritize healing a relationship, arranging for care of pets, or organizing paperwork, these values are respected and the implied goals are identified and facilitated. Mental health practitioners in hospice are taught communication skills to actively listen, use presence as an intervention, and realize the work of "getting things in order" (Marrelli, 2005; p. 28).

Hospital Programs and Clinics

Within hospitals, people who are dying receive mental health services from numerous departments and specialties. Some hospitals, however, have services dedicated exclusively to interventions for people who are dying. These programs are housed in palliative care programs and/or in mental health clinics. Each of these is described below.

Palliative Care Programs

According to the World Health Organization (WHO) (2009),

Palliative Care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;

- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (<http://www.who.int/cancer/palliative/definition/en>)

From this definition, it is apparent that some persons who are within six months of death will use hospital-based palliative care programs, if available. However, hospital-based palliative care is potentially provided to any person who has a life-threatening illness. Also by definition, some hospice programs are also palliative care programs that only serve persons expected to die within six months. It is possible for persons approaching death to use hospital-based palliative care services, hospice services, both, or neither (World Health Organization, 2009). Many people who initially choose hospital-based palliative care ultimately transfer to hospice services as their death approaches (Teno & Connor, 2009).

There are currently more than 1400 hospital-based palliative care teams in the United States (Teno & Connor, 2009). According to the American Hospital Association (2007), more than 75% of hospitals with at least 250 beds have a hospital-based palliative care program and nearly 100% of all Veterans Administration hospitals have a program. Compared to hospice, hospital-based palliative care services are relatively new and may not be available in some urban and many rural areas (Teno & Connor, 2009). As hospital-based palliative care services have developed over the past decades, they have grown and changed. Currently the experts, consumers, legislators, and judges who make up the National Quality Forum have established that the key components of a Palliative Care Service are: holistic care provided by interdisciplinary teams that attend to the patients' desired physical comfort and emotional support through evidence-based practice,

the promotion of shared decision making, attention to the needs of the family for information and skills to participate in patient care, provision of bereavement services prior to and after the patient's death, and coordination of care across settings of care to accommodate the patient's disease trajectory (National Quality Forum, 2006).

Hospital-based palliative care programs can potentially provide any or all of the services offered in hospice settings and such programs vary greatly. A hospital-based palliative care program could range from having one specially trained nurse visiting patients throughout a facility to having a complete interdisciplinary team with a dedicated inpatient unit, home care program, and outpatient program. Generally, hospital-based palliative care programs tend to offer fewer volunteer, spiritual, and bereavement services than are available in hospice programs. Hospital-based palliative care programs are most likely to provide services only in the hospital, but some programs have home-based and/or out-patient services (Teno & Connor, 2009).

Other Hospital Settings

Most people who are within six months of death receive mental health services in hospice or hospital-based palliative care programs (Teno & Connor, 2009). Others, as will be discussed in the next section, receive services from, and sometimes in addition to, a religious counselor or leader. Within hospital systems, however, there are other ways in which persons who are approaching death might receive mental health services. Data on the utilization of end-of-life therapy are not available (Vachon, 1988), but persons who are dying do receive services in hospital departments of psychiatry, psychology, social work, and wellness (e.g., Stuych, 2008; Vachon, 1988; Weiser, 2006).

Interventions offered certainly depend on the hospital and available programming.

However, persons who are approaching death receive services including clinical assessment and diagnosis, psychotropic medication prescription and monitoring, insight-oriented psychodynamic therapy, cognitive-behavioral therapy, supportive therapy, self-

hypnosis to control symptoms, and/or professionally- or peer- led support groups (e.g., Vachon, 1988; Weiser, 2006).

Pastoral and Religious Services

In the United States, pastoral counseling began as a formal discipline shortly after World War II when it became a standard part of seminary curricula (Clinebell, 1990). Pastoral counseling is a branch of counseling in which ordained ministers, rabbis, priests and others provide therapy services. Pastoral Counselors integrate modern psychological thought and method with traditional religious training. In the United States, pastoral counselors have training at a master's or doctoral level. According to the American Association of Pastoral Counselors (AAPC) (2009), pastoral counseling accounts for three million hours of treatment annually in institutional and private settings, although it is unknown how many of those hours are dedicated to the treatment of persons who are dying. Although pastoral counseling is a relatively new discipline, it is growing quickly. The number of AAPC-certified pastoral counselors has tripled in the last 20 years (AAPC, 2009).

As mentioned in the previous descriptions of hospice and hospital-based palliative care programs, spiritual services are often offered and provided in both settings and may be provided in coordination with other mental health services. Medicare-certified hospices are required to provide spiritual counseling (Centers for Medicare & Medicaid Services, 2008) and the holistic focus of palliative care includes attention to spiritual concerns (WHO, 2009). Most of the professionals who provide spiritual and religious counseling to persons who are dying in hospice and hospital-based palliative care settings are pastoral counselors (AAPC, 2009) and are often called "chaplains" in these settings (Meador, 2004).

Pastoral counseling has been included in hospice since its inception forty years ago (AAPC, 2009) and is increasingly being included in hospital-based palliative care teams (Meador, 2004). Meador (2004) writes that pastoral counselors should be included

in the medical teams treating people who are dying as often as possible since their dual training in psychological and spiritual matters is often needed. People who are nearing death agree with this assertion and identify spiritual counseling as something they desire while hospitalized in the latest stages of life (Steinhauser, Christakis, Clipp, McNeilly, McIntyre, & Tulsky, 2000). Individuals sometimes seek mental health services from their own spiritual leader and/or pastoral counselor as they approach death, rather than using services from a pastoral counselor who works for a hospital, palliative care service, or hospice (Wicks, Parsons, & Capps, 2003). An individual's spiritual leader may work independently with the person who is dying or can be included in the hospice or hospital-based palliative care service provision, as is preferred by the person who is dying (Wicks, Parsons, & Capps, 2003).

Community Clinics

The vast majority of mental health service provision to persons who are dying occurs in hospitals or hospices. However, some services are provided in private, outpatient offices or through these offices in client homes (American Institute of Health Care Professionals, 2009). Services typically provided to persons who are dying in and/or through community clinics include individual counseling, music thanatology, and hypnosis, each of which is considered below. Some clinicians provide individual counseling or therapy in clinic and home settings (American Institute of Health Care Professionals, 2009). In recent years, clinicians practicing applied thanatology and music thanatology have established credentialing and education standards and are providing private services. Thanatologists are persons who study death, dying, and grief and either do research in the field or apply their knowledge clinically (Center For Thanatology Research and Education, 2009). Music thanatologists provide therapeutic music to persons who are dying in order to decrease physiological and emotional distress (Freeman, Caserta, Lund, Rossa, Dowdy, & Partenheimer, 2006). Finally, hypnosis is offered in these settings for persons who are dying (Zahourek, 1990).

The first section of this literature review provides information on the mental health professionals who currently provide the bulk of mental health services to persons who are dying. The majority of mental health services to the dying are provided by doctors, nurses, social workers, and the clergy (APA, 2006). Mental health services are provided to persons who are dying in hospices, hospitals, palliative care departments, community clinics, and in individuals' homes by agency professionals. These many mental health professionals provide services such as individual therapy, religious services, music thanatology vigils, and medication management. The second section of this review will focus on the specific, published interventions that mental health professionals offer to persons who are dying.

Population-Specific Treatments

Rodin and Gillies (2000) state that the two most common psychotherapeutic approaches utilized with persons approaching death due to disease are:

- 1) the promotion of active coping strategies to maintain the level of functioning, and 2) assistance with understanding, managing, and working through feelings related to the disease (p. 191).

They add that “these approaches can often be successfully integrated for optimal care” (p. 191). Rodin and Gillies also state that providing therapeutic treatment to persons approaching death requires flexibility from the therapist to accommodate changing levels of affect, awareness, fatigue, and pain. The work also requires flexibility to be willing to change focus in treatment when the client's needs change. One session might need to be short, one might need to be held at a client's bed-side, one might need to focus on psychological interventions for pain, and one might need to focus on strategies for healing a relationship. So, flexibility in therapeutic approach and session content and timing is required in work with the dying.

With that tenet in mind, there are specific approaches available for persons in the dying process. These will be reviewed below in sections generally determined by the

main theoretical approach or emphasis area of the professionals who authored them. Interventions are described from psychodynamic theory, existential theory, spiritual emphasis, religious emphasis, and cognitive behavioral theory, in that order. The order of the interventions reflects, in general, the interventions' applicability and appropriateness for the majority of persons who are facing death. Generally, fewer persons expected to live six months or less will seek, receive, and/or benefit from psychodynamic interventions. In contrast, many people who are facing death will seek, receive, and/or benefit from spiritual, religious, and cognitive behavioral interventions.

Psychodynamic Interventions

There are many therapies and approaches that deal with death and dying in psychodynamic literature. Clearly, aspects of psychodynamic theory and practice are likely used to some degree in many therapeutic interactions with people who are in the dying process as treatment with this population tends to be integrative (Rodin & Gillies, 2000). Three psychodynamic cases are described clearly in extant literature (Griffith, 2007a; 2007b; Lacy & Higgins, 2005; Shaverien, 2002). Each published case describes a course of individual treatment, why and how the issue of death is involved in the treatment, outcomes, and suggestions for applying the tenets of the case to other clinical work. It should be noted that all of the cases described in the psychodynamic literature are long-term clients. In the current study, the professionals interviewed only discussed their experience of working with clients assumed to be in the last six months of life (See definition of dying in Chapter I.).

Griffith (2007a; 2007b) writes about treating a man with Schizophrenia who is approaching death. From the perspective of a psychiatrist providing medication management and psychotherapy to this man through his local hospice, Griffith describes a number of important features of the appropriate clinical work. For example, with Borderline Personality Disorder, Post-Traumatic Stress Disorder, Major Depressive Disorder, and numerous health problems, whom they refer to as "Carla.". She discusses

the value of including support systems and family members in all end-of-life cases, but particularly with persons with similarly complex presentations since adjunct sources of information can be helpful and caregivers can help continue therapeutic interventions in the psychiatrist's absence. Griffith also describes the challenge of appropriately including religion in the content of psychotherapy with persons who are dying by inviting participation of religious leaders if the client desires that, being culturally sensitive to a client's religious beliefs, and being transparent about one's expertise in providing spiritual counsel. Griffith also highlights the clinical issue of managing one's personal stress and emotional reaction to a client's deterioration and death and also managing one's professional boundaries (physical touch, confidentiality, presence during medical procedures) as a psychotherapist who provides services in her patients' homes.

As mentioned in Chapter I, Shernoff (1999) and Archer (2006) agree that traditional talk therapy with an individual who is dying is most likely to occur when an on-going client contracts a terminal disease or condition and is less likely to occur when a person in the process of dying seeks individual treatment. The most likely scenario, an on-going client becoming very ill, is discussed in extant literature. Lacy and Higgins (2005) describe how to work with a client who becomes terminally ill during the course of long-term therapy. Dr. Higgins, this client's psychotherapist, is both a psychiatrist and family practice physician and provided medical and psychiatric care for this client for four and one-half years. Lacy and Higgins describe the course of treatment with this client, a woman diagnosed with Borderline Personality Disorder, Post-Traumatic Stress Disorder, Major Depressive Disorder, and numerous health problems, whom they refer to as "Carla." Carla was suddenly diagnosed with metastatic appendiceal cancer and Lacy and Higgins describe the changes in Carla's treatment as her death approached. These authors highlight the importance of approaching diagnostically complex individuals who are dying with the creative application of integrated therapeutic strategies. Specifically,

Carla's treatment required application of different theoretical orientations, the incorporation of family members, and different foci during sessions.

Following her cancer diagnosis, Carla used individual sessions to discuss her parents, her children, God, and death. She became able to openly discuss re-emergences of her depressive disorder and was able to reflect on her growing ability to trust her therapist although it had taken nearly a year for her to achieve that trust.

After intentionally discussing her views of the past and her attachment to members of her family, Carla asked to use session time to discuss her history of childhood sexual abuse by her father, a topic she had never discussed with anyone. She used sessions to discuss the details of the abuse, her past and present feelings about it, and her reactions to discussing these things in session.

Over the next year, Carla's physical condition deteriorated and required additional adjustments in service provision in order to meet Carla's changing needs and psychological condition. Existential issues and Carla's perceived "pressure to survive" (p. 627) became important to her. Her husband and daughter joined treatment sessions in order to assist her and her family to adjust to Carla's changing medical needs and to increase interpersonal and physical intimacy in her relationship with her husband.

In the final conversation Carla had with her therapist, she shared that she felt that she and her therapist had worked well together. Clinically, Lacy and Higgins observed Carla to be nearly symptom-free and well-managed on psychotropic medications. She died in the hospital holding her husband's hand.

Lacy and Higgins (2005) describe the successful treatment of a person in the dying process and highlight that therapists need to change content, approach, and modality of treatment, as appropriate, in order to meet the individual needs of a client who is dying.

The final example of working psychoanalytically with a person who is dying is provided by Shaverien (2002) who describes her analysis over two years of a middle-

aged man who was diagnosed with and died of cancer during the course of treatment. Schaverien vividly describes her work with James and how his terminal diagnosis and his awareness of his own death impacted the psychotherapy. However, this work focuses more on general tenets of psychoanalytic work and less on how James' death impacts the treatment.

Shaverien describes how, as James' death becomes more imminent, his dreams and emotional state change, each reflecting the other. She also discusses how James' psychological need to find fulfillment contributes significantly to an erotic transference. Lastly, James presented to treatment with depressed mood and an inability to independently exact change in his life. Although maintaining the psychoanalytic frame was reportedly difficult at times for Shaverien, she ultimately determined that insisting on maintaining therapeutic boundaries with James in the face of his imminent death and the erotic transference is what led to his successful treatment. He was able to achieve an integrated and unified sense of self before his death.

These therapeutic applications from psychodynamic theory are all longer term therapies than the ones participants discussed in the current study. However, they also illustrate what service provision can be within an established therapeutic relationship with a client who is verbal, aware, well-supported, and invested in challenging therapeutic work at the end of life. Although not typical, these psychodynamic interventions capture what is possible with this population at the higher levels of functioning and therapeutic alliance. The next section discusses interventions from existential therapy.

Existential Interventions

Existential theories (e.g., Yalom, 1980) often posit that meaning and purpose are catalyzed by experiences with mortality. And, aspects of existential work are clearly present in the cases described in this above section on psychodynamic treatment.

Yalom's (2008) most recent book, *Staring At the Sun: Overcoming the Terror of Death*,

discusses in depth how the pervasive fear of death creates pathology and that confronting death anxiety can be psychologically and symptomatically healing. This book and existential work in general, however, address the treatment needs of high-functioning and psychologically minded individuals who are willing and able to do emotionally demanding work. Persons likely to die within six months are less likely to have the needed emotional and physical strength to benefit from existential work. Rodin and Gillies (2000) state that intense, talk-based psychotherapies can be contraindicated and psychologically damaging to the majority of persons facing a fairly imminent death. However, individual differences abound and some individuals assumed to be within six months of death will be good candidates for existential therapy. Spira, a psychologist, (2000) has described an existential intervention specifically for persons who are dying. This treatment model is described below.

Spira's (2000) main objectives for his existential treatment for persons in palliative care settings are to reduce suffering and increase the client's ability to live life to the fullest. More specifically, Spira emphasizes six foci of the treatment: 1) develop an authentic relationship between therapist and client and between the client and others, 2) value client experiences, resources, and his or her capacity to develop at any point in the lifespan, 3) facilitate the breakdown of conditioned habitual, inauthentic assumptions about life, 4) assist client to accept the present suffering and coming death without attempting to cover it up, 5) help client to trust in the present moment as the fullest experience possible in this life, and 6) engage in activities which bring the client the greatest meaning, purpose, and value to his or her remaining life.

Of the foci above, the third, facilitate the breakdown of conditioned habitual assumptions about life, is the most difficult to understand on first reading and is therefore explained further. This is one of the most distinctive features of this therapeutic approach. Spira explains that "facilitating the breakdown" is a process of exploring suffering, learning to take multiple perspectives on a single situation, and to leave behind

assumptions about life and self that are not helpful in finding meaning and purpose in the end of life.

Spira suggests exercises to facilitate the process of “the breakdown” in three different areas: 1) living in the face of dying, 2) restrictive beliefs, and 3) being in the moment. In the living in the face of dying exercise, clients use written or oral narrative or imagery to explore what would be most meaningful to experience in the next year, month, week, and/or day of life. Problem-solving and goal setting discussion proceeds from the exercise to, as appropriate, help clients experience meaningful situations while anticipating death. Secondly, Spira describes exercises which help clients identify restrictive beliefs. Beliefs, attitudes, assumptions, and/or ideas that are unhelpful are identified and, as appropriate, challenged and reframed. Clients might find benefit in identifying and changing beliefs such as “I am a burden” or “I am completely dependent.” Spira emphasizes that, optimally, this exploration of restrictive beliefs is an exchange which highlights the client’s limitations *and* potentials. Thirdly, Spira’s exercises for being in the moment utilize meditation and acceptance techniques to help inspire a “moment of vision” when the clients are able to see that they are more than their narrow views of themselves and let go of stagnant assumptions about self and the world. Yoga and tai chi can assist with moments of vision for persons who have the physical ability to participate in them.

In summary, existential therapists often use awareness of mortality and fear of death in their work (e.g., Yalom, 1980). One existential therapist, Spira (2000) describes an existential model of treatment with clients who are dying. Similar to the psychodynamic approaches, Spira’s existential approach relies heavily on more traditional talk therapy, requiring significant emotional engagement from the client and striving for relatively global change as its outcome. Spira’s approach also has some commonalities with cognitive behavioral approaches for this population, which will be

discussed later. Before that, a summary of spiritual and religious (the difference is defined below) interventions is provided.

