

A STUDY ON THE RELATIONSHIP OF DEATH ANXIETY AND THE COMPLETION OF
ADVANCE DIRECTIVES FOR ONCOLOGY SOCIAL WORKERS

A Dissertation

presented to

the Faculty of the Graduate School
at the University of Missouri-Columbia

In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

by

MARLYS R. PECK

Dr. Debra Parker-Oliver, Dissertation Supervisor

MAY 2008

© Copyright by Marlys R. Peck 2008

All Rights Reserved

The undersigned, appointed by the dean of the Graduate School, have examined the dissertation entitled

A STUDY ON THE RELATIONSHIP OF DEATH ANXIETY AND THE COMPLETION OF
ADVANCE DIRECTIVES FOR ONCOLOGY SOCIAL WORKERS

presented by Marlys R. Peck,

a candidate for the degree of Doctor of Philosophy,

and hereby certify that, in their opinion, it is worthy of acceptance.

Dr. Debra Parker-Oliver

Dr. Judith Davenport

Dr. Colleen Galambos

Dr. Martha Markward

Dr. Clay Anderson

Dr. Steven Zweig

DEDICATION

While only my name is on the front page of this dissertation I dedicate it to my family, as it would have never been completed without their love and support. It would be impossible to name every family member that has encouraged me. You know who you are—my siblings and spouses, niece and nephews, aunts, uncles, and cousins. I thank you from my heart.

A very special thank you goes to my parents, Earl and Barbara Peck, for providing so many opportunities for my educational pursuits. Your time, dinners, listening, and help in allowing me to experience this process on my own terms has been invaluable. I would not have wanted to do this without you. I am so proud to be your daughter.

Thank you to my sons. To Chitamawe for your unwavering belief in me, and your phone calls on the days they were needed most. Zondwayo, my PhD is in social work! Thank you for asking the question when you were eight years old and for all the talks and laughter as an adult once I started back to school. And thank you so very much to Daniel, who has lived half of his life in a home focused on a doctorate. Thank you for being quiet, bringing me water, learning to make coffee, eating pizza (over and over), and listening to me talk incessantly on a topic I care about deeply. You saw this through to the end and I will always remember your kindness to me.

I also want to say a special thank you to my aunt and uncle, Dr. M. T. and Karen Fouad. Thank you for providing me with a wonderful retreat in your home in which to rest and rejuvenate. Thank you, Uncle Taher, for helping me see it was okay to move myself to the top of the priority list and start this journey. And thank you for helping me to really understand the importance of my education.

ACKNOWLEDGEMENTS

I would like to recognize and thank individuals whose support and encouragement made the realization of this work possible. To begin with, I want to thank the chair of my committee, Dr. Debra Parker-Oliver, whose patience, encouragement, and belief in my abilities guided me throughout this journey. Dr. Oliver has a wonderful gift of positive energy that is contagious yet never overpowering. I would also like to thank the other members of my committee, Dr. Judith Davenport, Dr. Colleen Galambos, Dr. Martha Markword, Dr. Steven Zweig, and Dr. Clay Anderson. For many years, these individuals have been an integral part of my professional growth as a social worker in the field and as a social work student. I am truly grateful for the influence you each have had in my development.

To my colleagues and staff at the University of Central Missouri, thank you for the support, assistance, and kindness shown to me at every turn. You will never know how your books, words, and smiles always came at the right time. I am grateful for the thoughtfulness of my Department Chair, Jean Nuernberger, and Program Director, Dr. Freda Herrington, for mentoring me through the process of managing a full-time faculty position while I completed my dissertation. Thank you for sharing Jim's wisdom to *push on doggedly*.

Thank you to Laura Parker, Mike Perkins, and Lia Willis, my former colleagues at Columbia College. I appreciate your willingness to hire someone with no experience and start me down the path of a major career change. Thank you, Mike, for asking me "have you ever considered teaching?"

Thank you to Dr. Kathy Black for consulting with me and allowing me to use her survey. Many thanks also go to the Association of Oncology Social Work staff and members for assisting me in reaching the social workers that responded to my survey. Dr. Brad Zebrack was very supportive and helped guide me in the early stages of my work by

asking very simple questions that made very big differences. Thank you for caring and taking the time to help me learn and improve my work. And finally, a huge thank you to the social workers that took the time to respond to the survey and provide feedback. Without your participation this work could not have been completed. Thank you.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	ii
LIST OF TABLES	v
ABSTRACT	vi
Chapter	
1. INTRODUCTION	1
Conceptual Framework	
Statement of the Problem	
Significance of the Study	
Statement of Purpose	
Directionality	
Theoretical Definitions of Terms	
Operational Definitions	
Assumption	
Limitations and Delimitations	
Conclusion	
2. LITERATURE REVIEW	12
Social Work	
Advance Directives	
Death Anxiety Defined	
Attitudes toward Death	
Terror Management Theory	
Personal Construct Theory	
Death Anxiety and Health Professionals	
Advance Directives and Health Professionals	
Attitudes toward Advance Directives	
Conclusion	
3. METHOD OF STUDY	30
Design	
Target Population and Sample	
Instrumentation	
Internal Consistency	
External Consistency	
Data Collection	
Data Analysis and Statistical Procedures	
4. RESULTS	40