Spiritual and Religious Interventions

Polling indicates that more than 60% of terminally ill individuals are concerned about not being forgiven by God or have fears that they may be denied closeness to God or a Higher Power upon their deaths (The Nathan Cummings Foundation and Fetzer Institute, 1997). This indicates that many persons who are approaching death might have a need for religious counseling. Additionally, religious people and non-religious people may have need for spiritual counseling in the end of life. According to Fuller (2001), one in seven Americans is indifferent to religion and one of every five Americans describes him- or her- self as “spiritual, but not religious” (Fuller, 2001).

Fuller (2001) defines the distinction between religious and spiritual. Both connote belief in a Higher Power of some kind, imply a desire to enter into a more intense relationship with the Higher Power, and both connote interest in rituals, practices, and daily moral behaviors. People who are religious also endorse public membership in religious institutions, participation in formal rituals, and adherence to official denominational doctrines. Spirituality, in contrast, is associated with individuals’ higher levels of interest in mysticism, experimentation with unorthodox beliefs and practices, and negative feelings toward both clergy and churches. Reed (1992) defines spirituality as:

The propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual. This relatedness may be experienced intrapersonally (as a connectedness within oneself), interpersonally (in the context of others and the natural environment), and transpersonally (referring to a sense of relatedness to the unseen, God, or power greater than the self and ordinary resources) (p. 350).

There is variability, flexibility, and commonalities in these categorizations, indicative of the many ways individuals might identify with religiosity and spirituality. Interventions should be carefully matched to individuals’ preferences and belief systems around

religion, spirituality, or neither (Doka, 2009; Fuller, 2001; Johnson, 2003; Wicks, Parsons & Capps, 2003). The following sub-sections will describe the spiritual interventions and the religious interventions available for persons facing death.

Spiritual

Doka (1993; 2009) stated that people anticipating an imminent death often feel compelled to finish spiritual tasks or explore spiritual issues. He says that individuals who are dying have three spiritual needs: 1) to die in a way that is similar to how they lived, 2) to have a sense of the meaning and purpose in their life, and 3) to metaphorically live on after their death. Doka (2009) recommends participation in a spiritual therapy, the most common of which is Life Review Therapy, and/or Rousseau's model of treatment, both discussed below.

Life Review Therapy (Butler 1963, 1974) is very commonly used in hospices and nursing homes (<http://www.growthhouse.org/lifereview.html>). Life Review Therapy involves two processes, exercises to encourage reminiscences by the person who is dying and therapeutic contributions that record the person's history and explore the emotional meaning of events. Exercises to facilitate reminiscences might be looking at photographs, listening to music from bygone eras, recalling historical events, discussing employment history, writing journals, family trees, and/or genograms, telling family stories and jokes, and smelling or eating favorite foods. The therapist uses skillful observation and questioning to explore with clients what events meant to them, how they changed as people over time, what regrets they might have, and what aspects of joy and success they have enjoyed in their lives (Butler, 1963; Butler, 1974; Doka, 2009).

Rousseau (2000) has developed a therapeutic model for facilitating spiritual healing which centers on seven principles. Rousseau, a physician, proposes a model which includes basic psychotherapeutic principles, aspects of Life Review Therapy, and explicitly instructs physicians/therapists to discuss religion, as appropriate, with patients/clients. The seven principles of the model are: 1) controlling physical

symptoms; 2) providing a supportive presence; 3) encouraging life review to help recognize purpose, value, and meaning; 4) exploring guilt, remorse, forgiveness, and reconciliation; 5) facilitating religious expression; 6) reframing goals; and 7) encouraging meditative practices.

Rousseau (2000) describes how to do a good clinical evaluation of the dying person's spiritual history and also describes specific interventions. Regarding the clinical evaluation, he recommends taking time, being non-judgmental, and openly beginning the discussion of spirituality. The evaluation should gather information in four domains, which can be remembered with the acronym FICA:

Faiths or beliefs

What is your faith or belief?

Do you consider yourself spiritual or religious?

What things do you believe in that give meaning to life?

Importance and influence

Is it important to your life?

What influence does it have on how you take care of yourself?

How have your beliefs influenced your behavior during this illness?

Community

Are you part of a spiritual or religious community?

Is this of support to you, and how?

Is there a person or group of people whom you really love or who are really important to you?

Address

How would you like me, your health care provider, to address these issues in your care? (p. 55s).

The specific interventions Rousseau recommends to alleviate spiritual distress include controlling physical symptoms with medication; providing a supportive presence; encouraging life review to assist in recognizing purpose, value, and meaning; exploring issues of guilt, remorse, forgiveness, and reconciliation; facilitating religious expression; reframing goals into short-term endeavors that can be accomplished; and encouraging use of meditation, guided imagery, music, reading, poetry, and art, all focusing on spiritual healing rather than physical cure.

Spiritual interventions have commonality with existential interventions in that aspects of both facilitate a sense of meaning and purpose in the person who is dying. Any of the interventions discussed thus far could include exploration of the client's Higher Power and Rousseau's spiritual intervention includes that specifically as one of its key features. Like the definitions of spirituality and religion, there are also commonalities in spiritual and religious interventions. The religious interventions, which follow, include the discussion of not only the idea of a Higher Power, but of the client's specific religious beliefs.

Religious

A review of pastoral and religious interventions is impossible due to the number of religions, sects, and creeds that individuals who are dying belong to (Meador, 2004; Woodson, 1978). Different religious traditions and different individuals who subscribe to those traditions experience spiritual pain in the face of death in innumerable ways (Gonda & Ruark, 1984). Generally, pastoral and religious interventions at the end of life often include general counseling interventions like problem solving, communication about emotions and thoughts, and the provision of encouragement and support. Many pastoral and religious counselors subscribe to one or multiple theoretical orientations and may include interventions from that orientation (American Association of Pastoral Counselors, 2009; Gonda & Ruark, 1984; Wicks, Parsons, & Capps, 2003). Examples of specific spiritual interventions include discussion of faith beliefs such as what happens after death, praying, reading religion-specific texts, facilitating forgiveness between the individual who is dying and family members, and coordinating services and goods for the dying person and their family, often including other members of the religious community (Meador, 2004; Wicks, Parsons, & Capps, 2003).

Cognitive Behavioral Interventions

Although different approaches exist for therapists working with clients who are dying, skill-based, short-term treatments tend to be the most used and beneficial

treatments with persons facing death (Rodin & Gillies, 2000). For many people anticipating death, cognitive behavioral interventions are the most ideal, particularly when people are very close to death. Cognitive behavioral talk therapy, a cognitive behavioral coping skills treatment by Turk and Rennert (1981), and cognitive behavioral pain management are all described below.

Turk and Rennert (1981), Turk and Feldman (2000), and Carroll (1985) all discuss that cognitive reframing, examination of cognitive distortions, and teaching clients about dysfunctional thought patterns can have great utility with persons who are facing death. Similar to other traditional talk therapies discussed earlier in this literature review (e.g., psychodynamic, existential), cognitive behavioral talk therapy is generally appropriate for people at the beginning of the dying process. Talk therapies are much less likely to be a good fit or of benefit to persons in the final stages of dying, particularly if a serious illness is part of the person's presentation. Due to high levels of pain, high levels of medication, and short amounts of time, these talk-based interventions are less well suited than behavioral interventions for pain management, relaxation, and distraction.

Turk and Rennert (1981) describe the treatment of people who are in the dying process *and* of persons who are terminally diagnosed, but may conceivably have years of life ahead of them. This description of Turk and Rennert's work focuses as much as possible on the interventions they endorse for the last six months of life. Turk and Rennert recommend an in-depth assessment of the client's needs and discuss how numerous cognitive behavioral techniques are useful with persons in the dying process. They state that relaxation techniques such as controlled breathing, progressive muscle relaxation, autogenic training, and meditation are useful. Additionally, attentional training interventions like distraction, imagery, and hypnosis are particularly useful with persons in the most advanced stages of their illness.

Turk and Rennert (1981) encourage therapists to provide psychoeducation to clients about the inter-related nature of negative emotions like depression and anxiety and increased physical pain. After psychoeducation, Turk and Rennert provide a phase of treatment they call Conceptualization in which clients are asked to think about pain differently. Turk and Rennert build on the foundation of psychoeducation to emphasize clients' understanding of the connection between physical and psychological pain and provide examples of individuals who are able to work through pain with little awareness of it. Professional athletes, for example, often function with minimal attention to physical discomfort. Clients are asked to use imagery to remember times of physical pain in their histories and to assess how thoughts and feelings associated with pain impacted their experiences of that pain. Next, people who are dying are taught specific techniques for relaxation (breathing, progressive relaxation, autogenic messaging) and distraction (imagery, attending to external stimuli, focusing on positive thoughts). The specific techniques taught to individuals who are close to death should be chosen with consideration of the individual's preferences, level of lucidity, and chronicity and intensity of pain. Again, depending on the emotional and physical state of the individual, some clients may be able to practice relaxation and distraction techniques outside of session time; some may not be able or motivated. Turk and Rennert (1981) also explain that clients are better able to practice and better able to benefit from extensive psychoeducation about the impact of one's appraisals on the experience of pain earlier in the disease process.

Schultz (1978) stated that interventions to assist clients with physical pain are "probably the most important need of the dying patient" (p.76) and nearly 50% of terminally ill patients experience severe chronic pain (Gonda & Ruark, 1984). Some individuals experience the dying process in so much pain that pharmacological and psychological interventions for pain are all that can be provided. Turk and Rennert (1981) assert that teaching clients cognitive behavioral interventions for pain is effective

and that facilitating a decrease in physical pain will also decrease psychological distress; physical pain and psychological distress are highly correlated. Carey (1975) also stated that the level of physical discomfort was negatively related to emotional adjustment. “That is, the more discomfort an individual suffered, the less able he was to maintain a high level of emotional adjustment” (p.79). Carroll (1985) stated, “Anxiety control is pain control” (p.96).

This second section of reviewed literature has described the published interventions available specifically for persons who are facing death. The interventions were presented in order of applicability and appropriateness for the majority of persons who are facing death, from psychodynamic, existential, spiritual, religious, and cognitive behavioral perspectives. In general, traditional talk therapies are most helpful in the earlier stages of the dying process, around or before the estimated timeframe of six months before death. In contrast, as the six month timeframe nears its end, cognitive behavioral interventions for pain management, spiritual and/or religious comfort, and interventions based less on traditional talk therapy may be the only appropriate mental health interventions. All of the interventions for persons who are dying, independent of theoretical basis, emphasize flexibility in therapeutic approach and session content to meet the physical, emotional, and religious needs of the individual client. The final section of this literature review, below, provides a discussion of qualitative research, phenomenological research, and how this type of research has been used to increase the quality of services provided to persons who are dying.

Literature Informing Design and Methodology

This section describes the extant literature relevant to this study’s design and methodology in three sections. First, the features of qualitative inquiry and the characteristics of the more specific phenomenological method are described. Then, details about this particular qualitative and phenomenological study are illustrated. Throughout the discussion of qualitative and phenomenological inquiry, rationales for

this study's phenomenological approach are provided. Third and finally, examples of phenomenological research's utility to facilitate quality service provision are reviewed.

Qualitative Research

Denzin and Lincoln (2005) define qualitative research:

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. The practices transform the world. They turn the world into a series of representations, including fieldnotes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them (p. 3).

Denzin and Lincoln believe strongly in the transformative nature of qualitative research, that it can powerfully effect change in the world. This belief is strongly reflected in their definition. Creswell's (2007) definition focuses more on the design and process of qualitative research:

Qualitative research begins with assumptions, a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem. To study this problem, qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is inductive and establishes patterns or themes. The final written report or presentation includes the voices of participants, the reflexivity of the researcher, and a complex description and interpretation of the problem, and it extends the literature or signals a call for action (p.37).

A synthesis of these definitions of qualitative research establishes that qualitative research has nine general characteristics: 1) natural setting, 2) researcher as key instrument, 3) multiple sources of data, 4) inductive data analysis, 5) participants' meanings, 6) emergent design, 7) theoretical lens, 8) interpretive inquiry, and 9) holistic account.

To explain each of these in more detail, 1) qualitative researchers collect data in a natural setting where the participants experience the issue or problem under study. They do not use labs or other contrived situations to collect information. Information is gathered by talking directly to people and watching them behave in their natural setting.

2) Qualitative researchers are the key instrument for collecting data and rarely send out surveys or instruments for participants to complete. They may use a protocol, an instrument for collecting data, but this protocol is typically flexibly used and is not heavily relied upon.

3) Qualitative research uses multiple sources of data such as interviews, observations, and documents. All of this data is reviewed and organized into categories or themes.

4) Qualitative research is inductive. The process of finding patterns, themes, and/or categories is done with increasingly more abstract units of information.

5) In the entire process of conducting qualitative research, the focus is on learning the meaning that the participant has about the problem or issue and meanings that the researcher might have from personal experience, other researchers, or literature is subjugated.

6) Qualitative research uses emergent design. The initial plan for research cannot be tightly prescribed so that the process can change as the researcher begins to collect data. The problem or issue is explored from the participants' perspective rather than the researcher's agenda. Researchers may identify a need to change the questions they ask, the sites they visit, or the participants they interact with.

7) Qualitative researchers often use a lens through which to view their studies, often culture, gender, race, or class. Sometimes, the study and researcher use a lens of a social, political, or historical context related to the problem of study.

8) Qualitative researchers make an interpretation of what they see, hear, and understand. Although the researcher attempts to minimize the impact of his or her

background, history, context, and previous understandings, the researchers cannot be entirely separate from them and they will impact his or her interpretations. The study will be interpreted again every time the research report is read; this process perpetuates a fuller understanding of the problem since multiple views of the problem will emerge.

9) Qualitative research attempts to provide holistic accounts of the problem or issue under study. It attempts to record multiple perspectives, identify multiple factors involved, and generally describe the complex picture that emerges from the data. Researchers who use qualitative methodology are not bound to identify cause-and-effect relationships, but more often identify the complex interactions of factors in a situation (Denzin & Lincoln, 2005; Creswell, 2007).

The current study used a qualitative design because, as was discussed in Chapter 1, the problem of psychologists entering the field of providing mental health services to the dying is an emerging and developing one (e.g., APA, 2006; Teno & Connor, 2009; Weiser, 2006). It is appropriate to conduct qualitative research on problems that are unexplored, problems about which we do not yet have a solid understanding (Creswell, 2007, Denzin & Lincoln, 2005). Qualitative research is appropriate when we require studies that provide a complex, detailed understanding of the issue and that level of detail can only be established by talking directly with people in a way that is unencumbered by the expectations of the researcher (Creswell, 2007, Denzin & Lincoln, 2005). To join with the mental health professionals who are already providing many mental health services to people who are dying (APA, 2006), psychologists need to understand professional experiences of people already doing that work (e.g., Carbine, 2008; Kersting, 2004; Lair, 1996). We conduct qualitative research because quantitative measures and statistical analyses do not fit the research question (Creswell, 2007). As above, the research questions for the present study are:

1. What is the lived experience of mental health professionals as they provide mental health services to people who are dying?

2. What situations and contexts influence the lived experience of providing mental health services to people who are dying?
3. What, based on the accounts of the experience, is a way to describe the overall, unifying experience of providing mental health service to persons who are dying?

For these research questions, there are no available quantitative methods or published research that can answer in a complex, detailed way what it is like to provide mental health services to people who are dying (Vachon, 1988). Thus far, this discussion has provided a foundation of information regarding the characteristics of qualitative research and why a qualitative methodology was used in this study. A similar review and rationale follow, focusing on phenomenology.

Phenomenological Research

Creswell (2007) stated that “phenomenological study describes the meaning for several individuals of the lived experiences of a concept or phenomenon” (p. 57). Phenomenology differs from other qualitative methods because it uses several individuals, compared to using the report of a single individual as in narrative study, because phenomenological research focuses on description rather than developing a theory as in grounded theory, because phenomenological research describes an experience rather than a culture-sharing group as in ethnography, and because phenomenological seeks to describe the essence of an experience rather than describe and analyze it as in a case study (Creswell, 2007).

Phenomenological studies have the above unique characteristics and many of the characteristics common to all qualitative studies. Lester (2009) stated that phenomenological studies “are powerful for understanding subjective experience, gaining insights into people’s motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom” (<http://www.sld.demon.co.uk/resmethy.pdf>). Although Lester’s quote is a concise summary of this type of research, more information is provided below on the general approach, purpose, and steps of

phenomenological research. In Chapter III, the specific methodology used in this study is described.

Phenomenological research has commonality with other qualitative approaches including ethnography, hermeneutics and symbolic interactionism (Lester, 2009). Pure phenomenological research seeks, essentially, to describe rather than explain. Interview procedures are often part of qualitative inquiry and have been useful in equipping researchers with the ability to develop first-person descriptions of diverse human experiences (Kvale, 1996; Polkinghorne, 1989; Thomas & Pollio, 2002). Interviews are the most common way to collect phenomenological data, although discussions and participant observation modalities (e.g., focus meetings, action research) can also be used in isolation or in combination with interviewing (Lester, 2009). The phenomenological interview is one in which a participant is given the ability to describe his or her experience with as little influence from the interviewer as possible (Kvale, 1996; Lester, 2009; Polkinghorne, 1989; Thomas & Pollio, 2002). Phenomenological interviewing seeks to explore the core of an experience and seeks to comprehend specific meanings uniquely characterizing that experience (Polkinghorne, 1989; Thomas & Pollio, 2002).

Research conducted from a phenomenological perspective attempts to understand the nature of events and interactions as they are understood by the ordinary people who experienced the particular situation under study (Douglas, 1976; Moustakas, 1994; Thomas & Pollio, 2002). Phenomenological research, in fact, emphasizes the subjective aspects of people's actions and interpretations and seeks to capture the experience of study participants in their own words. Phenomenological approaches are based in a paradigm of personal knowledge and subjectivity which emphasizes the importance of personal perspective and interpretation (Lester, 2009). This approach attempts to gain entry into the conceptual worlds of the participants in order to understand how and what they experience in their lives (Geertz, 1973). The purpose of the phenomenological

approach is to illuminate specific details of experience, and to identify phenomena as they are perceived by the people who participate in a situation (Lester, 2009).

Phenomenological researchers do not assume they know what things mean to the people who they are studying (Douglas, 1976; Moustakas, 1994; Thomas & Pollio, 2002). Phenomenological researchers attempt to “bracket out”, or disallow the influence of, their personal perspectives and preconceptions. Phenomenology is concerned with the study of experience from the perspective of the participant which requires the researcher to remove assumptions and usual ways of perceiving things from the interviews and from the data analysis (Lester, 2009). To the extent that he or she is able, the researcher objectively analyzes the interview data to identify themes. Themes are derived from the interview data using either the language of the interviewee and/or the language of the profession for which the study is being conducted (Kvale, 1996; Polkinghorne, 1989; Thomas & Pollio, 2002).

With that understanding of what phenomenological inquiry is, it is now prudent to explore what questions and issues are appropriate for this type of inquiry.

Phenomenological approaches are effective at describing profound and mysterious aspects of human experience and allowing individuals to explain those experiences in their own voice. Phenomenological studies effectively describe the experiences and perceptions of individuals from their own perspectives. Phenomenological data cut through assumptions, prompting action or challenging complacency and are particularly useful in challenging structural or normative assumptions. Phenomenological data can also inform, support or challenge policy and action (Creswell, 2007; Lester, 2009; Moustakas, 1984).

In addition to being a good fit for qualitative research in general, this study was best suited to phenomenological methodology. In order to help psychologists understand what it is like to provide mental health services to the dying, they will need to understand the perspectives of the multiple different professionals who provide service currently.

Creswell (2007) states that “phenomenological study describes the meaning for several individuals of the lived experiences of a concept or phenomenon” (p. 57).

Phenomenology was the best qualitative approach for this study. Phenomenology uses several individuals’ perspectives, focuses on description, and yields a rich understanding of the essence of the experience. Phenomenological approaches are appropriate for describing profound and mysterious aspects of human experience (Creswell, 2007; Lester, 2009), which providing mental health services to persons close to death clearly is, and allowing individuals to explain those experiences in their own voice (Creswell, 2007; Denzin & Lincoln, 2005; Hycner, 1985), a format psychologists will need to provide more and better quality services to the population.

There are two main types of phenomenological research (Creswell, 2007), hermeneutic (e.g., van Manen, 1990) and transcendental or psychological phenomenology (e.g., Colaizzi, 1978; Giorgi, 1985; Giorgi, 1994; Moustakas, 1994; Van Kaam, 1966). Both are described below.

Hermeneutic Phenomenology

One researcher, van Manen, is widely cited in health literature (Morse & Field, 1995) and van Manen (1990) describes his phenomenological approach as oriented toward lived experience and interpreting the “texts of life” (p. 4). He does not provide rules to follow or methods in which to engage, but describes his process of data analysis as a dynamic, unordered interplay of six research activities (van Manen, 1990). He describes a researcher “turning to” a phenomenon with an “abiding concern” (p. 31). The phenomenon could be driving, mothering, reading, or another topic in which the researcher is seriously interested. The researcher reflects on the essential themes of what constitutes the nature of this lived experience, his or her own experience and the experiences of participants in the research. The researcher following van Manen’s process writes a description of the phenomenon, maintaining a strong interest in and connection to the topic of inquiry. The description focuses on the parts of the experience

and the whole essence of the experience, each balanced with the other. The researcher is the ultimate interpreter of the experience, serving as a mediator between the different meanings.

Transcendental or Psychological Phenomenology

Transcendental or psychological phenomenology (e.g., Colaizzi, 1978; Giorgi, 1975; Moustakas, 1994; Van Kaam, 1966) is focused less on the interpretations of the researcher and more on a description of the experiences of participants. Setting aside the experience of the researcher, as much as possible, is part of this research method. Husserl (1970) initially discussed the idea of epoche or bracketing in which investigators aim to take a fresh perspective on the phenomenon in question and sublimate their preconceived notions of what it is like to have the experience personally (Creswell, 2007; Moustakas, 1994). The term transcendental means “in which everything is perceived freshly, as if for the first time” (Moustakas, 1994, p. 34). Another major difference from hermeneutic phenomenology is that there are more formal, procedural steps for the analysis process. In general, the steps for a transcendental or psychological phenomenological researcher are to identify a phenomenon of interest, bracket out their own experiences, collect data from a number of individuals who have experienced the phenomenon, ask the participants about that experience in an open way, and analyze the resulting data to identify significant statements, put those significant statements into themes, and understand the importance of the participants’ context in regard to the themes (Creswell, 2007; Dukes, 1984; Giorgi, 1975, 1994; Hycner, 1985; Polkinghorne, 1989; Tesch, 1990).

The transcendental or psychological phenomenology method by Moustakas (1994) is the specific qualitative phenomenological method used in this study. Hermeneutic phenomenology (van Manen, 1990) was not appropriate for this researcher since it requires the researcher to also explore his or her lived experience of the phenomenon. Since this researcher has not provided mental health services to a person in

the dying process, this methodology could not be utilized. The transcendental or psychological phenomenological methods (e.g., Colaizzi, 1978; Giorgi, 1985; Giorgi, 1994; Moustakas, 1994; Van Kaam, 1966) were more appropriate for this research question and this researcher since they do not require the researcher's experience of the phenomenon for analysis and because there are more formal, procedural steps for the analysis process (Creswell, 2007; Hycner, 1985). Creswell (2007) specifically recommends the Moustakas (1994) methodology for researchers who have not independently completed the phenomenological research process before since it is well-suited to helping researchers maintain the spirit of transcendental or psychological phenomenological inquiry while also providing structure which assists with the method being carried out correctly.

In summary, this research study was best suited to qualitative phenomenological methodology given the research problem, research questions, availability of information on the problem, and nature of the information required. This methodology does, however, bring with it characteristics which differ from other qualitative methodologies.

Implications of Methodology

The use of Moustakas' (1994) methodology introduced additional unique features when compared to other qualitative methodologies, including that the methodology drove the formulation of the research questions and that the methodology precluded the incorporation of a theoretical frameworks.. Each of these implications of the methodology is discussed below.

This study's research questions were driven by the methodology. Moustakas' (1994) approach to phenomenological inquiry prescribes research questions which, although somewhat formulaic, assist researchers in reducing the impact of preconceptions and biases from the outset of the study (Creswell, 2007; Moustakas, 1994). The research questions in the current study, listed below at the end of Chapter II, are transparently based on the methodology and the focus of the study. This study's research questions,

therefore, are about the experience of professionals who provide mental health services to the dying, what situations and contexts influence their experience, and how the participant's individual experiences can be described in an single, integrated description.

Although theoretical frameworks are common in many qualitative methodologies, guiding research with a theoretical framework is not consistent with the phenomenological approach (Morse, 1994). The phenomenological approach seeks to remove all preconceived understandings from data analysis which renders a theoretical framework inappropriate (Creswell, 2007; Moustakas, 1994). However, seeking to remove all researcher understandings of data is impossible and phenomenological research has inherent assumptions about what should be measured and how knowledge is elicited from data (Denzin & Lincoln; Moustakas, 1994). The constructivist paradigm is the underlying, inherent theoretical framework of phenomenological research. The constructivist framework posits that individuals construct reality in interaction with their social worlds and that, in research, meaning is not discovered but constructed (Guba & Lincoln, 2004). Constructivism, in the current study, describes the inherent assumption that participants' understandings of their experience of providing mental health services to persons who are dying is constructed as they *do* it and further constructed as they discuss it with others, including the author of this study. The underlying framework for this study is that through interviews and interactive dialectical exchanges, a description of this phenomenon is constructed that is "more informed and sophisticated than any of the predecessor constructions" (Guba & Lincoln, 2004; p. 27).

Thus far, this section has described the methodology used in this study and the rationale for and implications of its use. With that established, examples from existing research that further establish that qualitative phenomenological studies can assist professionals in providing services to persons who are dying are reviewed next.

Phenomenological Studies Which Have Facilitated Better Service Provision to Persons who are Dying

Qualitative, phenomenological research has been used in death and dying research previously with valuable results. For example, Anderson and Spencer (2002) conducted and published a study on how 58 patients with Auto-Immune Deficiency Syndrome (AIDS) understood their own medication adherence and other health behaviors. The study provided in-depth descriptions of individual experiences and found over-arching, cohesive themes in the patients' reports of imagining AIDS as death, bodily destruction, and just a disease. Coping focused on wiping AIDS out of the mind, hoping for the right drug, and caring for oneself. The discussion and recommendations from this study offered valuable suggestions for professionals (nurses, in this case) for assessing patients' coping processes, enhancing their professional relationships with patients who are dying, and facilitating medication adherence and healthier behaviors.

A small number of qualitative studies have been conducted using interview data from health professionals who provide services to persons who are dying. One study which informs the current study was carried out by Ungureanu and Sandberg (2008). These scientists interviewed seven therapists who work with dying children and their families. The study identified details about this work, including that therapists often experience shifts in priorities, relationships, and beliefs about life and death, and that their professional work can elicit professional growth. The study also found that this group of professionals experience significant costs such as emotional exhaustion, and hyper-vigilance about death. The present study adds to this body of knowledge, offering details about the experiences of a wider variety of mental health professionals who provide mental health services to the dying.

Summary

This chapter reviewed literature pertinent to this study in order to summarize what is already established in professional literature about providing mental health services to

persons who are dying and to provide a background for the current qualitative, phenomenological study. The literature described that mental health services are provided to persons who are dying in a number of settings. In general, mental health services are most likely to be provided in hospices and hospital-based palliative care units, although services are also provided in hospital-based clinics, community clinics, and in clients' homes. There are a number of mental health interventions in the literature that are specifically designed for use with persons who are dying. In order of increasing applicability and appropriateness for the majority of persons who are facing death, those interventions are from psychodynamic, existential, spiritual, religious, and cognitive behavioral theoretical perspectives. In general, traditional talk-based therapies from psychodynamic, existential, and cognitive orientations are most helpful in the earlier stages of the dying process and behavioral interventions for pain management, spiritual and/or religious comfort, and interventions based less on traditional talk therapy are generally most appropriate as death is increasingly imminent. All of the interventions reviewed, regardless of theoretical basis, emphasized flexibility in therapeutic approach and session content to meet the clients' physical, emotional, and religious needs.

The present study adds to this body of knowledge, and does so utilizing a qualitative phenomenological methodology. The review revealed that qualitative study was best suited to this inquiry since the subject and problem under study is not yet well understood and the information required has a complex level of detail which can only be established by talking directly with people in a way that is unencumbered by the expectations of the researcher (Creswell, 2007, Denzin & Lincoln, 2005). In addition to appropriately being a qualitative study, this study was correctly conducted as a phenomenological study. The phenomenological approach was ideal to describe the profound human experience (Creswell, 2007; Lester, 2009) of providing mental health service to persons close to death and to allow those professionals to explain those experiences in their own voice (Creswell, 2007; Denzin & Lincoln, 2005; Hycner, 1985).

The theoretical framework of this study was described. Additionally, examples from existing research that further establish that qualitative phenomenological studies can assist professionals in providing services to persons who are dying were reviewed.

Therefore, the problem under study here was that psychologists are and will be increasingly called upon to provide mental health services to persons who are dying, this population has specialized needs that psychologists must learn to address appropriately, and that psychologists need all the information available from persons currently doing this therapeutic work in order to join professions actively doing end-of-life mental health care. The purpose of this study, then, was to explore and document the lived experience of a number of mental health professionals who provide mental health services to persons who are dying to more fully establish the characteristics and nuances of what it is like to do this work. To this end, the specific research questions addressed in this study were:

1. What is the lived experience of mental health professionals as they provide mental health services to people who are dying?
2. What situations and contexts influence the lived experience of providing mental health services to people who are dying?
3. What, based on the accounts of the experience, is a way to describe the overall, unifying experience of providing mental health service to persons who are dying?

CHAPTER III: RESEARCH DESIGN AND METHODOLOGY

In this chapter, the details of the current study are illustrated, including procedures for recruitment, characteristics of the participants, and the specific data analysis methodology. An Institutional Review Board approved methods of participant recruitment, the interview protocol, methods of analysis, and methods of data handling used in this study.

Participants

The initial section of this chapter describes the participants in the study, how they were invited to participate in the research, how they were selected, and their characteristics as a group of professionals. The second section of this chapter describes how interview data were gathered and analyzed.

Recruitment

Since therapeutic intervention as part of the dying process is such a specialized area of service, the professionals who provide these services are clearly identified in a local website: "Guide to Resources in the Last Months of Life" [<http://www.ohsu.edu/ethics/counties.shtml#multnomah>]. Participants were recruited using phone calls to 1) professionals listed on this website and 2) professionals referred by other participants. Thirty-five people were contacted by phone and invited to participate. Nine people (25.71% of those invited) were left voicemail messages explaining the study and did not call the researcher back. Four individuals (11.43% of those invited) called the researcher back and declined to participate, all four citing lack of time as the reason for not participating. Twenty-two individuals (62.86% of those invited) were willing to participate. Ten individuals (47.62% of those invited; 45.45% of those willing to participate) were ultimately selected for inclusion in the study. The decision-making process of the researcher regarding individuals' inclusion in the study is described below in the Sampling section.

All 35 potential participants were contacted by telephone and told about the study. Of those interested in hearing more (22 individuals), potential participants were then asked about inclusion criteria, and any additional questions about the study were answered. Potential participants typically had questions. The most common questions from potential participants were about how the researcher found the professionals' contact information and about why the researcher was conducting research in a geographic area so far from her graduate institution. Potential participants also asked why the researcher was interested in this topic, how long the interview would take, and what might be involved in the interview.

Inclusion Criteria

All 22 individuals interested in participating in the study were asked about inclusion criteria and the researcher made notes regarding potential participants' personal and professional characteristics. Inclusion criteria for this study were:

- 1) Licensed mental health providers
- 2) Have provided therapeutic services to at least ten persons who are dying in the course of their professional work
- 3) Can speak English
- 4) Willing to participate in an in-person or over-the-phone interview that is audio recorded
- 5) Live within 1.5 hours drive from researcher's home.

In the course of assessing potential participants' match with inclusion criteria, additional information was offered. Individuals, without fail, offered information about the settings in which they work, aspects of their professional responsibilities, estimates of how many dying persons they have worked with, and details about their credentialing. The inclusion criteria coupled with additional information that they elicited assisted the author to select an appropriate group of participants for the study.

Selection of Participants

Purposeful selection of participants was used in this study. It is the most commonly used selection technique in qualitative research (Marshall, 1996) and involved the researcher actively selecting the most appropriate participants to answer the research question(s).

It is a logical strategy based on the subject matter, available participants, and addresses the emerging needs of the data pool more effectively than the simple demographic stratification (Coyne, 1997; Marshall, 1996). In this study, participants were chosen to maximize variability in gender and profession. Of the persons willing to participate in the study, participants were selected to maximize a broad range of disciplines (maximum variation sampling), and experience and/or credentialing (key informant sampling). And, since there were more women interested in participating, if two potential participants, one male and one female, had similar experience and credentialing, the male was selected for inclusion in the study. Twelve individuals (34.28% of those invited; 54.54% of those willing to participate) who were willing to participate in the study were ultimately not scheduled for interviews since their demographics, discipline, experience, and/or credentialing were less suited to the emerging data set than other individuals who were willing to participate.

Participants were sometimes able to recommend potential candidates for participation (snowball sampling) (Marshall, 1996). Three (8.57% of those invited; 30% of those included) of the ten participants who were included in data collection were recruited as a result of a recommendation by another participant.

Participants who assented to participation and who were selected by the researcher for inclusion in the study scheduled an in-person interview at a time and place of his or her choosing. Although telephone interviews were offered as an option, all participants elected in-person meetings.

Participants' Characteristics

Participants in this study were 10 mental health professionals, three men and seven women. Participants were trained in various fields and included three from pastoral counseling, two from nursing, one from counseling, one from psychiatry, one from psychology, and one from thanatology. The participants' fields of expertise and the settings in which they gained it are summarized in the table which follows the explanation of the quantity of participants selected for this study. Participants had between five and 43 years of experience providing mental health services to persons who are dying (mean=20.3, mode=5; standard deviation=11.87). They, as a group, had seen between 200 and 3,328 patients/clients in the dying process (mean=1464.3, mode=3000; standard deviation=1196.04). Eight participants were of Americans of European ancestry and two were Americans of African ancestry, one of which was born in the United States. The participants in this study were all licensed professionals with at least two years of graduate education in their field. Six participants were educated at the master's level and four at the doctoral level.

Quantity of Participants

This study had 10 participants. The quantity of participants for this study was determined in two ways, each of which will be explained in turn. First, the researcher judged the 10 selected persons to appropriately reflect the proportions and variety of professionals who provide mental health services to persons who are dying. As was discussed in Chapters I and II, most services to this population are provided by hospital and hospice personnel, so the participants were primarily of persons who practiced in these settings. Similarly, the participants represent the variety of professions involved in service provision to people who are dying. Readers may note that a social worker is not included in the study. The author invited seven social workers to participate; six did not return the researcher's voicemail and one declined to participate, citing his busy schedule as the reason. Unfortunately, the study does not include a social worker. It does,

however, otherwise reflect the proportions and variety of professionals who provide mental health services to persons who are dying.