Participants
Dependent Variables
Hypotheses
Additional Findings

5. DISCUSSION50

Results of Hypotheses
Policy
Practice
Future Research
Limitations
Conclusions

REFERENCES72

VITA82

LIST OF TABLES

Table	Page
1. Demographics of Independent Variables	60
2. Death Anxiety Dependent Variables.....	61
3. Own Advance Directive Completion	63
4. Communication Dependent Variables	64
5. Personal Characteristics and Death Anxiety Correlations	68
6. Summary of Regression Analysis for Variables Predicting Death Anxiety Scores	69
7. Death Anxiety and Communication Correlations	70

ABSTRACT

This study examined the extent to which the death anxiety of oncology social workers impacts the facilitation of the completion of their personal advance directives, and communication about advance directives with patients. Members of the Association of Oncology Social Work completed death anxiety and advance directive communication practices survey instruments. Terror Management Theory and Personal Construct Theory guided the examination of the results. Respondents having more years of work experience reported higher death anxiety scores. And, as the death anxiety scores increased the communication scores decreased related to disclosure of information about advance directives and values in living. In spite of limitations, the study findings contribute to the furthering of understanding oncology social workers in this context. The combined use of Terror Management Theory and Personal Construct Theory has seldom been used to study oncology social workers and the statistically significant findings suggest future research may be warranted.

Chapter 1

Introduction

Not only is death certain, it can come at any time and can result from any number of unpleasant causes; at any moment we may crash our car, fall victim to violence, or discover that fatal tumor. Thus, we humans are aware that our most basic desire for continued life inevitably will be thwarted.
(Goldenberg, Pyszczynski, Greenberg, & Solomon, 2000)

Since the early 1970's, the plights of individuals like Karen Ann Quinlan, Nancy Cruzan, Robert Wedland, and Terri Schiavo have been thrown into the public arena and the legal system (Fulton & Saunders, 2001). Questions of by whom and how decisions should be made regarding care for the medically dependent are ongoing (Forsythe, 2005). The legal systems' answer has been the creation of documents called advance directives, or living wills, which allow competent individuals to participate in future medical decisions through personal statements stating their choices regarding medical care and decision making (Perkins, 2007). Advance care planning and the communications that accompany the process are the means for matching patient wishes with professional interventions (Bullock, 2006).

Given the complexities of the process and the sensitive nature of the discussions required, an interdisciplinary approach is appropriate, which involves both the patients and their families in decision-making and the completion of advance directives (Tammelleo, 2000; Werner, Carmel, & Ziedenberg, 2004a). To date, no discipline within the medical arena has been deemed the most qualified to discuss advance directives with patients and their appropriate others (Jezewski et al., 2005). However, recent research

does suggest that individuals prefer social workers as the ones to take the lead responsibility in assisting in the communication and completion of advance directives (Black, 2005a).

Advance directives have been available in the United States for several decades, yet only 4 to 15 percent of Americans have completed a formal document (Forsythe, 2005; Galambos, 1998; Perkins, 2007; Vandecreek & Frankowski, 1996). Some of the reasons why so few people have participated in an opportunity to plan in advance apparently include a lack of awareness as to the importance of advance directives in meeting their own needs; as reluctance to talk about death and planning for death; and a basic lack of information about advance directives (Wilkinson, Wenger, & Shugarman, 2007). Further, there is some reason to suspect that the corresponding attitudes towards death and dying on the part of social workers themselves may be a contributing factor in the circumstance that so few people have executed advance directives for themselves. This dissertation will explore the impact of the practitioners' personal anxiety related to dying and communicating with patients as a possible contributing factor to the issue.

The completion or lack of completion of an advance directive may be a response to death anxiety. The fear of death is universal (Mooney, 2005), and as individuals become aware that their *own* death is inevitable, the realization becomes terrifying (Becker, 1973). Further, as primary partners in a helping relationship, oncology social workers may not realize how their own perceptions, including death anxiety, may be influencing their interactions in the helping process (Christ & Blacker, 2006), which includes communication about to advance directives. This study determines the impact that oncology social workers' death anxiety has on the completion of personal advance

directives and communication about advance directives with patients. The findings in this study have implications for policy, practice, and research.

Conceptual Framework

Personal Construct Theory (PCT) and Terror Management Theory (TMT) provide frameworks in which to discuss the relationship between death anxiety and the completion of and about communication of advance directives. The shared basis of these psychological theories lies in the ability of humans to maintain an element of control while anticipating future events. Realizations about control and anticipation of the future are based upon the knowledge that one is moving towards an end-of-self, or death. When one is able to grasp the reality of death, one can construct meaning and realize relief from anxiety (Brown, 2005). Variations of this position are expanded in each of these two psychological theories.

George Kelly's Personal Construct Theory was developed as a means to explain how individuals construct their own meaning with respect to difficult situations and learn to be in control of their lives through making decisions. This theory posits that a hierarchy of elements form subsystems, or core constructs, of each individual's worldview and self-identity (Evans, Walters, & Hatch-Woodruff, 1999; Neimeyer, 1994). Worldviews include values and belief systems layered with what Kelly calls "upper level constructs" which provide the most meaning to a person at a particular time or circumstance in her/his life. These constructs are challenged and tested throughout life as new information is acquired, and subsystems changes are frequent. Death is often considered an upper level construct. As such, changes in this construct may cause foundational changes in one's overall system as past, or old knowledge is bridged to

realization about the future (Evans et al., 1999; Neimeyer, 1994). The very process of providing information about an advance directive is educational, interactive, and ongoing (Black, 2000), and may therefore engender changes in the way an individual thinks about death. Indeed, communication practices providing new information about advance directives may be seen by the patient as highly threatening to her/his existing construct about death.