The second way that the quantity of participants was determined was mandated by the qualitative methodology. The methodological approach of this study required that data be gathered from participants and analyzed after each collection in order to compare data and search for themes as they emerged. After analyzing the initial eight interviews, no new themes emerged from interview data. The process of assuring that new themes are not emerging is called saturation. In this study, after the eighth interview was analyzed, new ideas were no longer being introduced into the emerging data pool. Data were accumulating predictably around themes, which will be presented next in Chapter IV. To ensure saturation (and to maximize variability, as explained above), two additional interviews were conducted for a total of 10 participants (Guest, Bunce, & Johnson, 2006; Creswell, 2007).

Ten participants in a study is appropriate, given available literature and phenomenological theory. For example, Lester (2009) states that phenomenological studies can legitimately be done with one subject and often use 10 or fewer participants. Polkinghorne (1989) recommends using between five and 25 participants. Published articles using this design and methodology have had seven participants (Mc Gonagle, Halloran, & O' Reilly, 2004), 10 (Copen, 1993), and 58 (Anderson & Spencer, 2002).

Table 1, below, summarizes the characteristics of the participants, including their professions, years of practice, number of individuals who are dying they have provided services to, and the settings in which they have practiced. The numbers in the table do *not* reflect the order in which the participants interviewed; the table is numbered for readability rather than to reflect the order of participation and analysis.

Thus far, Chapter III has provided a discussion of the recruitment and sampling techniques used and the characteristics of the 10 participants. The final section of this chapter will describe in detail how interview data were gathered and analyzed.

Table 1 Characteristics of the Participants

<u>Participant</u>	1	2	3	4	5	6	7	8	9	10
Field	Pastoral	Pastoral	Pastoral	Pastoral	Nursing	Nursing	Thanatology	Medicine	Counseling	Psychology
Years of Experience	20	5	28	24	37	43	10	5	32	11
Number of Clients	400	300	215	1900	3000	950	1350	3000	3328	200
Gender	M	F	M	M	F	F	F	F	F	F
Hospice	X			X	X	X	X	X		
Hospital Palliative Care	X		X	X	X	X	X	X		X
Other Hospital Setting		X		X	X	X			X	X
Community Clinic				X					X	
Client Homes	X		X		X	X	X	X		X

Research Methodology

Moustakas' (1994) phenomenological data analysis procedures were used.

Transcribed interview data were analyzed by extracting significant statements from interviews that provided an understanding of how the participants experienced the

process of providing mental health services to persons who are dying. A detailed description of that process follows.

Interview Protocol

Interviews took place in participants' professional offices in nine cases and in one participant's home. Interviews lasted between 23 and 95 minutes (mean=50.3, mode=34, standard deviation=22.21). Lester (2009) states that single interviews with research participants lasting under one hour are very common in phenomenological research. He adds that this is not ideal, but time constraints for participants in research is part of what must be considered; quality inquiry cannot be done if participants feel pressured to give more time or information than they are able.

At the outset of the interview, participants were read a consent script. Appendix A is a copy of this consent script. With each participant's consent to participate and audio record, interviews began. Every participant was asked to respond to three interview prompts, in accordance with Moustakas (1994). Moustakas (1994) prescribes that three general questions be asked of each participant to capture each person's lived experience of the phenomenon (Creswell, 2007). These questions were based on Moustakas' (1994) general format (Moustakas, 1994, p. 114; Creswell, 2007, p. 61) and are as follows:

- 1) What have you experienced as you have provided mental health services to persons who are dying?
- 2) What contexts or situations have typically influenced or affected your experiences of doing this type of work?
- 3) What else would you like me to know about what it is like to work with persons who are dying?

Some participants were also asked questions to clarify their responses. Clarifying questions were used by the researcher when she was unsure of what the participant was trying to communicate. As part of the researcher's constant effort to not assume

understanding of this phenomenon for each participant, participants were asked to clearly state, restate, or explain aspects of their experience. Examples of typical follow-up questions are:

- 1) You mentioned that the context of working in a Catholic agency has influenced your experience of providing therapy to persons who are dying. Can you tell me how that context influences your experience?
- 2) You said earlier that part of your experience was being aware of your personal emotions and stress level. I'd like to hear more about that part of your experience and how it impacts you.
- 3) I didn't understand when you said _____. Would you please clarify that concept for me?
- 4) I was listening carefully to your response to the ___ question earlier. I want to make sure that I understand you. From what I was hearing, the main aspects of your experience are _____, _____, and _____. Is that accurate or have I misunderstood you?

At the close of the interview, all participants were asked if they were willing to be contacted again if additional clarification was needed during analysis of the interview data. Two participants were contacted by phone (which was the stated preference of both) following in-person interviews for clarification of their responses. Clarified responses were audio recorded with consent of the participants and added to the participants' transcribed interview data.

Transcription

All interviews were transcribed by the researcher using Gee's (1999) transcription key. This key is included as Appendix B. The recordings of the interviews were transcribed to include the literal statements of the participants and, as much as possible, significant non-verbal and paralinguistic communications. Each transcription, when complete, was checked for accuracy against the original recording. The check for

accuracy was performed by the researcher by listening to the interview in its entirety and comparing it to the transcription. Any omissions or errors in the interview data were corrected.

Analysis

The analysis process in general and the specific way it was used in this study are described below. First, a brief summary of Moustakas (1994) methodology is presented. Then, the specific steps of the analysis as they were applied to this study are described. According to Moustakas (1994), the general steps of analysis are as follows:

- 1) Using a phenomenological approach, obtain a full description of your own experience of the phenomenon.
- 2) From the verbatim transcript, complete the following steps:
 - a. Consider each statement with respect to significance for description of the experience
 - b. Record all relevant statements.
 - c. List each non-repetitive, non-overlapping statement.
 - d. Relate and cluster the invariant meaning units into themes.
 - e. Synthesize the invariant meaning units and themes into a description of the textures of the experience. Include verbatim examples.
 - f. Reflect on your own textural description. Through imaginative variation, construct a description of the structures of your experience.
 - g. Construct a textural-structural description of the meanings and essences of your experience.
- 3) From the verbatim transcripts of each of the other co-researchers, complete the above steps, a through g.
- 4) From the individual textural-structural descriptions of all co-researchers, construct a composite description of the meanings and essences of the experience, integrating all the individual textural-structural descriptions into a universal description of the experience representing the group as a whole (Moustakas, 1994, p. 122).

Given this overview of the steps in Moustakas' (1994) phenomenological analysis, each will now be explained in detail in the way it was utilized in the current study.

Epoche or Bracketing

In this study, bracketing of personal experience integrated as a formal, initial step in the analysis process was not used, but the spirit of bracketing out personal biases,

perceptions, and preconceptions was included throughout the study. Bracketing was not used as a formal step to begin the analysis since the primary investigator has never provided mental health services to a person who is dying. Of course, every effort was made during interviews, transcription, analysis, and reporting to gain entry into the conceptual worlds of the participants in order to understand how they experience providing service to people in the dying process and to hear what participants had to say and objectively approach the data (Geertz, 1973). The purpose of the phenomenological approach is to illuminate specific details of experience, and to disallow the influence of the researcher's personal perspectives and preconceptions (Douglas, 1976; Lester, 2009; Moustakas, 1994; Thomas & Pollio, 2002) and the researcher was true to this purpose.

For example, the author's personal reactions, as often as they were identified, were written down in notes taken during the interviews (field notes), as soon as possible after the interview (process notes), while transcribing (process notes), and while analyzing (in margins of analysis, coded as "bracketing"). Examples of notes are, "Felt lectured to; remember subjectivity", "I don't know what this means. Call Participant #__", "Connects to your personal memory of your uncle. Listen to HER, not you."

Attending to the Interview

Each interview was listened to numerous times, at least four, during both transcription as well as the process of attending to the content and nuances of the participants' data. The researcher listened to each interview once during recording, once during transcription, and once to check for accuracy of the transcription. Before beginning analysis, the researcher listened to the interview in its entirety one more time while reading the transcription. During this review of the interview, the recordings were often stopped for the interviewer to review field notes, process notes, and to record personal reactions and biases that needed to be bracketed. As is recommended for phenomenological analysis (Creswell, 2007; Hycner, 1985; Moustakas, 1994), the author attended to both the meaning of the whole interview and to the specific details of the

interview. Attention to the whole interview helped the researcher maintain attention to the participant's meaning and the entire context of what he or she was communicating (Giorgi, 1975). Attending to the details of the interview, such as pitch, intonation, pauses, and emphases, helped the researcher become attuned to the nuances of what the participant was communicating. Constant listening, reading, noting, and bracketing personal reactions occurred during this process.

Significant Statements

The transcription of each participant's interview was analyzed and significant statements were coded. Statements were coded as significant if they contained content directly related to the methodology and the research questions (Creswell, 2007; Moustakas, 1994). Hycner (1985) explains this process by stating, "The researcher addresses the research question to the units of general meaning to determine whether what the participant has said responds to and illuminates the research question. If it appears to do so, then it is noted as a unit of relevant meaning...." (p. 284). In this study, units of general meaning were determined irrelevant if they did *not* relate to what it is like to provide mental health services to people who are dying. Irrelevant statements were not used in subsequent steps of the analysis. This study's methodology determines that significant statements are secondarily coded as either textural (related to the lived experience) or structural (related to the context or setting which may have influenced the experience (Creswell, 2007; Moustakas, 1994). The research questions, as above, were:

1. What is the lived experience of mental health professionals as they provide mental health services to people who are dying?
2. What situations and contexts influence the lived experience of providing mental health services to people who are dying?
3. What, based on the accounts of the experience, is a way to describe the overall, unifying experience of providing mental health service to persons who are dying?

Significant statements, then, are those that relate to a professional's experiences, and/or contexts of participating in the phenomenon of providing mental health services to persons who are dying. Creswell (2007) adds that significant statements should be "sentences or quotes that provide an understanding of how the participant experienced the phenomenon" (p.61). Each of the relevant terms, experience and context, is operationalized below.

Significant Statements that are Also Textural

Textural statements relate to the experience, what it is like to experience a phenomenon. "Experience," according to the Merriam-Webster Dictionary (2009), is "something personally encountered, undergone, or lived through." Significant statements regarding "experience", in this study, were coded as such if they contained a personal pronoun and a verb, contained an adjective(s), and/or they contained a combination of these. Data containing a phrase like "it is" or "every time" were also coded as "experience" data since these phrases refer to what *it*, the experience, is or refer to something that is consistently experienced while providing service to persons who are dying. Examples of "experience" data are, "I am drained after seeing one patient" and "Working with people who are dying, it does make me wonder how I am going to die and what are my fears around death and dying." These statements from interviews document the experiences of being drained and wondering about personal mortality, respectively. Significant statements that capture "experience" form the foundation for Moustakas' (1994) textural description later in the analysis process.

Significant Statements that are Also Structural

Structural statements relate to contexts and influencing situations which relate to the experience. "Context," according to the Merriam-Webster Dictionary (2009), is "the interrelated conditions in which something exists or occurs." Creswell (2007) adds that in phenomenological research, contexts are usually "settings" or physical or emotional "situations" (p.61). In this study, examples of data coded as "context" include "We're

just one little piece of the puzzle, of the interdisciplinary team that is taking care of this patient” and “And it was very awkward. The children were uncomfortable with the new wife being there. There was this odd, tense dynamic with all of them there.” This interview data captures the contexts of interdisciplinary teams and strained familial relationships. Significant statements related to “context” form the foundation for the *structural description* in this design (Moustakas, 1994).

Example of Coding

Procedurally, transcribed data were coded using the “Comment” feature of Microsoft Vista’s Word program. Each code was introduced into the transcribed interview using a comment; transcribed data became a column on the left and analytical codes became a column on the right. Each significant statement, its additional coding of textural and/or structural, and a synopsis of the meaning unit were entered into “comments” in the right-hand column. An example of coded interview data follows. In this case, the transcribed text is both textural, having to do with the experience of providing service to a person who is dying, and structural, having to do with the situation and context that influence providing service (Creswell, 2007; Hycner, 1985; Moustakas, 1994).

Invariant Meaning Units

After each transcribed interview was coded for “experience” (textural) and “context” (structural) significant statements, each was reviewed to identify repetitive and overlapping statements. Non-repetitive and non-overlapping statements become invariant meaning units, those interview components that describe most clearly aspects of “experience” and “context.” For example, the following data are from a single interview:

I try to form a personal connection, something that reminds me of people in my life. And, this is why. Because I feel like if I can make that internal connection with someone who is really close to me, I can more easily get into their lives and help extract things from them that will help improve the care that they get in the end.

Figure 1 Example of Coded Interview Data

<u>Transcribed Text</u>	<u>Coding</u>		
<p>I have had one situation where I was called out by hospice for a 80 or 90 year man who was actively dying. His grown children were there with him, but also this man's new wife of two weeks was there. Can you imagine getting married and two weeks later, your husband is dying? And, it was very awkward. The children were uncomfortable with the new wife being there. There was this odd, tense, dynamic with all of them there. And, they were all there with a common purpose.</p>	<table border="1"> <tr> <td data-bbox="922 464 1344 657"> Bracketing Stay with PARTICIPANT'S understanding and experience. </td> </tr> <tr> <td data-bbox="922 667 1344 968"> Significant Statement Textural Emotion of feeling awkward Structural Context of others being present, changing dynamic </td> </tr> </table>	Bracketing Stay with PARTICIPANT'S understanding and experience.	Significant Statement Textural Emotion of feeling awkward Structural Context of others being present, changing dynamic
Bracketing Stay with PARTICIPANT'S understanding and experience.			
Significant Statement Textural Emotion of feeling awkward Structural Context of others being present, changing dynamic			

“I make it personal only for me. I don't share that with the patient. I don't say, you remind me of blah, blah, blah. I make it personal for me, only for me.”

“Ummm, so, it can't happen 100 percent of the time. But, I still try to make it personal, envision some sort of emotional connection to something. Find a connection as soon as you walk in.”

These three statements occur at different points in the interview, but are overlapping and repetitive. The first statement contains all the details of the second and third. Although one, two, and three were initially coded as textural (experience) the first

statement became the invariant meaning unit. These invariant meaning units are the intermediary step between significant statements and textural and structural descriptions.

The following table, Table 2, summarizes the types of coding used in this study, what they mean in Moustakas' (1994) methodology, and how this researcher applied them to interview data.

Themes

The process of identifying invariant meaning units was used to identify themes in the experiences of professionals providing services to persons who are dying. As an example, identifying the above invariant meaning unit was a parallel process to identifying the themes in the interview data of this participant's personal connection to his/her patients. At this point in the analysis process, verbatim transcripts have been coded for significant statements that are either textural (experience) or structural (context). Themes in each participant's interviews are identified as the significant statements are organized to identify invariant meaning units. These themes and meaning units then become textural and structural descriptions.

Textural and Structural Descriptions

Each participant's data was then organized into a textural description and a structural description. Textural descriptions illustrate *what* was experienced and structural descriptions exemplify what *influenced* the experience (Creswell, 2007; Moustakas, 1994). The textural description of each interview includes the invariant meaning units, themes, and verbatim examples from all the data that were originally coded textural (experience). Similarly, the structural description includes the invariant meaning units, themes, and verbatim examples from all the data that was originally coded structural (context). As an example, the above overlapping and repetitive interview data from one participant about making personal connections to his/her patients became part of the textural description of that participant's experience. A portion of this interviewee's textural description reads,

Table 2 Types of Coding and Their Application

Type of Coding	Definition	How Researcher Identified It	Coding Example
Epoche/Bracketing	researcher's personal perspectives and preconceptions	Attending to personal cognitions, memories, affect	Felt lectured to; remember subjectivity
Significant Statement* <small>*Each of these is eventually also coded as "textural" or "structural." Each could be coded as both and might also be coded as "invariant meaning unit"</small>	Relates to participants experiences, and/or contexts of participating in the phenomenon of providing mental health services to persons who are dying	Compared all units of meaning to research questions; labeled relevant interview data as "Significant Statement" and no longer considered the irrelevant statements	Significant Statement Learning from each dying client how to live
Textural	"Experience" data; phrases refer to what it, the experience is, or to something that is consistently experienced in providing service to persons who are dying	Transcribed data contained 1) a personal pronoun and a verb, 2) adjective(s), 3) a combination of 1) and 2), 4) phrases like "it is" or "every time"	Significant Statement Respect for human nature Textural
Structural	"Context" data; the interrelated conditions in which something exists or occurs, usually "settings" or physical or emotional "situations"	Transcribed data contained a reference to a setting or situation that altered the participant's experience of the phenomenon	Significant Statement Personal life experiences Structural
Invariant meaning units	Non-repetitive and non-overlapping significant statements; data which most clearly describe aspects of "experience" and "context"	Reviewed all Significant Statements with similar themes; assessed them for clarity and inclusiveness; identified most clear and inclusive as the invariant meaning unit	Significant Statement Textural Theme of Personal Connection Meaning Unit

Participant experiences a Personal Connection with his/her patients. “I try to form a personal connection, something that reminds me of people in my life. And, this is why. Because I feel like if I can make that internal connection with someone who is really close to me, I can more easily get into their lives and help extract things from them that will help improve the care that they get in the end.” Although this personal connection improves service provision, it is not always easy: “Ummm, so, it can’t happen 100 percent of the time. But, I still, I try to make it personal, envision some sort of emotional connection to something.” Participant does not share this practice with the patient: “I make it personal only for me. I don’t share that with the patient.”

This participant had other themes and invariant meaning units: Teaching and learning, Willingness to be vulnerable, and Joy. Each of these was also described in the full textural description.