Terror Management Theory (TMT) is based on the idea that there is an ongoing, lifelong struggle within everybody which allows us to manage awareness of death only by denying that it is intended for us (Becker, 1973). This mixture of understanding death as reality and our basic instinct for self-preservation produces terror that can be paralyzing. In response, defenses are created. One defense is to not think about death as something eminent, but rather as a distant event to be acknowledged at some point in the future. Another defense is to protect ones constructed worldview by surrounding oneself by like-minded people (Smieja, Kalaska, & Adamczyk, 2006). Both patients and oncology social workers bring their respective worldviews to discussions about end of life strategies, and death anxiety may remain if identification with others holding similar worldviews does not occur (Brown, 2005). If differences are present in this relationship it may impede both the completion of advance directives and communication about the documents with patients.

Statement of Problem

During the twentieth century, technological advances in the field of medicine have made it possible to keep people alive longer at a cost of thousands of dollars each year to the health care system. In other words, with expanding treatment options, people

live longer. Not surprisingly, questions about and expectations regarding appropriate end-of-life care have emerged as a consequence of this situation (Foster & McLellan, 2002; Volker, 2003; Wilkinson et al., 2007). Passed in 1990, the Patient Self Determination Act (PSDA) was the first nationwide formal attempt to provide the public with advance directive information and a recognized means of making treatment decisions (Bradley & Rizzo, 1999; Salmond & David, 2005; Wilkinson et al., 2007). The PSDA continues to require health care facilities receiving federal money, such as hospitals, nursing homes, and hospices, to provide persons with written information about their decision-making rights and the opportunity to discuss advance directives (Connell & Mallory, 2007; Gockel & Morrow-Howell, 1998). Additionally, most states have some form of law or statute that supports advance directives (Ditto, Hawkins, & Pizarro, 2005; Tammelleo, 2000), and the designation of a healthcare agent to make decisions is allowed in every state (Black, 2005b; Wilkinson et al., 2007).

Despite the national attention generated by high profile cases and the resulting legislative mandates, estimates suggest that fewer than 15 percent of Americans have completed advance directives, or documents directing end-of-life care (Galambos, 1998; Perkins, 2007; Vandecreek & Frankowski, 1996). As a result, end-of-life decisions, including a patient's right to refuse treatment, become legal cases that would have been preventable had there been written directives or a designated agent for health care decisions in place. In the absence of such directions, and if the individual in question is unable to provide them after becoming disabled, resulting family disagreements can continue for many years without resolution (Ditto et al., 2005; Stern & Goddard, 2003).

Over time, Western society has undergone changes in how it experiences and perceives death. Society as a whole, at least in the United States, perpetuates the suppression of death awareness, resulting in denial and ignorance of issues surrounding the event. Even social work texts have supported the denial of death, identifying it as normal for persons in the process of dying and thus not of concern to social workers (Germaine, 1984). During the twentieth century, the commercialization of funerals and the medicalization of death further removed familiarity with death from most people. More than 70 percent of deaths for instance now occur in hospitals or institutions, away from family members. Professional caregivers now replace family members in providing primary care for patients not only while they are sick, but as they are dying (Reese, Chan, Perry, Wiersgalla, & Schlinger, 2005; Roscoe, Osman, & Haley, 2006; Servaty, Krejci, & Hayslip Jr., 1996).

On the other hand, professional organizations have made public statements in support of advance directive planning. For example, in the early 1990's the Association of Oncology Social Work and the Oncology Nursing Society developed a joint policy statement in response to the PSDA, acknowledging the significance of this legislation in practice. The original policy stated that the

capacity for autonomous patient and medical decision-making must be extended through the use of advanced care directives. All patients and families have the right to accurate information related to advance care planning and end-of-life decision making to minimize psychological distress (AOSW, 2006).

More recently, a policy update states that “Quality care at the end of life requires . . . increased public and professional education regarding the preparation of advanced healthcare directives and the right of each individual to excellent end-of-life care” (AOSW, 2007). Despite this professional social work policy, research has shown that the lack of communication surrounding options at the end-of-life have hindered professional relationships regarding discussions about death (Black, 2005a).

Significance of the Study

Medicine, nursing, bio-ethics, and philosophy professionals have conducted the majority of research concerning end-of-life care issues and, specifically, advance directives (Claibourne, 2000; Connell & Mallory, 2007; Hinkka, Kosunen, Metsanoja, Lammi, & Kellokumpu-Lehtinen, 2002; Huffman, 2001; Mooney, 2005; O'Neill, 2001). However, social work research related to advance directives has been inadequate, considering the challenge and impacts of these discussions (Gockel & Morrow-Howell, 1998). As a result, social work educators fail to adequately prepare practitioners for work with terminally ill clients (Christ & Sormanti, 1999).

There is very little research examining the involvement of oncology social workers in communicating with patients about advance directives. Research focusing on professionals with repeated exposure to death has shown a reported increase in death-related anxiety (Wass & Neimeyer, 1995). Lower death anxiety has been related to less hesitation in communicating with dying persons (Mooney, 2005). However, little is known about the relationship between death anxieties among social workers relative to their communications with patients concerning advance directives. If the personal death anxiety of social workers is having a negative impact upon their practice of facilitating

advance care planning by patients, a disconnect between the formal policy and actual practice may go unnoticed without research into the problem. Such research may influence policy to guide practice for all medical social workers.