Composite Description

After each transcript was coded for significant statements that were either textural or structural, themes were identified concurrent with identifying invariant meaning units. These themes and meaning units were then organized into textural and structural descriptions, one textural-structural description for each interview. Textural-structural descriptions integrate the experiences and contexts of the participant as they provide mental health service to individuals who are dying. An example follows. In the textural-structural description, the participant is referred to as Underlined portions of the description are recurring themes in this participant’s description of what it is like for him/her to provide mental health services to people who are dying.

Participant experiences a profound respect for “folks who are facing the imminent end of life.” Participant experiences “my belief that each person has inside his or her self, the right way to die.” Participant believes that each person “will be able to find that place...and it is different for everyone.” Participant experiences learning from each client. “Everyone who comes through my door has something to teach me about their lives and therefore about my life” and clients teach Participant as much about dying as they do about living. “Well, there is no question it

keeps me keeping my priorities straight.” Participant experiences a need for authentic behavior with clients, to be “real.” “... People who are dealing with issues around the end of their lives are really not interested in being with someone who is not real. Because getting toward the end of your life has such intensity. You cut to the chase. Dying people aren’t interested in being around people who are not real and authentic.” Participant experiences a sense of personal mortality and hopes that s/he will have a chance to say goodbye to the people s/he loves and hopes to die with few interpersonal regrets. Participant experiences “a very clear sense of boundaries.” I’m fortunate. I’ve always seemed to be able to work with people with the sense that *they* will figure out what to do with their pain. “I witness pain, not fix it.” If Participant does not maintain boundaries and becomes “overwhelmed by their pain”, “they end up having to take care of me.” Participant’s experience is influenced by people and personal life experiences. Colleagues, supervisors, and writers like Viktor Frankl have influenced Participant and his/her work. Personal life experiences with death and in interpersonal relationships influence him/her. “I think we are the sum total of all of our experiences.”

Each participant’s coded interview eventually yielded a textural-structural description like the one above. Finally, the data from each interview about the experiences and contexts of providing mental health services to people who are dying was integrated into one description. This description captures the “essence of the phenomenon,” a cohesive description of what it is like for this group of participants to provide mental health to persons who are dying (Creswell, 2007; Moustakas, 1994, p. 121). The analysis process is summarized in Figure 2, which follows.

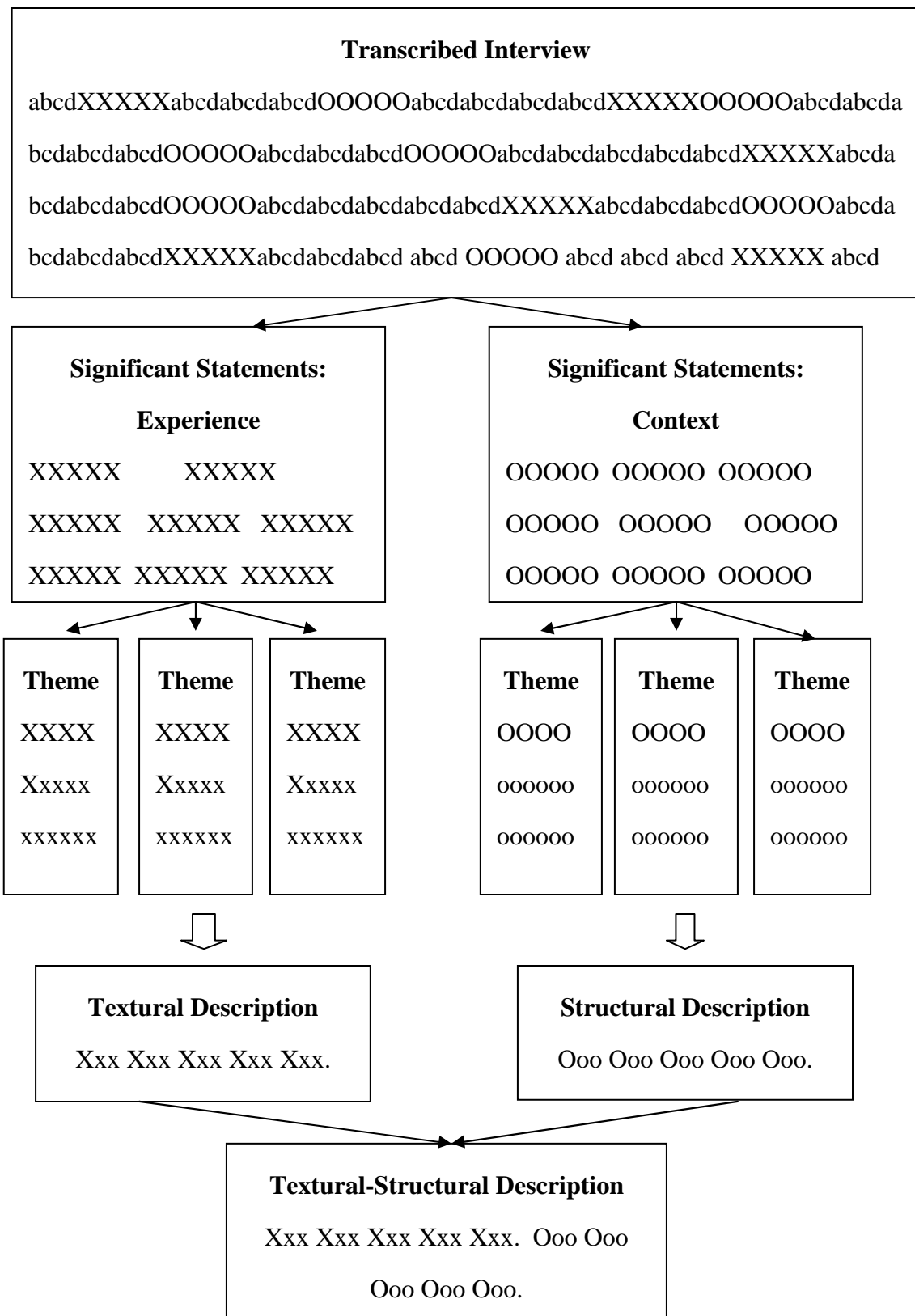
The data for each interview were analyzed in this manner. Finally, the textural-structural descriptions for all 10 participants were integrated into a composite description of the meanings and essences of the experience (Moustakas, 1994). The final description of the lived experience of these 10 participants as they provide mental health services to persons approaching death became an integrated, universal description of the experience representing the group as a whole. Details of the resulting composite description are provided in the Chapter IV: Results.

Robustness of the Analysis

Research team members reviewed two samples of data analysis (transcriptions, coding of meaning units, identification of themes, and textural and structural

descriptions), made suggestions for clarification in presentation of analyzed data, and endorsed this author's application of the methodology. Additionally, this author assured her own fidelity to the phenomenological method by: transcribing and analyzing interviews as soon as possible after interviews; using fieldnotes and process notes while analyzing; and reviewing the finished analysis at least once after it was initially completed. This was done in an attempt to assess any omissions, interference of personal opinion, typographical errors, errors in coding, and/or conceptual errors in theme- and meaning-making.

Figure 2 Phenomenological Research Analysis



CHAPTER IV: RESULTS

This chapter summarizes the results of the present study. First, information about the number and nature of themes identified in the interview data is provided. A description of how themes in the study were clustered and consolidated follows. Then, each textural and structural theme is described and explained using the perspectives and words of the participants. Finally, the composite description of the phenomenology of providing mental health services to persons who are dying is provided.

Themes

The textural-structural descriptions of the 10 interviews in this study yielded 49 textural “experience” themes and 25 structural “context” themes. The textural (experience) themes ranged from “either a very negative or a very blessed experience” to “listening” to “clients choosing when to die.” Examples of structural (context) themes are “patient’s family”, “hospital setting”, and “my emotionality.” All of these themes, and the interview content they represent, were then organized into larger thematic units. Those divisions are described next.

Themes Within Themes

To find the commonalities within the interview data, themes were identified among the participants’ interview themes. Six textural themes and five structural themes were identified within the 74 total themes in the participants’ textural-structural descriptions. The 11 group themes, six textural and five structural, were identified by identifying commonalities in participants’ themes. Those divisions, textural and then structural, are described next.

Textural Themes

Six textural (experience) themes were identified: 1) Emotional Experience, 2) Experiences of Effective Service Provision, 3) Experiencing the Otherworldly, 4) Experiencing Teaching and Learning, 5) Anecdotal, but Convincing Experiences, and 6) Experiencing Death and Death Awareness. The group themes are listed below

accompanied by the participant themes that contributed to the larger themes. In the next part of Chapter IV, the group themes will be explained fully using examples and quotes from participant interviews. These initial lists simply document how participant themes were merged into larger themes.

I. Emotional Experience

- i. The gamut of human emotion
- ii. Joy
- iii. Respect
- iv. Awe and honor
- v. Profound emotions
- vi. Love of the work
- vii. Strong emotions
- viii. Range of emotions
- ix. Self in every room
- x. Variety of emotions
- xi. Personal feelings
- xii. A whole range of emotions
- xiii. Compassion fatigue
- xiv. Either a very negative or a very blessed experience

II. Experiences of Effective Service Provision

- i. Being truly present
- ii. Personal connection
- iii. Willingness to be vulnerable
- iv. Need for authentic behavior
- v. A very clear sense of boundaries
- vi. Intuitive process
- vii. Powerful connection

- viii. Need to individualize treatment*
- ix. Need to individualize treatment*
- x. The ministry of presence
- xi. Listening
- xii. Listening to clients
- xiii. Individualized, holistic treatment

*This theme occurred in two interviews.

III. Experiencing the Otherworldly

- i. Spiritual awareness
- ii. Vessel experiences
- iii. Mobile confessional
- iv. Work as a calling
- v. On holy ground
- vi. Calling in the midst of crisis
- vii. Sacred
- viii. Feeling channeled

IV. Experiencing Teaching and Learning

- i. Teaching and learning
- ii. Learning from each client
- iii. Learns
- iv. Learns from his/her clients
- v. Learns from clients

V. Anecdotal, but Convincing Experiences

- i. Each person has inside his or her self, the right way to die
- ii. Clients know what they need from the clinician
- iii. People choose when to die
- iv. Clients choose when to die

- v. Clients die like they lived
- VI. Experiencing Death and Death Awareness
 - i. Awareness of his/her own mortality
 - ii. Sense of personal mortality
 - iii. Awareness of personal mortality
 - iv. Pondering death

Structural Themes

Five structural (context) themes were identified from the ten participant textural-structural descriptions. The themes are: 1) The Influence of People, 2) The Influence of Emotions, 3) The Influence of Work Setting, 4) The Influence of Personal and Professional Histories, and 5) The Influence of Client Characteristics. Each of these main themes includes participant themes and those divisions are explicated in the lists below.

- I. The Influence of People
 - i. Others being present
 - ii. Working within a team
 - iii. Patient's family
 - iv. People
 - v. Family members*
 - vi. Family members*
 - vii. Who is in the room
 - viii. Anxiety of clients' families
 - ix. Team
 - x. Family relationships

*This theme occurred in two interviews.

- II. The Influence of Emotions
 - i. Emotionality

- ii. Emotions*
- iii. Emotions*
- iv. Dealing with emotions
- v. Emotionality

*This theme occurred in two interviews.

III. The Influence of Personal and Professional Histories

- i. Personal history and development
- ii. Personal life experiences
- iii. Past work experiences
- iv. Previous job experience
- v. Own family and faith

IV. The Influence of the Work Setting

- i. Setting
- ii. Hospital setting
- iii. Hospital

V. The Influence of Client Characteristics

- i. Life history and age of the client
- ii. Negative history with the healthcare system

With the above summary of the 11 themes in the study, six textural and five structural, each of the study's themes, or findings, will be presented. The findings are presented in the order they were presented above. The order in each section is generally reflective of the frequency that theme appeared in interview data. Interview data provided are exemplars of the themes; data are not presented in their entirety.

Findings: Essences of the Experience

Emotional Experience

Participants described the experience of providing mental health services to persons in the process of dying as very emotional, running "the gamut of human

emotion.” Doing this work can be “either a very negative or a very blessed experience.” This speaks to the emotionality of this phenomenon being on a continuum from profoundly pleasant to “really, really hard”; participants spoke about this continuum as a “range” and a “variety.” Both the positive and challenging aspects of this emotional experience were discussed and are described, in that order, below.

The positive emotional aspects of providing mental health services to people who are dying were deeply rewarding and inspired deep awe and respect in these participants. The “very first thing that comes to mind is this sense of awe and honor that I have” when “people will share this major life event with me” and “allow me to experience with someone the emotion and the thoughts that they have as they sort of process this giant existential hoop.” “It is so great, super-duper, and fun to know you can have that kind of impact.” This work is “pretty remarkable” and “a real gift to people who are dying.” “Working in this profession is really one of the happiest, most joyful, wonderful options that I can think of. I just love it.” “...Being part of someone’s death can be an incredible thing”, “a marvelous thing.” Participants also identified feeling “hope”, “peace” and “joy” as part of providing mental health services to this population.

The challenging emotional aspects of providing services to people who are dying include: experiencing overwhelming emotions of large scope like being “angry at God”; being “engulfed with the grief”; and being “angry”: I get physically {touching chest; pausing}, I just, my body does not understand this.” Mental health providers also described distressing emotional experiences that are more transitory and less overwhelming like “sadness”, “fear of the unknown”, “anxiety about discussing death”, and having painful personal reminiscences of family members who have died. There are also challenging emotional aspects of the work that occur on a predictable, daily basis. This is “really, really hard work. And, I am drained after seeing one patient.” Every interaction with a client can involve feeling like “I am helpless to change the situation.

My client is going to die.” The cumulative effects of doing this challenging work can be “compassion fatigue”, also called “sorrow saturation” in this study.

Experiences of Effective Service Provision

All of the participants in this study discussed aspects of providing mental health services to people who are approaching death which they experience as necessary for being effective with clients. Their experiences of effective service provision involve: 1) making an invested and authentic connection with the client, 2) listening very carefully while being “present”, and 3) individualizing the content of treatment to the client’s unique needs. Each of these aspects of the experience is described below.

To make an invested and authentic connection with a client, these participants found a number of interventions effective. One participant said,

I try to form a personal connection, something that reminds me of people in my life. And, this is why. Because I feel like if I can make that internal connection with someone who is really close to me, I can more easily get into their lives and help extract things from them that will help improve the care that they get in the end.

Other participants established connection by “summarizing things back to the person” and “meeting people’s eyes.” Participants emphasized that the connection must be authentic to be effective. For example,

[In] my experience, Jennifer, with people who are dealing with issues around the end of their lives are really not interested in being with someone who is not real. Because getting toward the end of your life has such intensity. You cut to the chase. Dying people aren’t interested in being around people who are not real and authentic.

The second feature of experiencing effective service provision was “being present” and “listening.” These concepts were related to one another in the experience of participants and being present and listening were often mentioned in conjunction with each other. Participants described this aspect of effectiveness in a number of ways:

I think it is willingness to be vulnerable. That might be different than vulnerability. The openness to the awareness that your patients are going through *a lot*. They are going through the

worst experience *of their life*. And, you are trying to get clinical? And trying to focus on symptoms? That is really important, but there is a human being who is experiencing that, you know? And, please don't get me wrong. I am not saying clinicians should share their story with the patient, but if you open yourself up, you allow that person to effect you, that patient will really appreciate that..I believe that you have to be a good listener, you have to be caring, you have to be open, you have to be willing to be vulnerable. Those are things that a lot of people are not willing to do because it hurts too much.

The following quote also captures how participants discussed the value of “being present” and “listening.”

I stayed. I stayed and I listened. He wanted to talk although a lot of what he said did not make sense. After a while, I asked if he wanted me to pray with him. He did, so I did. And then, after, I stood up. He stood up. He extended his hand to me. And, uhhh, this is what really impacted me. He said, ‘Thank you for listening. No one has done that in a very long time.’ [weeping] It was just the kindness.

Another participant described this same phenomenon as “the ministry of presence” and said,

[It] is just being there [and avoiding the urgency to] *do* something. Sometimes there are no words in the face of death. Sometimes being there is all that people need. . . . I don't try to enter into a space and fix a situation. I don't have an answer for people. I try to be there and minister to people from where they are.

A focus on “where the client is” rather than on “my agenda” is alluded to in the above quote and was a key part of the third and final feature of experiencing effective service provision with clients who are dying. These participant statements elucidate how the group described the experience of individualizing the content of treatment to the client's individual needs.

Individualized treatment focuses “completely on what that persons wants” and “what is most important to them in the rest of their living” rather than on constraints of “billable time” and “personal agenda.”

I had to learn that. I had to learn that what I know might be best in my clinical opinion might not be best in this cultural situation or with this person's religious conviction or maybe this person may *need* to have pain to feel like they are still alive. . . .

Spending as much time as it takes with a patient and really being present is the most important part of what we do.

One important feature of keeping the focus on the individual client is maintaining good emotional boundaries:

I'm fortunate. I've always seemed to be able to work with people without the sense that I am overwhelmed by their pain. *They* will figure out what to do with their pain. I witness pain, not fix it. If that occurs [therapist becoming overwhelmed by the client's pain], they [the client] end up having to take care of me.

Individualized care that is effective and focused on the client is also holistic:

And that is very important no matter what discipline you come from. You are treating the whole person. You are treating the cultural, physical, socio-emotional, and you know, the psycho-social and you have to recognize the inter-relationship.

Holistic, individualized service provision takes into account a number of additional factors. Participants stated that effective care individualizes “the pace the person needs”, what to focus on in clinical interactions, the cognitive ability that person has (“how sentient they are”), and the verbal ability that person has (“sometimes there is a ventilator, etcetera”). There is also a need to individualize around client-therapist “match.” “My title might get me in the door, but if I am not the right match for that particular dying person, I won't get to stay there. Like anything therapeutic, a good match is what makes it.”