Statement of Purpose

This study examines the extent to which the death anxiety of oncology social workers impacts the facilitation of the completion of their personal advance directives, and communication about advance directives with patients. The purpose of this study is to answer the following research questions:

1. Which characteristics of oncology social workers predict their death anxiety?
2. To what extent does death anxiety correlate with the completion of personal advance directives?
3. To what extent does death anxiety correlate with the communication with patients about advance directives?

Directionality

Hypothesis 1: The personal characteristics of oncology social workers will predict their death anxiety scores.

Dependent variable is death anxiety score; Independent variables include age, race, gender, work setting (rural/urban), formal education (BSW, MSW, PhD), work status (full/part time) and years of experience.

Hypothesis 2: Oncology social workers with higher death anxiety scores will be less likely to have completed a personal advance directive.

The Death Anxiety Score will be higher for those who answer “no” to whether they completed an advance directive than for those who answered “yes.”

Hypothesis 3: Oncology social workers with higher death anxiety scores will be less likely to communicate with patients about advance directives.

The correlation between death anxiety scores and the willingness to communicate with patients about advance directives will be negative.

Theoretical Definitions of Terms

Three theoretical definitions are important to this study: advance directive, death anxiety, and communication with patients.

Advance Directive. An advance directive is a document that allows an individual to state preferences for or against medical treatment in a particular situation or, if the individual is not competent, who should be assigned to make such a decision (*Social Work Speaks*, 2003-2006). The discussion and process leading to the completion of such a document is referred to as advance care planning (Wilkinson et al., 2007).

Death Anxiety. Death anxiety is the fear of death due to the realization that death does not make sense outside of the understanding of one's beliefs or awareness. Death anxiety is produced by the realization that death is a necessary threat of nonexistence on the one hand, and the understanding of life completely on the other (Neimeyer, 1994).

Communication. Communication includes any interactions, whether verbal or written, with patients or families regarding advance directives (Black, 2005b).

Operational Definitions

The correlation of death anxiety scores of oncology social workers and the completion and discussion of advance directives are based on the following operational definitions:

Advance Directive. In this study, an advance directive is a written document an individual completes that indicates preferences for medical treatment, or appointment of an agent to make this decision, should the individual lose the capacity to make the decision. This directive may include the living will and/or durable power of attorney. A completed advance directive will be measured as a document recognized in the state of residence of the social worker.

Death Anxiety. In this study, death anxiety is the uneasiness toward death that is not in the conscious mind or thoughts, but is present in the unconscious. Death anxiety will be measured using the Revised Collett-Lester Fear of Death and Dying Scale (Neimeyer, 1994).

Communication. In this study, communication with patients is the interaction between social workers and patients/families and other professionals about advance directives. Communication will be measured using Black's (2000) Advance Directive Communication Practices Instrument, with modifications.

Assumption

One key assumption will be made in conducting this study. The assumption is that it is desirable for oncology social workers to have lower death anxiety scores, a personal advanced directive, and communications with patients about advance directives.

Limitations and Delimitations

Biases may exist in self-reports of oncology social workers regarding death anxiety due to interest in the topic. Also, the reports of death anxiety among oncology social workers may be no different than reports among social workers in general or other health care providers. Additionally, oncology social workers are not the only providers assisting

with advance directives; thus communications with patients about advance directive documents may not reflect only the outcome of social work interventions.

Because the sample in this study includes only oncology social workers who are members of the Association of Oncology Social Work, this delimitation is also a major limitation in terms of generalizing the findings. The generalizability of this study will be limited to oncology social workers. Characteristic factors such as level of education and years of experience may influence the results obtained. A replication of the study with different samples may be desirable.

Conclusion

This chapter identifies the completion of advance directives by less than 15 percent of the public as a significant health care issue. It proposes that the problem is facilitated by the death anxiety of social workers. The death anxiety of social workers is hypothesized as related to the completion of a personal advance directive as well as the likelihood that the social worker will communicate with patients about advance directives. Chapter 2 focuses on key literature related to this study. Chapters 3, 4, and 5 will discuss the methodology of the study, and the results and implications for future research, policy and practice.

Chapter 2

Literature Review

The intent of this literature review is to examine the role of oncology social workers communication in advance care directives, with particular attention to death anxiety as an impediment to such advance care planning. Two theories with relevance to death anxiety are discussed: Terror Management Theory (TMT) and Personal Construct Theory (PCT). Because the literature on oncology social workers is scarce, the review will address the more general role of social workers in end-of-life care and the particular role of oncology social workers in health care, when such research is available and relevant. Special attention is given to end-of-life care and advance-care-planning, and the role of the profession in promoting social work practice in death and dying.

The review focuses on attitudes and behavior toward advance directives with particular attention to social work practitioners, in addition to other health professionals, namely nurses and physicians. Advance directives are described, their limitations noted, and patients' attitudes towards advance directives are examined. Death anxiety, proposed as one factor influencing the implementation of advance directives, is defined, and attitudes toward death and experiences with end-of-life care among health professionals are explored, including physicians, nurses, social work students, and social work practitioners.