Experiencing the Otherworldly

Participants experienced the otherworldly as part of the phenomenon of providing mental health services to people who are dying. Experiences of this nature were described in two ways, one religious and one ethereal.

Participants described religious aspects of the phenomenon in general ways and in personal ways. For example, general religious awareness was described as “there is a mystery to it all” and “it is wonderful to witness sacred moments when family members share love with one another or the client dies and there is that sacred moment between

this world and the next.” Or, these general religious experiences are described as “being on holy ground”, knowing “that a higher power or God is there.”

In contrast, participants also experienced religious awareness in very personal ways. One participant described part of the experience of this phenomenon as being a “mobile confessional.” “I represent God to people” which s/he is careful not “to abuse” since it is a “scary” responsibility. As a mobile confessional, this participant experiences people being more trusting, honest, and open in the end of life and believes that talking to an anonymous stranger is sometimes easier than “their own pastor for instance.”

A number of participants referred to their work as “a calling” or “a ministry.” “This is sacred. This is a callin’. This is me. This is what I was supposed to do. [Pause] This is me. I find tremendous fulfillment in my work. I see myself as a vessel through which God works. I just let Him use me.” Another simply stated, “It is a very sacred work.” Religious awareness was also described as “calling in the midst of crisis” which is related to the first finding discussed, the continuum of emotions involved. “I love this job and hate this job.” It is both a calling and gives “me a great sense of meaning and purpose and fulfillment”, but it is also “very hard work.”

The second way that participants experienced the otherworldly is in ethereal, but non-religious ways. For example, “It probably sounds really cliché, but it is really soulful work.” Or, participants sometimes had difficulty putting exact words to this kind of otherworldly experience:

There are those undefined, unmediated ways of knowing that we don’t have a language for, but there is an inherent knowing or understanding within ourselves that doesn’t require words {pause} that just {pause} we are just aware of.

Other individuals described otherworldly experiences: “I felt channeled. I really did.” Or, another participant described “vessel experiences” which are “tingly” senses that clients are “pouring a sense of their immortality into me” by requesting the clinician do something after they die or asking the clinician to “remember something forever.”

Experiencing Teaching and Learning

Participants experienced teaching and learning as part of providing treatment to persons in the dying process. Both teaching and learning were experienced more often by the clinician than by the client. Clinicians described learning about how to live their own lives and learning about how to treat future clients more effectively.

Everyone who comes through my door has something to teach me about their lives and therefore about my life. [Clients] teach as much about dying as they do about living. {pause} Well, there is no question it keeps me keeping my priorities straight.

I have a realization that they are teaching me so much about what is happening in my own life and how to improve the care I provide to future patients or my kids, husband, parents, siblings, etcetera.

“They are my teachers and my mentors.” This learning process is experienced as a “gift” from each client and participants tried “to reflect on what I have learned, on what I am taking away.” The learning and teaching happens in positive *and* challenging situations. Participants learned “human lessons” about how to interact sensitively, be respectful of differences, and how to talk about “what is really scary like how long people have left.” Participants learned from mistakes made in treatment, ruptures in alliance, and from individuals who can “*really* talk about where they are in the dying process,” which is difficult to listen to and also profoundly educational and clinically interesting. One participant described his/her learning experiences when people “did not die well, died really the worst deaths.” “It is the failures where patients have not done well. Those are the ones I will never forget and will forever adjust what I do. They stay. I will never lose their face. Ever.”

Anecdotal, but Convincing Experiences

Participants experienced aspects of the phenomenon of providing mental health services to the dying that were themselves phenomena that are not scientifically validated. Participants described these by saying, “I know it is just circumstantial, but it seems to happen that way most if not all the time”, or, “I know it is anecdotal, but you

asked me how many dying people I've worked with. Over 3000. This happens more often than not." These anecdotal, but convincing, truisms about the experience of working with people in the dying process appeared in every interview in this study.

Examples of these experiences follow.

Clients have an innate ability to find a good and peaceful death:

I always come back to my belief that each person has inside his or her self, the right way to die. . . . Each person will be able to find that place . . . and it is different for everyone.

Clients know what they need from the clinician: "The client knows what they need to unburden or to talk about," and "Clients know what they need to discuss before death. Listen. Listen carefully. They will tell you. And, and when they tell you, just hear it. Don't try to fix it."

People choose when to die: People "hang on" "sometimes beyond what the body can take" in order to "wait for a family member to come", "reach a birthday or a holiday", or die "alone like the private person they are." Or,

Quite often the length of time it takes a person to die is the time that the family needs to make that adjustment. I have seen that happen over and over and over and over again. Sometimes families hear that the person is going to die and the person who is going to live adamantly denies that. I watch them slowly come to the place of acceptance of that. I have seen again and again that the person dies only after their family has made that adjustment. It is kind of uncanny.

A number of participants also experienced the phenomenon that "Clients die like they lived." One individual added, "Generally, we don't see deathbed confessions. People don't transform at the end of life." Clinicians experience that clients approach the last weeks of life similarly to the weeks and years preceding the end. As mentioned above, for example, people who have lived privately often want to die privately.

Experiencing Death and Death Awareness

A perpetual feature of providing mental health services to people approaching death is awareness of death and of personal mortality. Examples of these statements follow. The most common of these is an experience of an increased awareness of one's own mortality. Examples are, "It does make me wonder how I am going to die and what are my fears around death and dying?", "I get to be mindful about my own demise and think about and prepare for it," and "[I was] taken back by that experience because it was like seeing myself."

Awareness of one's mortality often inspired these individuals to plan for their deaths, to "stay current on relationships" in order to "die with few interpersonal regrets." Participants also "say 'I love you' more" after this increased awareness. Clinicians in this study hoped they would "have a chance to say goodbye" and "be able to have a good death." Participants also thought about death in general with more depth and frequency as a part of providing mental health to persons who are dying:

I have come to realize that death is a part of life. It does happen. We are not immune to it. It effect[s] the healthy and wealthy. The rich and the poor. Blacks, white[s], every race, every culture. So my perspective on death is different now. Initially, I was angry with God. I could not understand the dynamics of death.

They also said, "Once there was breath and movement in this body and now it is gone", and "I have come to believe that death is a sleep, [that] death is not final."

Textural Summary

Participants' interviews were distilled into six themes related to the experience of providing mental health services to persons who are dying. First, participants described providing mental health services to persons in the process of dying as a very emotional experience which can involve very positive and rewarding emotional aspects and very painful and distressing aspects. Secondly, all of the participants in this study discussed aspects of their work that they experience as necessary for being effective with clients.

Their experiences of effective service provision involved: 1) making an invested and authentic connection with the client, 2) listening very carefully while being “present”, and 3) individualizing the content of treatment to meet the client’s individual needs. The third finding was that participants experienced the otherworldly as part of the phenomenon of providing mental health services to people who are dying. Experiences of this nature were described in two ways, one religious and one ethereal. Fourth, participants in this study experienced teaching and learning and often described learning lessons from their clients regarding how to live and how to die. The fifth finding was that these professionals experienced phenomena in their work which are convincing, but anecdotal. Participants described the experiences, for example, of knowing that people choose when to die or that people die like they lived. Finally, for this group of professionals, a perpetual feature of providing mental health services to people approaching death was awareness of death and of personal mortality.

Given this summary of the textural themes in this study, the next section will describe the structural themes in the study. The author identified five structural themes: 1) The Influence of People, 2) The Influence of Emotions, 3) The Influence of Work Setting, 4) The Influence of Personal and Professional Histories, and 5) The Influence of Client Characteristics. Each of these structural themes is discussed individually below.

The Influence of People

People were a main source of contextual influence for these participants. People affecting the clinicians’ experience of the work appeared in the data as the influence of working on a team, the influence of having any other person present, and the influence of having family members present. In the case of teamwork, the influence was overwhelmingly positive. In the cases of other persons being present and family members of the client being present, the effect was positive and negative in different situations and with different service providers. Each of these categories of the influences of people on service provision to people who are dying is presented below.

Many participants work in settings where a team of service providers work with a single client, many times sharing responsibility for the client's mental health services. If participants worked on a team, they often discussed the team's influence on their experience of doing their professional duties. One participant said, "We're just one little piece of the puzzle, of the interdisciplinary team that is taking care of this patient. It takes a village." Another stated, "No one person and no one discipline can provide great care to a person who is dying. We need each other."

Participants relied on other members of their teams to increase the quality of service and the therapeutic alliance if they themselves were "not a good therapeutic match." One participant said, "Sometimes they do all the hard stuff and I come in and put the cap on." As these statements illustrate, participants who worked on teams felt that teamwork made mental health service provision more effective. Interestingly, participants who did not work on teams often mentioned using the emotional support of others for "self-care." Participants used "my professional organization", "colleagues in the department", and "my therapist and my wife."

Participants' experience of working with people who are dying was also influenced by "who is in the room." "Who is in the room" can positively and negatively impact providing mental health services. Examples of negative impact include "feeling more uncomfortable" when anyone else is present and "a tension, a tension against freedom to speak" from the client when others are present.

Family members were often discussed as a group of people who are "in the room." Family involvement had positive and negative effects on providing service. The effect of family involvement in one participant's opinion can be absolutely deterministic of outcome.

If a client has good communication and support with their family, therapeutic work and approach toward death are much more smooth. I would say that family are the most important contributors to how a person's death will go.

Some clinicians always make family members part of the process and find it beneficial.

You are just as important and I want to make sure that you know that. We will do as much as we can for you too. We are dealing with a few more symptoms with your husband, but emotionally, we are here for you. That is really, really important. . . The dying person is the primary focus, but family is also involved. I make it very clear when I go in to meet a patient that they are in charge and steer this ship. But, there are a lot of folks around you and we are also here for them.

Participants also described their work as often negatively impacted by family members who “are in denial about the person dying” or want the client to make different “advance-directive-type” decisions in the end of life (do not resuscitate, death with dignity act, medications, nutrition). Clients’ family members are often with them in hospital and hospice settings and are often anxious and/or uncomfortable. Participants in those settings stated: “If there is anxiety in the room, it is catching. You can’t miss it unless you are dead,” and “The children were uncomfortable with the new wife being there. There was this odd, tense, dynamic with all of them there.”

The Influence of Emotions

The first finding discussed in this chapter was the textural theme of The Emotional Experience and various intense emotional reactions were described. The emotional nature of providing mental health interventions to persons who are dying was described on a continuum of “the gamut of human emotion” from the very affirming to the very distressing. Participants described having “compassion fatigue” and “suffering saturation” as sequelae of doing clinical work with this population. The emotional nature of the work also affects the experience of the work. Some participants reported being particularly affected by the emotionality of providing service. For example, “I’m a very sensitive—extremely sensitive—and very emotional person. Some of these struggles are much more applicable to me than maybe for another person.”

Participants discussed an awareness that their emotions needed to be “in balance with being present for the client.” They generally stated that “the self cannot be the focus, but the personal reactions should not be ignored.” Particularly, individuals in this study reported being influenced by “my own personal mourning”, “my personal and professional history”, “loaded memories”, and “my own fears of death.” Participants agreed that the focus in treatment should be on the patient and that clinicians “must do their own emotional work” to provide effective interventions for clients who are dying.

The Influence of the Work Setting

The setting in which participants worked had an impact on the nature and quality of their service provision to clients in the dying process. For example, participants who provided services in more than one setting, often preferred one to the other. Clinicians who provided services in homes and in hospital or hospice settings preferred the therapeutic environment of the home where clients were less “formal”, “defended”, and “anxious”, compared to the hospital or hospice where they were more “superficial” or “private.” One participant stated, “People don’t take their wigs off in public, you know?”

Service providers who worked in hospital settings and/or with clients with advanced illness described the influences of these settings and circumstances. They gave examples like, “My clients here are on lots of medications” which impacts how much “energy they have and how much talking they feel like doing”, and “My people are so sick. That’s it. That’s what it is like here.” “It can be completely different in other settings.”

Two participants who worked in hospitals discussed that clients’ previous experiences with the healthcare system can powerfully impact “the trust and the relationship.” Particularly if a client has “been mistreated or misdiagnosed” by other healthcare providers, the therapeutic relationship is affected. “You have to prove to them that you are on their side even if other healthcare people have not been.”

The Influence of Personal and Professional Histories

Participants described themes of personal histories and professional histories influencing their work with clients. These are both described below using examples from participant interviews.

Participants described their personal histories as an influence on providing services to people who are dying. One individual stated, “I think we are the sum total of all our experiences and we don’t leave any of them at the door when we sit with a client.” Another said,

One’s family of origin and culture of origin have a huge impact on one’s psyche and one’s belief in one’s self. . . . And, so, as a child that impacts, umm, that impacts who you become as an adult. And, dealing with some of those issues I think as an adult. That is my context.

Participants also gave more specific examples of their personal histories influencing the experience of their work. Many mentioned instances of “painful reminiscences of family members dying” that intruded when working with a client. One individual described the absolute influence of his/her religious upbringing and how that affects his/her understanding of his/her job.

I was raised in a Christian home and by my grandmother who was a woman of faith and taught me to fear God. I am a Christian. And, as a Christian, I see my work as helping people to get to know God.

Previous professional experiences also influenced these participants’ experience of providing mental health services to persons approaching death. As mentioned in the textural description of Teaching and Learning, many participants apply the lessons they learn in the course of client interactions to their work with clients they see later. Specifically, one participant who had worked in another setting with another population learned a lesson that he/she uses often with patients who are dying. That lesson was that we “are all human beings, all struggle with life, and all have problems.” Another person

who had worked in a hospital intensive care, stated, “I have seen so many things worse than death in ICU”, so helping people “find a good death” is much more enjoyable work.

The Influence of Client Characteristics

Particular client characteristics influenced this group’s experience of providing treatment to people who are dying. The major characteristic that influenced what it was like for these people to do their work was the client’s age. Half of these participants mentioned the challenge of working with a client who is a child; one participant chooses not to work with children at all since it is too painful. Examples of participant descriptions of the influence of client characteristics include, “If someone has lived a good life or if I am working with a child who is experiencing suffering, those really impact what it is like to do my job,” and “If someone has lived a full, happy life and dies at peace at an older age, that is a, a peaceful kind of culmination of good things.”

As is mentioned in the Experiences of Effective Treatment section above, a major contributor to providing individualized care is taking into account the physical, emotional, situational, and cultural uniqueness of the individual. These themes are repeated in participants’ accounts of how individual client characteristics influence the experience of treating them as a group. The most often mentioned individual differences that impact service provision were “clients who are medically unable to speak” and “who are too medicated or there are other medical issues.” In these situations, participants discussed a greater reliance on “just presence” and other “non-verbal communications” like “the human touch.”

Textural-Structural Description

Participants’ interviews were refined into six themes related to the experience of providing mental health services to persons who are dying and four themes related to the contexts which contribute to variations in the experience. These themes are now integrated into Moustakas’ (1984) universal description of the experience representing the group as a whole, the composite textural-structural description. The composite

textural-structural description has six domains which integrate the experience and the context of the experience.

First, participants described providing mental health services to persons in the process of dying as a very emotional experience which can involve very positive and rewarding emotional aspects and very painful and distressing aspects. These professionals discussed that client characteristics such as working with a young child can powerfully influence their experience of their work by evoking powerful and challenging emotions. Feeling supported by a team of fellow co-workers influenced positive emotional experiences, whereas working with clients in difficult family situations contributed to the mental health service providers experiencing negative emotions. The emotional nature of the work also affects the experience of the work. Some participants reported being particularly affected by the emotionality of providing service and described having “compassion fatigue” and “suffering saturation” as sequelae of doing clinical work with this population.

Secondly, all of the participants in this study discussed aspects of their work that they experience as necessary for being effective with clients. Their experiences of effective service provision involved: 1) making an invested and authentic connection with the client, 2) listening very carefully while being “present”, 3) individualizing the content of treatment to individual characteristics and appropriately managing personal emotionality. Participants described a number of factors that influence their experience of working effectively. Those factors are the influence of other people in the room, which can be positive or negative; the influence of the clinician’s emotionality, which both contributed to feeling connected with clients in helpful ways and distracted from being present in negative ways; and the setting in which the services were provided, where more private, more homelike settings benefited the effectiveness of the work and their ability to be connected to the client.

The third finding was that participants experienced the otherworldly as part of the phenomenon of providing mental health services to people who are dying. Experiences of this nature were described in two ways, one religious and one ethereal. Experiencing the otherworldly was described in interview data as an emotional experience, one which can impact the experience of the work. This emotional influence was generally positive, associated with a peaceful sense of meaning and continuity with the spiritual world.

Fourth, participants in this study experienced teaching and learning and described often learning from their clients lessons on how to live and how to die. This experience was described as very positive and a particularly important benefit of providing mental health services to persons close to death.

The fifth finding is that these professionals experienced phenomena in their work which are convincing, but anecdotal. Participants described the experiences, for example, of knowing that people choose when to die, know how to find a peaceful death, or that people die like they lived.

Finally, for this group of professionals, a perpetual feature of providing mental health services to people approaching death was awareness of death and of personal mortality. This was both a positive experience and a challenging one. Participants were thankful for opportunities to learn lessons from their clients' lives and deaths and apply those positively to their own lives. Conversely, participants also experienced intrusive worries about dying or people close to them dying. They described that too many negative or intrusive thoughts about death and/or mortality can negatively impact the emotional quality of doing their work and the effectiveness of their work.

The next chapter discusses literature applicable to the textural-structural description and identifies implications for practice and training.

CHAPTER V: DISCUSSION

In this chapter, the findings presented in Chapter IV are compared to and integrated with extant literature. Conclusions and recommendations are made, both in general and regarding the professional preparation psychologists should consider before working with dying individuals. Following that, the limitations of this study are discussed and suggestions for future research are presented.

Implications of Findings

The final textural-structural description yielded six domains related to the experience of providing mental health services to persons who are dying. Each of the six domains contained information to more fully establish the characteristics and nuances of what it is like to practice with this population. Each of those domains will now be discussed and compared to other studies.

Emotions as the Experience and an Influence on the Experience

Participants in the present study described providing mental health services to persons in the process of dying as a very emotional experience which involved very positive and rewarding emotional aspects as well as very painful and distressing aspects. These professionals indicated that client characteristics, for example a client who might be very young can powerfully influence their experience of their work by evoking powerful and challenging emotions. Many texts for professionals in this field also generally describe the extremes of emotion that are part of this work without providing specific descriptions of the phenomena (Doka, 1993; 2009; Gonda & Ruark, 1984; Knight, 2004; Lair, 1996; Spira, 2000; Wicks, Parsons, & Capps, 2003). Providing mental health services to persons who are dying is often described in these texts as an emotionally variable experience with large emotional rewards and disadvantages, although more attention is paid to unnamed challenges and emotional difficulties than to emotional rewards. These texts also mention that some professionals will not be able to

tolerate the emotional intensity of the work (Knight, 2004; Wicks, Parsons, & Capps, 2003). In addition to these texts' general references to the emotional variability, rewards, and challenges of providing service to persons who are dying, two articles, discussed below, are most similar to the findings in the current study.

These two studies described findings most similar to the current study, but the studies only describe specific professions, nursing and medicine, respectively. Dobratz (1990) described a concept similar to the present participants' description of the emotional variability of providing services to persons very near to death. Dobratz's exploratory study indicated that one of the defining characteristics of a good palliative care nurse is to be able to balance one's self-care with the emotional complexities and intensities associated with repeated encounters with death. Pantilat and Isaac's (2008) article written by and for physicians, described the fact that professionals experience intense grief as part of caring for people who are dying and also that "the greatest reward for physicians in caring for patients approaching the end of life may be the sense of clarity about personal priorities that derives from helping dying patients make the most of the time they have remaining" (p.367). Pantilat and Isaac (2008) also suggested behaviors which may alleviate the experience of loss that occurs when each patient dies; they suggested that physicians talk with colleagues, friends, and/or partners; write about their emotional reactions; attend funerals or memorial services, and/or participation in other rituals to facilitate healing from grief.

General and specific references to the emotional nature of providing services to persons close to death exist in extant literature and were a consistent theme in the interviews of the participants in the current study. In contrast, many fundamental texts for practitioners in this field do not contain any references to the emotional challenges nor the emotional rewards that clinicians face when working with this population (e.g., Kinzbrunner, Weinreb, & Policzer, 2002; Taylor & Kurent, 2003). The current study indicates that the emotional variability and intensity of providing mental health

interventions to persons who are dying is a key element of the experience. The current study, Dobratz (1990), and Pantilat and Isaac (2008) all indicate that good therapeutic care involves both an awareness of one's own emotionality and an ability to manage the emotional intensity appropriately. Dobratz (1990), Pantilat and Isaac (2008), and the participants in the current study suggest that self-care, social support, and rituals of healing are ways to manage the emotional challenges of working with persons who are dying.

There are a number of articles in the medical literature which describe the intensity and variability of providing care to people who are dying, indicating that *mental* health service provision is not unique in this domain. For example, Anscombe (2008) described work with the parents of premature twins in a neonatal intensive care unit; one twin was seriously ill. She discussed her own and the parents' joy and pain in this situation, indicating that medical work with families in the face of possible death is also an emotionally varied experience. Ronayne (2009) conducted a phenomenological study with six nurses and found that feelings, with all of their variety and intensity, contributed to those participants' propensity to suffer a degree of cognitive dissonance which both perpetuated their stress and impacted their ability to perform job duties. The participants in Ronayne's (2009) study described their emotionality impacting job performance by increasing the difficulties they had explaining the brainstem death of patients to the patients' surviving relatives.

Linley and Joseph (2005) conducted a study with applicability to the current study's finding regarding intense, variable emotional experience. Although a study is not available on mental health professionals, Linley and Joseph studied funeral directors to determine the positive and negative emotional changes that occur with prolonged exposure to death. Multivariate hierarchical regression analyses suggested that longer-term positive emotional states were significantly and independently predicted by social

support, both at work and at home, and that negative emotional states were significantly and independently predicted by repeated exposure to death in one's occupation.

As many of the above studies also mention, emotional variability and intensity is the nature of the work and it also impacts professionals' experience of the work. In the current study, participants also described this phenomenon and discussed having "compassion fatigue" and "suffering saturation" as sequelae of doing clinical work with persons approaching death. Ungureanu and Sandberg's (2008) phenomenological study with seven therapists who worked with dying children and their families found that these professionals also experienced emotional exhaustion. Stebnicki (2007) suggested that "empathy fatigue", the term Stebnicki prefers to "compassion fatigue" results from the emotional, mental, physical, and occupational exhaustion that occurs as therapists continually work with clients. Empathy fatigue is common in clinical work which includes the therapist's exposure to clients' chronic illness, disability, trauma, grief, and loss. Indeed, these are aspects of providing mental health services to persons who are in the dying process.

The integration of the current study's finding of intense emotionality with the available research indicates, in summary, that mental health professionals who provide services to people in the dying process experience intense emotions that are both rewarding and challenging. Many more references are made in published literature about the emotional challenges of working with this population although many articles and books for professionals in this field do not address the aspect of professionals' emotionality as part of the service-delivery process. The current study's findings are most similar to existing literature that describes a continuum of positive and negative emotional experiences and that the emotional intensity of providing services to persons close to death can negatively impact the experience and effectiveness of service provision if it is not appropriately managed. Some literature and the present study support the idea that using social support and/or practicing rituals of healing such as journaling or

attending funerals are effective methods of self-care that combat the effects of empathy fatigue.

Effective Service Provision Mediated by Clients, People, Setting, and Clinician History

All of the participants in this study discussed aspects of their work that they experienced as necessary for being effective with clients. Their experiences of effective service provision involved 1) making an invested and authentic connection with the client, 2) listening very carefully while being “present”, and 3) individualizing the content of treatment to what the client’s individual needs dictated. These experiences of effective service provision precisely echo the assertions made in the bulk of population-specific interventions reviewed in Chapter II.

As examples from Chapter II, one of Spira’s (2000) main objectives for his use of existential treatment for persons in palliative care settings was to develop an authentic relationship between therapist and client and between the client and others. Rousseau’s (2000) therapeutic model for facilitating spiritual healing centered on seven principles, one of which was providing a supportive presence. All of the interventions for persons who are dying, independent of the theoretical bases, emphasized flexibility in therapeutic approach and session content to meet the client’s physical, emotional, and religious needs. Specifically, Lacy and Higgins’ (2005) description of their psychodynamic treatment of a person in the dying process highlighted the importance of changing content, approach, and modality of treatment over time in order to meet the shifting needs of their client, Carla. Rousseau (2000) described how to conduct an individualized evaluation of dying clients’ spiritual history and therapeutic needs. Turk and Rennert (1981) discussed the value of applying relaxation, distraction, and psychoeducational techniques depending on the emotional and physical state of the individual and the client’s motivation and ability.

The population-specific interventions reviewed in Chapter II, while proposing theory-based approaches, also stressed that common factors, willingness to listen and form a genuine connection, and a therapist's ability to account for individual cultural, physical, and emotional differences are paramount for effective therapeutic work with this population. This study's participants emphasized the importance of these already-established truisms.

Participants in the present study described a number of factors that influenced their experience of working effectively. Those factors were the influence of other people in the room, which can be positive or negative; the influence of the clinician's emotionality, which both contributed to feeling connected with clients in helpful ways and distracted him/her from being present in negative ways; and the setting in which the services were provided, where client homes or more private, homelike settings facilitated the effectiveness of the work and the therapist's ability to be connected to the client. The available interventions reviewed in Chapter II did not address the necessity of therapists adjusting practically and emotionally to other persons being present in the room. This author has not found another study in which mental health professionals assert that home-based treatment is more effective. While therapists are likely often in the habit of making the setting of therapy as comfortable as possible, therapists working with persons who are dying can utilize this knowledge, since the majority of services provided to this population are in hospital and hospice environments.

In addition to the present study's participants describing the impact of the setting in which services are provided, they also described the influence of the therapist's own emotionality on effective service provision. As presented in the preceding discussion on the domain of emotional variability and intensity of providing service to persons who are dying, the current study's participants and extant literature support the idea that the emotional distress of therapists has a distinct impact on their ability to effectively provide

services (e.g., Anscombe, 2008; Linley & Joseph, 2005; Ronayne, 2009; Stebnicki, 2007) as discussed above.

In conclusion, regarding effective service provision to persons who are dying, the present study reinforces themes in the existing literature that, independent of one's profession or theoretical orientation, effective provision of therapeutic services to clients who are dying will include four main features. These are the ability to form a genuine connection, to listen well and be fully present, to account for each client's individual cultural, familial, physical, spiritual, and emotional differences, and to account for one's own emotional reactions to working with this population. The current study contributed to the literature by adding the implication that the setting in which services are provided and the presence of others during therapeutic interactions should also be included when individualizing treatment for maximum effectiveness.

Experiencing the Otherworldly

Participants in the current study experienced the otherworldly as part of the phenomenon of providing mental health services to people who are dying. Experiences of this nature were described in two ways, one religious and one ethereal. Participants whose job included a religious facet, the pastoral counselors, tended to discuss this aspect of providing mental health services to people in the dying process in a religious way. Certainly, understanding the otherworldly aspects of the work as religious is part of these professionals' worldviews and their professional training. Other professionals in this group of professionals may have been less likely to frame experiences with the otherworldly as religious since they may not have subscribed to a certain religion or may not make a practice of introducing their religious beliefs into their professional behaviors. Stafford (2006) makes a case that human beings are inherently predisposed to participate in spiritual meaning-making in the face of death. She states that this process includes a complex interaction with individuals' personal histories, which might explain why some participants experienced the otherworldly as religious versus ethereal.

Experiencing the otherworldly was described in the current study's interview data as an emotional experience, one which can impact the experience of the work. This emotional influence was generally positive, and associated with a peaceful sense of meaning and continuity with the spiritual world. The process of spiritual/religious/ethereal meaning-making, it seems, is part of what makes this work so rewarding, and part of what contributes to the positive emotional rewards of providing mental health services to persons who are dying. Therefore this study further contributes to the existing literature by highlighting the importance of spiritual/religious/ethereal meaning-making as a potential source of support for providers working with patients who are dying.

Experiencing Teaching and Learning

Participants in the present study experienced teaching and learning and often described learning lessons on how to live and how to die from their clients. This experience was described as very positive and a particularly important benefit of providing mental health services to persons close to death. Similar results were found by Ungureanu and Sandberg (2008), whose phenomenological study with seven therapists who worked with dying children and their families revealed that those therapists often experienced shifts in priorities, relationships, and that their professional work elicited professional growth. An example of this phenomenon also exists in the nursing literature. Blake's (1976) book collects perspectives of nurses who describe patients' deaths produced the most profound effect on them. Specifically, Blake outlines how these nurses learned from their patients regarding how to view death, and how their patients influenced their attitudes toward death and dying. Nurses described powerful memories of particular patients and the life lessons and professional lessons they gleaned from interactions with patients.

In summary, the present study's domain of teaching and learning adds to a small body of literature discussing the aspect of providing service to the dying as a learning

experience which can richly influence clinicians' personal and professional lives. As discussed above regarding the emotional aspects of the experience and the relative lack of information regarding the *positive* aspects of working with people who are dying, the present study's participants appropriately stressed that learning from one's clients is a profoundly positive facet to providing services to this population.

Anecdotal, But Convincing Experiences

In the current study, professionals experienced end-of-life phenomena in their work which were convincing, but anecdotal. Participants described the experiences, for example, of knowing that people choose when to die, know the best way for them to die, or that people die like they lived. These anecdotal phenomena were discussed by participants with emphatic assuredness that the phenomena occur with regularity and were a powerful part of providing mental health interventions with this population. This researcher's initial review of literature and her review after data analysis provided little corroboration that these are a part of the professional discussion. Certainly, the absence in professional literature does not preclude the truth of these phenomena. Similar phenomena are discussed often in other arenas. For example, therapists often refer to "knowing" after an initial meeting with a client that the client has a personality disorder or "sense" that a client may have a history of trauma (Bove & Rizzi, 2009; Parnell, 2007).

It is likely that one, some, or all of the phenomena identified by the professionals in this study are: 1) true and not yet established in the research, 2) seem true, but are otherwise explainable, or 3) are further examples of the human predisposition to find meaning in the face of death. The minimal available professional discussion provides preliminary support for each of the above explanations of the phenomena identified by the current participants. Each of these possibilities, as presented in available literature, is discussed below.

Work by Johnson (1974), Doka (1993; 2009), and Stafford (2006) suggested that aspects of end-of life phenomena are true and are not yet fully backed by scientific inquiry. Johnson (1974) presented a theoretical explanation of why the manner in which people have lived their lives determines the manner in which they will die. In Johnson's experience, the relationship between behavior in life and behavior in the dying process was connected to persons' preoccupation with the material world—with possessing things. Johnson observed and documented that persons who were very attached to material possessions had dramatic deaths in which they appeared to refuse to die, holding on to life and to their possessions. Similarly, he perceived that persons whose connection and involvement in life was with people, rather than things, achieved peaceful deaths. As mentioned in Chapter II, a main therapeutic task of Doka's (1993; 2009) spiritual intervention is to help clients die in a manner similar to how they lived.

Stafford (2006) discussed aspects of end-of-life phenomena that seem to be supported by a preponderance of the evidence. In Stafford's discussion, she describes how persons near death often report visions of deceased relatives and friends. Scientists, in general, assume that these experiences are hallucinations rather than visions of real people who live in an afterlife environment. Stafford makes a case that these experiences are more likely to be real experiences of which science is rejecting or that these experiences are a complex interaction of individuals' personal histories and meaning-making in the face of death.

Regarding the view that the anecdotal, but convincing, phenomena can be otherwise explained, there is some support that end-of-life phenomena seem believable and true, but can be explained in an alternative fashion. For example, Benjamin and Shermer (2006) discussed that individuals have dream premonitions of their own deaths so often that "it would be a miracle, in fact" if some of those premonitions did not come true (p. 223). The idea of confirmation bias, that people remember circumstances which confirm their belief in a phenomenon and disregard those that do not, may be at work

when individuals have premonition dreams of their own deaths, know when and how they want to die, and die in ways that are symbolically similar to the way they lived.

Chapman and Chapman (1990) presented a discussion of a phenomenon of five pregnant women who had presentiments that their unborn children would die. Two of the women delivered stillborn children. The authors explained that the presentiment was likely false, an illusion, based on the close physical relationship that pregnant women and unborn children share and that the particular difficulties experienced by the pregnant women.

Finally, the end-of-life phenomena described by the participants in this study could be examples of how mental health professionals cope with the emotional variability and intensity of working with this population. Stafford (2006) makes a case that human beings are inherently predisposed to participate in spiritual meaning-making in the face of death. This study's participants' mentions of end-of-life phenomena may be an additional way that they made meaning and integrated spiritual, religious, and/or ethereal understanding of their experience. Given the multiple references by the participants in the current study to the emotional challenges of providing mental health services to persons who are dying, finding end-of-life phenomena may be a coping mechanism, another example of how participants facilitate effective self-care. Participants' end-of-life phenomena framed death in ways that might increase positive coping. Thinking that individuals choose when to die frames death as a choice over which we have control rather than an inevitable, random occurrence. The belief that people die similarly to how they lived frames the experience of death with a pleasing continuity between the processes of life and death which may more helpful to professionals than framing death as an uncontrolled, indiscriminate, and unmanageable process.

In summary, participants in the current study experienced anecdotal end-of-life phenomena in their work such as knowing that people choose when to die, know the best way for them to die, or that people die as they lived. Participants described these

phenomena with certainty that they occur regularly and described them as a powerful part of providing mental health interventions to people who are dying. Existing literature, sparse as it is, indicates that these phenomena may be an aspect of providing services to this population that is largely unexplored in available research or that these phenomena may be explainable by other mechanisms, such as confirmation bias or as a unique coping skill used by professionals to deal with the emotional intensity of the work.

Experiencing Death and Death Awareness

Finally, for the present participants, a perpetual feature of providing mental health services to people approaching death was awareness of death and of personal mortality. Awareness of clinician and client mortality can be an aspect of many therapies, particularly existential ones, as discussed in Chapter II (Spira, 2000; Yalom, 1980). Similar to the findings in the present study, though, Ungureanu and Sandberg's (2008) phenomenological study with seven therapists who worked with dying children and their families also found that therapists experienced reflection about their beliefs about life and death and hyper-vigilance about death. For participants in the present study, awareness of death and mortality was both a positive experience and a challenging one. Participants were thankful for opportunities to learn lessons from their clients' lives and deaths and apply those positively to their own lives. Conversely, participants also experienced intrusive worries about dying or people close to them dying. They described that too many negative or intrusive thoughts about death and/or mortality negatively impacts the emotional quality of doing their work and the effectiveness of their work. Comparable results were found in Linley and Joseph's (2005) multivariate hierarchical regression study of funeral directors. They reported that positive adjustment was significantly and independently predicted by an approach acceptance death attitude and that emotional negativity was associated with intrusive thoughts of death and avoidant attitudes toward death.