Social Work

Social workers have long been recognized as having a central role in health care and advance care end-of-life planning for their clients (Christ & Blacker, 2005; Luptak, 2004). More than 20 years ago they were referred to as “the hub of the inter-

disciplinary team that provides comprehensive medical and support services to patients facing death” (Taylor-Brown & Sormanti, 2004, p. 3). Today, social workers are playing an even greater role in end-of-life care brought about by the aging of the baby boom population; by increased life expectancy; by change in the leading causes of death from acute to chronic; by life-sustaining medical and technological advances; and by the shift in setting of death from home to hospital or nursing home (Clark, 2006; Rosen & O’Neill, 1998; Cohen, McGuinnis & Wing, 2006; Taylor-Brown and Sormanti, 2004; Wilkinson et al., 2007).

Social workers in health care have been trained to help patients and their families cope with challenges associated with acute care and chronic conditions. However, because life and death are not predictable, any social worker – not just those working with ill or older patients – may be called upon to deal with end-of-life decision-making. This can include working inclusively with the individual, the family, and the medical and social systems (Heyman & Gutheil, 2003).

Along with other health professionals, social workers play a key role in advance care planning, allowing patients to take control of their medical care through advance directives (Brandsen, 2005; Christ & Blacker, 2005; Emanuel & Emanuel, 1993).

Advance directives assist individuals in communicating their wishes for future medical care. This is accomplished through the health care proxy, or durable power of attorney for health care, in which another person is designated to make health care decisions for an individual who is unable to do so. The living will documents an individual’s desires regarding medical treatment, and can be thought of as a physician’s guide (Heyman & Gutheil, 2003). Advance care planning, as used by the National Association of Social

Work, “encompasses all aspects of an individual’s desires for end-of-life care, including living will and health care proxy, along with ‘do not resuscitate’ orders and funeral planning” (National Association of Social Work, 2003-2006).

Historically, a number of major developments have contributed to social work practice with death and dying. These include the hospice movement; the creation and promotion of advance health care directives in the 1970s and 1980s; the Patient Self-Determination Act of 1990; and the National Association of Social Worker’s first policy statement on end-of-life care, in 1993. More recently, to reinforce existing practices and foster improved practices, the National Association of Social Workers (NASW) developed *Standards for Social Workers in Palliative and End-of-Life Care* (NASW, 2003-2006) (Hoffman, 1994; Rosen & O’Neill, 1998; Taylor-Brown and Sormanti, 2004).

In 2005, a national agenda for social work research in palliative and end-of-life care was proposed, based on the rationale that “Social work is the most broadly based profession in relation to contexts of care for people who have a life-threatening condition or have experienced a death in their social network or a profound and traumatic loss” (Kramer, Christ, Bern-Klug & Francoeur, 2005, p. 419). Despite broad-based efforts to promote the use of advance directives through government legislation and initiatives of advocacy organizations such as the American Medical Association and the National Cancer Institute, the acceptance of advance directives by the medical, legal, and lay communities remains disappointingly low (Cohen, 2007; Ditto et al., 2005; Douglas & Brown, 2002; Heyman & Gutheil, 2003). "Lack of communication . . . and misunderstandings about the appropriateness and purpose of advance directives may explain why completion rates remain low" (Rosen & O’Neill, 1998).

Oncology Social Work

Oncology social work represents a specialty area within social work. Working in a variety of settings such as hospitals, clinics, hospice and community based programs, oncology social workers function as primary providers of psychosocial services to people with cancer (Association of Oncology Social Work, 2008). More specifically, oncology social workers assist patients, families, and colleagues, as they encounter complex matters such as advance directives, treatment decisions, choices about end-of-life care, and communication with the medical team (Rosen & O'Neill, 1998).

The Association of Oncology Social Work (AOSW) has 1,073 active members (AOSW, 2008), although all practicing oncology social workers are not members of the organization. The AOSW (2006) conducted a survey of its membership in 2005 (with responses from 622 out of the 844 members surveyed). The large majority of respondents held a Master's Degree in Social Work (88.9 percent) and was licensed in social work (84.7 percent). More than half (57.7 percent) practiced in urban areas, with the rest in suburban (29.2 percent) or rural (13.2 percent) areas. The primary practice setting for just over two-thirds of respondents (64.8 percent) was a hospital, clinic, or long-term care facility. For the rest, an academic/university health system (16.5 percent); an agency or community based organization (10.0 percent); a private practice (9.9 percent); a hospice; a mental health/medical office (3.1 percent); homecare (1.3 percent); or some other setting (12.0 percent). The typical oncology social worker worked 40 hours or more per week in their primary practice setting (70.6 percent), averaging 104 client contacts per month.

On the whole, survey respondents reported a very high degree of competence in the areas of end-of-life issues (99.6 percent) in general, and advance directives in particular (72.9 percent). However, the survey also identified a number of challenges to the profession, including the following: most adult cancer patients were seen and treated in community settings, though most oncology social workers practiced in high level tertiary settings; and persons over the age of 65 comprised about two-thirds of all people diagnosed with cancer, while only 44 percent of the work time of oncology social workers was devoted to older and elderly patients (AOSW, 2006).

Oncology social work related to advance directive planning has particular significance when considering that one of every four deaths in the United States is caused by cancer—the second most common cause of death today. Statistics also indicate that in 2007, approximately 1,500 persons per day died as a result of cancer (American Cancer Society, 2007). Most people with newly diagnosed cancer are over age 65, a fact that will significantly impact oncology social work as the first of more than 77 million baby boomers begin to reach that age in 2011 (Clark, 2006).

Advance Directives

Advance health care directives, introduced in the late 1960's by the attorney Louis Kutner, offer a practical solution to ensuring patient autonomy at the end-of-life. Advance directives provide specific instructions, prepared in advance, that direct medical care should a patient become unable to do so in the future because of a terminal illness or life-threatening injury. By encouraging patients and families to communicate with health providers about treatment wishes, advance directives can contribute to improved end-of-life care, and by eliminating unwanted end-of-life treatment, they can also contribute to

cost containment efforts. Kutner first proposed advance directives because technological advances were changing quickly in the medical field. Mechanical ventilation and artificial hydration/nutrition were allowing people to be kept alive for years in a persistent vegetative state, the landmark case being Karen Ann Quinlan (Ditto et al., 2005; Osman & Becker, 2003).

According to Wilkinson et al., (2007), advance directives are most effective as part of a “comprehensive, ongoing, and holistic” advance care planning process (p. 1). Similarly, The National Association of Social Work (2006) has maintained that end-of-life decisions should “be considered at numerous junctures over the course of one’s life, not just when diagnosed with a terminal illness, or faced with an acute life-ending event” (p. 129).

Promotion of Advance Directives

Since the introduction of advance directives, there has been an increase in support for the right to end-of-life autonomy, and self-determination in end-of-life decision-making (Luptak, 2006). To educate health care professionals and consumers about their right to prepare advance directives, Congress passed the Patient Self-Determination Act (PSDA) of 1990. Implemented in 1991, this Act requires all health facilities (including hospitals, home health agencies, and hospices) that receive federal funds to provide all patients with information about advance directives. This information is to inform patients of their rights to complete an advance directive and, as such, to accept or refuse treatment (Douglas & Brown, 2002; Rosen, 1998). More specifically, the PSDA established that designated providers:

(a) maintain written policies and procedures regarding the rights of adult patients to accept/decline health care services, and to formulate advance directives; (b) maintain policies and procedures regarding the implementation of patients' advance directives; (c) document in the medical record whether or not the patient has formulated an advance directive; (e) provide care regardless of whether the patient has or has not executed an advance directive; and (e) provide education to staff and the community on the availability and applicability of advance directives (Osman & Becker, 2003, pp. 29-30).

However, despite such policies and laws that encourage and/or protect patients' rights to determine their end-of-life care, little has been done to ensure compliance or impose sanctions when these rights are violated. For instance, health care facilities that are noncompliant with the 1991 Patient Self-Determination Act rarely have federal funds withheld (Connell & Mallory, 2007).

Limitations of Advance Directives

Emanuel and Emanuel (1993) identified two distinct limitations of prior written directives, though on the surface living wills and other instructional directives "seem to be an unproblematic way of ensuring desired care when it is not possible to speak for oneself" (p. 2). One concern referred to the inherent limitations of giving prior instructions. Patients may not adequately understand all the medical issues, may find that clinical circumstances have changed from what they anticipated, and may want to make different decisions. A second issue is relevant to patients who have completed advance directives: the document may not be available when needed the most, or physicians may not honor them. Additionally, limitations are associated with the lack of the proxy's

ability to match patients' wishes in order to execute the same choices the patient would make, if a proxy has been designated.

Ditto et al. (2005) noted that much of the recent research has questioned whether or not most people in fact want "tight control over their end-of-life care" (p. 498). As stated earlier, although people tend to support the idea of advance directives, relatively few people--whether healthy or seriously ill--actually complete them (Ditto et al., 2005; Wilkinson et al., 2007). In a retrospective study of medical records after patient deaths, 55 percent of cancer patients had advance directives as compared with only 14 to 24 percent of severely or terminally ill non-cancer patients (as cited by Wilkinson et al., 2007). Completed advance care directives alone have not always been an indicator of the patients' satisfaction with their care; satisfaction with primary care has been noted following *discussions* about advance directives (Tierney et al., 2001).

Death Anxiety Defined

Death anxiety has been defined by Neimeyer as "that experienced in everyday life rather than in acute situations where there are immediate threats to life" (Payne, Dean & Kalus, 1998, p. 701). Because death anxiety is multifaceted, it includes anticipating one's own death and fear of the process of dying. However, Neimeyer extended the discussion to include death anxiety for health professionals who deal with death on a daily basis. Avoidance as a coping strategy was more likely to be used by professionals with higher death anxiety (Payne et al., 1998).

Noting definitional problems regarding the concept of death anxiety, Nyatanga & de Vocht (2006) offered the following definition: "an unpleasant emotion of multidimensional concerns that is of an existential origin provoked on contemplation of

death of self or others” (p. 413). Although anxiety and fear are often used interchangeably, it is appropriate to avoid confusion between the terms. Specifically, *fear* is prompted by a clear object, an imminent threat or actual danger, whereas *anxiety* is prompted by an element of uncertainty. Of particular importance for this literature review was the authors’ assertion that an emotion such as death anxiety “can be felt when caring and witnessing death and dying experiences of palliative care patients and not just close relations” (p. 413). Pyszczynski (2004) identified fear and anxiety as “inherent aspects of the human condition” (p. 827). He suggests that all animals, including humans, experience *fear* when faced with survival threats, while only humans experience *anxiety*, “a more diffuse form of fear in which it is not always obvious just what it is we are afraid of” (p. 827).