Regarding the domain of awareness of death and personal mortality, the current study adds to available research and further establishes that working in a field, therapeutic or otherwise, that involves numerous exposures to others' deaths leads to professionals' acute awareness that death is a part of life and increased worries about death. The present study also reinforces the ideas that professionals in this field might: 1) use exposure to death as a personal opportunity to plan for their own living and dying, and 2) have an increased need for self-care techniques to manage emotional stress.

Summary

Thus far, this chapter has discussed the findings of Chapter IV in light of the research presented in Chapter II and other applicable literature. Each of the six facets of the textural-structural description generated in Chapter III has been discussed. A summary of each of the six domains of that description follows:

1) Participants described providing mental health services to persons in the process of dying as a very emotional experience which involved very positive and rewarding emotional aspects and very painful and distressing aspects. Some existing literature does not include any reference to this aspect of the experience; some makes general references to emotional variability, challenge, and reward; and two articles have similar findings to the current study. The current study and the two most like it emphasize a continuum of positive and negative emotional experiences as part of working with this population, and add that the distressing emotional aspects can negatively impact the experience and effectiveness of service provision if it is not appropriately managed.

2) Participants discussed aspects of their work that they experience as necessary for being effective with clients: 1) making an invested and authentic connection with the client, 2) listening very carefully while being "present", 3) individualizing the content of treatment to what the client's individual needs dictate, and 4) appropriately managing emotionality. These experiences of effective service provision are well described and

emphasized in other literature and therapists are well advised to emphasize common factors, willingness to listen and form a genuine connection, and to account for individual cultural, physical, and emotional differences in addition to using theoretically-informed interventions. As above, managing the emotional intensity of working with this population is paramount. Additions to the literature identified in the present study include the importance of considering other persons present in the room and making hospital and hospice settings as homelike as possible.

3) Participants experienced the otherworldly as part of the phenomenon of providing mental health services to people who are dying. Experiences of this nature were described in two ways, one religious and one ethereal. Pastoral counselors tended to discuss this aspect of providing mental health services to people in the dying process in a religious way, whereas other professionals tended to describe them ethereally. Available professional discussion posits that human beings are inherently predisposed to participate in spiritual meaning-making in the face of death and the present study adds that this aspect of the experience is part of what makes working with persons who are dying *rewarding* as well as distressing.

4) Participants experienced teaching and learning and described this as a positive aspect of the work in which they learned from their clients how to live and how to die. Similar results were found in other studies, describing learning to make shifts in priorities and relationships, facilitating professional growth, and developing richer views of death and attitudes toward death and dying.

5) Participants described experiencing end-of-life phenomena in their work which are convincing, but anecdotal, such as knowing that people choose when to die, know the best way for them to die, or that people die like they lived. Existing literature indicates that these phenomena may be an aspect of providing services to this population that is largely unexplored in available research or that these phenomena may be explainable by

other mechanisms, such as professionals' confirmation bias, meaning-making, and/or coping.

6) Finally, participants experienced awareness of death and of personal mortality, both of which were positive experiences and challenging ones. The current study adds to available research establishing that working in a field involving multiple exposures to others' deaths leads to professionals' acute awareness that death is inevitable and to increased worries about death. This aspect of working with this population necessitates good clinician self-care. The present study also reinforces the idea that professionals in this field might use exposure to death as an opportunity to plan for their own living and dying.

Implications for Psychologists' Preparedness

With the above summary of the implications of the present study, this chapter now turns to an integration of this knowledge and the issue of psychologists joining the professionals already routinely providing service to people who are dying. Weiser (2006), a psychologist, asserts that providing therapy to the dying involves "numerous therapeutic issues . . . the likes of which I never dealt with in my graduate school training" (p. 12) and shares written accounts of her experiences working with persons who are dying in order to assist other professionals. Weiser's comment about never learning in her graduate training the therapeutic nuances of working with the dying is an important issue. Psychologists are ethically obligated to practice within the scope of their competence "based on their education, training, supervised experience, consultation, study, or professional experience" (APA, 2002, http://www.apa.org/ethics/code2002.html#2_01). Psychologists must have appropriate knowledge, training and expertise in order to fully integrate into the group of professionals who currently provide the bulk of mental health interventions for people who are dying. The current study coupled with extant training literature can offer a solution for psychologists who wish to enter the field of end-of-life therapeutic service delivery before doctoral programs include formal

training on providing services to persons approaching death. Details of the applicable findings of the current study integrated with extant training models follow.

The final textural-structural description of the current study contained six domains of the experience, two of which directly relate to the professional preparation psychologists should have before working with dying individuals. The domains of interest here are the first and last ones discussed above: 1) the emotionality of this work and how it can influence effective service provision and 2) the awareness of death and personal mortality that are part of and an influence on providing quality mental health services to people who are dying. These are most applicable since they were both consistently referenced by participants in the current study and because the current study and extant literature indicate that these factors can dramatically influence the quality of service provision. To best prepare psychologists to work with persons who are dying, suggestions for managing the emotionality of providing services to the dying and for facilitating psychologists' awareness of personal mortality follow.

Managing Emotional Intensity

Professionals who work in situations that expose them to death have long been of interest to traumatic stress research (Linley & Joseph, 2005). Psychologists beginning work with clients who are dying should have skills to avoid the negative emotional impact of providing services to this population. Stebnicki (2007) provides applicable suggestions regarding facilitation of this skill-set. His article is directed to therapists who persistently do challenging work with clients and, although his work is not specifically tailored to professionals who provide mental health services to the dying, his discussion of empathy fatigue and its prevention are clearly pertinent. Empathy fatigue, the term Stebnicki prefers to "compassion fatigue" results from the emotional, mental, physical, and occupational exhaustion that occurs as therapists continually work with clients. Empathy fatigue is common in clinical work that includes the therapist's exposure to clients' chronic illness, disability, trauma, grief, and loss.

Stebnicki (2007) presents self-care strategies that promote resiliency for the prevention of empathy fatigue and the facilitation of therapists' emotional, physical, and spiritual well-being. These four strategies are:

- 1) Identify and be aware of empathy fatigue risk factors. Conduct a self-assessment or enlist the help of a trusted other to globally assess strengths and weaknesses in self-care. The psychologist should assess: current and preexisting personality traits, history of emotional or psychiatric problems, coping behaviors that are maladaptive, age and experience-related factors, organizational and system dynamics in one's place of employment, specific job duties and position in the organization, unique socio-cultural attributes, response to past critical events and stressful events, and level of support and resources.
- 2) Ask the following solution-focused questions to facilitate problem-solving toward increasing one's professional resiliency:
 - a. Who are the people in my life who encourage me to care for myself?
 - b. What are self-care activities I have done or would like to do that do not take much time, energy, or money?
 - c. What are self-care activities I have that would require more time, energy, or money?
 - d. What are three barriers I experience when I try to practice self-care (Miller, 2005; Stebnicki, 2007)?
- 3) Develop an orientation toward professional wellness early in one's professional career, while still in training if possible (Meyers & Sweeney, 2005; Stebnicki, 2007).
- 4) Use professional connections at the national, state, and local levels to find collegial support and to generate ideas for self-care.

Interestingly, participants in the current study and Woodson (1987) also mentioned that positive professional relationships dramatically impacted the experience of working with the dying. In the current study, one participant specifically mentioned that using his professional organization as a support helped him maintain spiritual and emotional health in his personal and professional life. Ronayne's (2009) phenomenological study of intensive care nurses concluded that nurses needed more education and support from personal and professional sources to enable them to overcome cognitive dissonance and to give relatives honest information about brainstem death.

Managing Awareness of Death and Personal Mortality

In addition to learning skills to manage the emotionality of working with persons approaching death, psychologists beginning this work are also well-advised to develop proficiencies in thinking about death, dying, end-of life issues, and personal mortality. Duba and Magenta (2008) have developed a training program to teach master's level counselors how to work with clients who are dying and it is applicable to all in the counseling fields, including psychologists.

The main goals of the program are to desensitize professionals to the idea of death and to process personal feelings about death. Both facets of the training facilitate the struggle of facing death that this work inherently involves and minimizes the impact of the therapist's adjustment on client care.

To engage in desensitization to death, psychologists should engage in experiential activities such as attending a wake or a funeral, interviewing the family member of a dying or terminally ill individual, reading personal stories related to death and dying, conducting role plays between dying client, family members, and counselor about death, developing relationships with hospice professionals, and/or volunteering at hospice (Duba & Magenta, 2008).

To process personal feelings and thoughts about death, psychologists should make journal entries about their reactions to the above experiential activities, seek to discuss their reactions with others, and intentionally use time and energy to identify and acknowledge values and feelings about death. Psychologists can also journal about specific questions such as: 1) Do you accept the practice of euthanasia as an appropriate manifestation of an individual's right to live and die with dignity?, 2) Do you believe that all killing, including taking part in a good and easy death facilitated by pain medications, is morally wrong?, and 3) How will you work best with clients who have different ideas about death than you have? (Duba & Magenta, 2008)?

Stebnicki (2007) and Duba and Magenta (2008) offer practical preparation advice for psychologists beginning to work in the field of death and dying. Since psychologists are newly integrating themselves into the field, most doctoral training and continuing education opportunities do not yet include an emphasis on providing mental health services to persons who are dying. Since this is the case, it is particularly important that the suggestions for training offered here can be conducted by individual psychologists, independent of agency or training program support. As psychologists continue to provide these services, as will be necessary in coming decades, this author hopes that training programs and mental health agencies will make this type of professional preparation regularly available. Obviously, it is impossible to make any doctoral psychology curriculum exhaustive. However, the author believes some degree of training on end-of-life therapeutic service delivery would be an excellent addition to such curricula.

Thus far, Chapter V has provided a discussion of the implications of this study's findings with regards to extant literature, both in general and in ways that apply to psychologists entering the field. The remainder of this chapter discusses the limitations of the present study and offers suggestions for future research.

Limitations

This research study contained limiting conditions, some of which are inherent in the qualitative methodology, some of which are inherent in phenomenological research, and some of which are unique to this author's application of Moustakas' (1994) design in this particular study. Each of these areas is described below.

Limitations of Qualitative Methodology

Qualitative studies are limited by researcher subjectivity. Therefore, this researcher's biases, assumptions, interests, perceptions, and needs have, to some extent, influenced the implementation of this study and the analysis of data (e.g., Bloomberg & Volpe, 2008; Creswell, 2007; Denzin & Lincoln, 2005). As was described in preceding chapters, the author used bracketing through data analysis to minimize the impact of her subjectivity. As suggested, no theoretical framework beyond the constructivist frame of phenomenology was used to further increase objectivity. An additional factor which likely curtails the effect of researcher subjectivity is that this researcher has not provided mental health services to a person assumed to be six months from death, so personal experiences of the phenomena did not influence data analysis.

Limitations of Phenomenological Research

The main vehicle for data collection in phenomenological research is the interview. Therefore, a construct Maxwell (1996) called participant reactivity may have introduced limitations in these data. Participants in this study may have had a variety of reactions to the researcher taking the role of interviewer. Participants may have been overly cooperative and may have tried to offer the responses they perceived as desirable. Alternatively, participants not used to the role of interviewee may have been hostile, uncomfortable, or guarded. The researcher reflected constantly during interviews on ways she might have influenced participants and every effort was made to facilitate an environment of open, comfortable dialogue.

Limitations Unique to this Study

One major limitation of this study is that it did not incorporate independent judges in the analysis process. All analysis decisions were made by the researcher. To restrict the impact of this decision, the researcher consulted with professionals knowledgeable in qualitative research regarding the appropriateness of analysis decisions. The major consultation took place in person with two accomplished qualitative researchers after the author had analyzed the initial two interviews. Those two consultants requested that additional information about specific analysis processes be included in Chapter III of this document, but affirmed this researcher's approach to analysis seemed appropriate.

In this study, the participants were selected from a restricted locale. Participants were selected from an area within one and one-half hour driving time from the researcher. Due to this restriction, participants may have aspects of cultural and regional commonality which contributed to the commonalities in their lived experiences of providing mental health services to persons who are dying. Generalizability to other regions may, therefore, have been affected. The impact of this limitation was minimized in this study by the author's inclusion of rich and detailed descriptions of the participants' experiences and by describing the settings in which the participants provide service. Given these attempts to moderate the consequences of a restricted group of professionals, users of this study can assess the applicability of the information and employ it appropriately in other contexts.

Suggestions for Future Research

The present study might serve as a model for obtaining rich data on small, local populations of mental health professionals who provide services to persons who are dying. For example, a single hospice agency might be interested in understanding the experience of providing mental health treatment for all the providers employed there.

The present study might also stimulate research on specific aspects of providing mental health services to people who are dying. For example, this study generated the

possibility that religious professionals might interpret otherworldly phenomena in a religious way and non-religious professionals might interpret the same or similar phenomena with an ethereal framework. A study focusing on the benefits of mental health professionals who provide services to the dying might contribute to focusing themes in the current study and could also contribute information about combating empathy fatigue. Future studies might also focus on end-of-life phenomena and how they are most appropriately explained, the impact on service provision after individual psychologists build skill-sets to manage empathy fatigue and awareness of mortality, and the perspectives of health care administrators and doctoral training programs on the need for program-based training for psychologists to provide services to persons who are dying.

Finally, future studies might address the limitations of the present study, such as conducting similar research with less localized participants, adding independent judges to the analysis process, and examining the experiences of mental health professionals in this field with more generalizable, quantitative methodologies.

Summary

The primary issue addressed in this study was that psychologists are and will be increasingly called upon to provide mental health services to persons who are dying. This population has specialized needs that psychologists must learn to address appropriately. In addition, psychologists need all of the information available from professionals currently doing such therapeutic work in order to continue increased involvement in end-of-life mental health care. This study explored and documented the lived experience of 10 mental health professionals who provide mental health services to persons who are dying in order to more fully establish the characteristics and nuances of what it is like to do this work. To this end, the specific research questions addressed in this study were:

1. What is the lived experience of mental health professionals as they provide mental health services to people who are dying?
2. What situations and contexts influence the lived experience of providing mental health services to people who are dying?
3. What, based on the accounts of the experience, is a way to describe the overall, unifying experience of providing mental health service to persons who are dying?

Moustakas (1994) phenomenological methodology appeared to be the most appropriate for this research problem and questions. Following analysis of the 10 qualitative interviews, six facets of the experience were deemed essential to the phenomenon. They were:

- 1) Emotional experience which involved very positive and rewarding emotional aspects and very painful and distressing aspects;
- 2) Experiences of effective service provision involving
 - a) Making an invested and authentic connection with the client,
 - b) Listening very carefully while being “present”,
 - c) Individualizing the content of treatment to what the client’s individual needs dictate, and
 - d) Managing emotionality;
- 3) Experiences of the otherworldly, either religious or ethereal;
- 4) Experiences of teaching and learning, which were welcome opportunities to learn from their clients how to live and how to die;
- 5) End-of-life phenomena which were convincing, but anecdotal, such as knowing that people choose when to die, know the best way for them to die, or that people die like they lived; and
- 6) Awareness of death and of personal mortality, which were both a positive experiences and challenging ones.

The final six domains of the experience had varying amounts of support in existing research. Some of the findings and implications of this study are new contributions to what is understood about this phenomenon.

Two aspects of working with people who are dying were identified that relate to psychologists' professional preparation before working with dying individuals. The domains of interest here are: 1) the emotionality of this work and how it can influence effective service provision and 2) the awareness of death and personal mortality that are part of and an influence on providing quality mental health services to people who are dying. Stebnicki (2007) provided applicable suggestions for psychologists regarding facilitation of self-care skills to avoid the negative emotional impact of providing services to this population. Duba and Magenta's (2008) training program was adapted for psychologists to desensitize themselves to the idea of death and to process personal feelings regarding death.

APPENDIX A: CONSENT SCRIPT

We invite you to participate in a research study being conducted by investigators from The University of Iowa. The purpose of the study is to understand more about the experiences of therapists who provide mental health services to people who are dying.

We are inviting you to be in the study because you are listed online as a treatment provider for people who are dying or you have been identified by other professionals as a person who provides services to persons who are dying. As many as 30 professionals will take part in this study.

If you agree to participate, we would like you to participate in an in-person or phone interview. During the interview, I will ask you to discuss your experiences while providing health services to persons who are dying. If you agree, I would like to audio record the interview. You do not need to agree to the audio recording in order to participate in the study. I will ask you if you agree to the recording before starting the recorder. You are free to skip any questions that you prefer not to answer. It will take approximately 30 to 60 minutes.

If you agree, I may re-contact you after reviewing your interview to ask questions to clarify your responses or to ask for additional information.

We will not collect your name or any identifying information about you. Your tape-recorded interview and any paper transcriptions or notes of the interview will be kept under lock and key and will not be labeled with your name or other identifying information. All computer files associated with his study will be password protected to ensure your confidentiality. When we write a report about this study we will do so in such a way that you cannot be identified.

Taking part in this research study is completely voluntary. If you have any questions about the research study itself, please contact Jennifer Hill at (319) 530-0764.

If you have questions about the rights of research subjects please contact the Human Subjects Office, 300 College of Medicine Administration Building, The University of Iowa, Iowa City, IA 522242, (319) 335-6564, or e-mail irb@uiowa.edu. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

Thank you very much for your consideration. If you are willing to participate in this study, please give me permission to begin the interview and the audio recording.

APPENDIX B: GEE'S TRANSCRIPTION KEY

CAPS	Vocal Emphasis
?	Rising intonation or pitch glide
.	Falling intonation or pitch glide
1.	Utterance broken off
=	Successive utterance with no gap
[]	Interviewer utterance
{}	Author Explanations
{p}	Short pause
{P}	Longer pause
/	Separates idea units or phrases with one pitch glide
Hard return	Indicates a line or one topic
Blank line	Separates stanzas or paragraphs

(Gee, 1999)

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