Attitudes toward Death

Neimeyer, Wittkowski & Moser (2004) document that for more than 50 years, attitudes toward death have been a topic of interest. From the early work with geriatric and mentally ill populations in the late 1950s by Feifel, through the 1970s and 1980s, a broad range of areas dealing with death attitudes have been measured. Research efforts have focused on the elderly; physical and mental health; and, of particular relevance for this review, death anxiety among medical and non-medical caregivers.

Although studies (Neimeyer et al., 2004) have indicated that the personal death anxiety of professionals working with persons who are dying might be lower, perhaps the more salient question addresses the impact that anxiety has on performing their jobs. Over the years, research has shown that higher death anxiety has had a negative impact on the responsiveness of medical staff interactions with patients related to death.

Age and gender have also been found to influence death anxiety, with young adults and women generally reporting greater anxiety than their counterparts. Based on these findings (as cited by Russac, Gatliff, Reece & Spottswood, 2007), early research efforts ignored the effects of age-related changes during the adult years based on the belief that age would have little impact “once a mature understanding of death [was] achieved” (p. 549). Some later research, however, identified changes in death anxiety over time. The impact of gender on death anxiety was also re-examined, and findings have been inconclusive (Neimeyer et al., 2004; Reese et al., 2005).

To further examine how death anxiety varied among men and women by age, Russac et al. (2007) conducted two studies of death anxiety across the adult years. The first was a study of 304 men and women aged 18 to 87 years old. It showed that death anxiety, as measured by the Collett-Lester Fear of Death scale, peaked in both men and women during their late 20s and then declined significantly in the years to follow. Only women were found to show a secondary spike in death anxiety during their 50’s. The findings of a second study, based on 113 women aged 18 to 85 years old, were similar to Study 1. This study suggested that the cause of increased death anxiety among participants in their 20s and among women (not men) in their 50s should receive greater attention. Both studies indicated that by age 60, death anxiety appeared to stabilize among both men and women at a consistently low level.

Terror Management Theory

Terror Management Theory (TMT) emerged in 1986 from the work of Jeff Greenberg, Tom Pyszczynski, and Sheldon Solomon, contemporary social psychologists. TMT was inspired by the writings of the late Ernest Becker, a cultural anthropologist who examined

motives and functions of behavior. The premise of the theory is that human beings, because of their unique intellectual abilities, face a major problem – the certainty of death despite base instincts to live (Pyszynski, 2004). Stated simply, mortality awareness produces death anxiety, or terror (Hui, Bond & Ng, 2006-2007; Shehryar & Hunt, 2005).

This clash between desires for self-preservation in the face of inevitable death creates the potential for “paralyzing terror” (Pyszynski, 2004, p. 830). Proponents of TMT have argued that humans would be immobilized or debilitated if they had to live with the constant recognition of their mortality (Neimeyer et al., 2004). To manage this terror, humans must rely on a buffer that includes two parts: a cultural (shared) worldview that offers a meaningful explanation of life and our place in the cosmos (i.e., there is something more enduring than one’s own physical life); and self-esteem or the belief that we are valuable contributors to this meaningful reality. Also part of TMT is the hope of transcending death and attaining immortality in one of two ways: literal immortality, i.e. death is not the end of existence in that we can live on in an ethereal heaven or through reincarnation; and symbolic immortality, i.e. death is not the end of existence in that we can live on through our children and families (as extensions of ourselves) and significant accomplishments (in terms of wealth or fame that endure beyond death) (Arndt, Routledge & Goldenberg, 2006; Hui et al., 2006-2007; Pyszynski, 2004).

According to Terror Management Theory related to health decisions, defenses against death anxiety include proximal and distal defenses referred to as a “dual defense model of terror management” (Arndt et al., 2006, p. 595). These defenses can be used to help move along “adaptive or maladaptive health trajectories” (Arndt et al., 2006, p. 596). Proximal defenses include positive engagement in healthy behaviors to help ward off the

possibility of death. An alternative proximal use is to suppress and rationalize away thoughts of death when they enter the consciousness. Distal defenses are used when death-related thoughts are prominent but outside of the conscious mind. These defenses include the need to reaffirm one's self-concept. Self-concept is how a person perceives her/his *self*, and is comprised of a variety of identities, attitudes, beliefs, and values (Arndt et al., 2006).

One of the limitations of current TMT research is that it does not explain how individuals structure their reality, and what effect this has on their responses to anxiety. Arndt & Vess (2008) suggest that the same thoughts that allow awareness and terror are also available to help alleviate terror. To help explore this aspect more we must consider a second conceptual framework, Personal Construct Theory.

Personal Construct Theory

Personal Construct Theory (PCT) was introduced in 1955 in a two-volume work, *The Psychology of Personal Constructs*, by the American psychologist George Kelly (Cote, 1995). In a radical departure from the dominant theoretical perspectives of the 1950s, behaviorism and psychoanalysis, Kelly sought to develop an approach that allowed people to be able to understand their life events, to make decisions based on this knowledge, and thus maintain control of their lives (Cote, 1995; Holland, Neimeyer, Currier & Berman, 2007). Kelly proposed that people are driven by the need for personal control. By continuously predicting events of their daily lives, individuals build structures that help with interpretation. Specifically, he believed that there was no one particular way of viewing reality. Rather, he believed that for any given event, people could rely on a number of viable alternatives to give meaning to even the most difficult circumstances.

PCT allows people to be “scientists” trying to make sense of their own reality (Holland et al., 2007). When faced with constructs or ideas that are not familiar, anxiety may be present if an event or expectation is not familiar and does not fit into one's current constructs. Constructs change as individuals face challenges. These changes are an attempt to better understand reality. PCT has been used in previous studies to consider how family members are able or unable to understand another's perspective; and in examining commonalities of work teams in the completion of mutual tasks (Neimeyer & Bridges, 2004).

Death Anxiety and Health Professionals

The origin of death-related attitudes among health professionals has been associated both with early experiences prior to medical training, such that pre-professionals may have selected a health career based on “already established attitudes toward death,” as well as with later experiences, such that health professionals may develop attitudes toward death in reaction to their medical training (Servaty et al., 1996, p. 151). Death anxiety has been found to be a key variable for social work and medical students that influences end-of-life treatment decisions and client outcomes. That is, a professional's death anxiety may prevent the client access to a full range of end-of-life care choices (Reese et al., 2005).

With deaths now occurring most often in institutionalized settings, including hospitals and nursing homes, research on attitudes toward death has come to focus on health professionals (Servaty et al., 1996). However, because of the relative paucity of research on the role of oncology social workers in their personal and professional use of advance directives, this review also examines how other health professionals have responded to

death and dying in general and the use of advance directives in particular, with possible implications for the field of social work.

Advance Directives and Health Professionals

Go et al. (2007) found that health care professionals caring for patients with cancer were not likely to have executed their own advance directives. The authors noted that among this group the rate of completion was still quite low, at about 35 percent. Among those who did have a completed advance directive, experiences at work and with family were the top reasons provided for having an advance directive. Lack of time was the reported primary barrier to the completion of the document.

Physicians

Although both patients and physicians recognize the importance of advance directives, such discussions have proven to be relatively uncommon. Patients tend to believe physicians should be responsible for initiating discussions about advance care, and physicians believe patients should raise the issue. Barriers to discussions between physicians and patients include time constraints, communication obstacles, and physician concern that the topic would be distressing to patients (Tierney et al., 2001). Medical schools in the U.S. traditionally have not offered training related to the various aspects of dying (Bickel-Swensen, 2007; Reese et al., 2005). A review of the literature by Wilkinson et al., (2007) found that providers have received little formal training in advance care planning and related issues, and many times are not comfortable having those discussions. A systematic literature review by Bickel-Swensen (2007) found uniformly that end-of-life curricula and clinical training was positively associated with the improved competency of medical students in addressing “the physical, emotional, and

psychosocial issues related to death and dying” (p. 233), including the development of appropriate plans for care.

Nurses

Death anxiety in nursing professionals has been well documented. One study (Chen, Del Ben, Fotson & Lewis, 2006) showed that nursing home personnel, including registered nurses, licensed practical nurses, and nurses aides, reported a higher measure of death anxiety when compared with those who worked in non-death-related occupations. This difference was most likely due to exposure and expectations related to death and the dying process. Another study (Payne et al., 1998) also found higher anxiety with hospital nurses when compared to hospice nurses. The hospice nurses also reported higher levels of comfort in caring for the terminally ill patients.

Social Work Students

The literature suggests that as with medicine and nursing, preparation for end-of-life care has been lacking in social work education and training (Csikai & Raymer, 2005). Curricula content on death and dying is usually presented in one or two lectures within other courses, and separate end-of-life courses are typically offered on an elective basis only. Moreover, only one-fourth of faculty surveyed believed that such courses adequately prepared students for providing end-of-life care to clients (Brandsen, 2005; Reese et al., 2005). According to a study by Csikai and Raymer (2005), the main source of end-of-life care content was continuing education, though time away from work and the expense of course attendance were cited by more than half the respondents as barriers to participation.

According to Heyman and Gutheil (2003), professional education can have a positive impact on students' attitudes toward end-of-life planning. Masters level students participated in a study based on the idea that graduate school can help prepare students to take a role in assisting clients with end-of-life planning that includes advance directives. A key finding of the study was that over half of the students had knowledge about advance directives, but the knowledge was not correct. There was also a concern that the students had not had an opportunity to work through their own feelings about end-of-life issues, and that this factor could present a barrier to working with patients.

Social Work Practitioners

According to Black (2004) social workers have a primary part to play in the communication of advance directives. Social workers have been identified as “the preferred staff member to discuss end-of-life family planning issues” (p. 132). However, Black (2005a; 2005b) examined how personal death attitudes and experiences of social workers were related to their advance directives communication practice behavior, and found death is not a topic that is comfortable for social workers. The author found that social workers' communication behavior was associated with their personal death attitudes and recent experiences related to death. Communication with patients and interdisciplinary work was negatively affected and, as such, posed barriers to advance directive interactions. Black noted the importance of having social workers address issues related to death and dying, both professionally and personally, throughout the social work educational process and professional careers.

Attitudes toward Advance Directives

The literature (Wilkinson et al., 2007) has identified five elements patients desire for discussions about advance care planning: a) feeling comfortable with the health care provider, b) feeling that the provider showed compassion and respect for the patient, c) having the provider clarify the degree of detail that patient/caregivers wanted, d) negotiating who should be present during the discussion, and e) involving their continuity physician in the discussion. Patient characteristics associated with the lack of completing advance directives have also been studied and may be summarized as follows: African Americans were more likely than Hispanics to defer decisions about end-of-life care to their family members; non-Hispanic Caucasians were more likely to allow physicians to make such decisions; the relationship between age and completion of advance directives were inconsistent; the relationship between gender and completion of advance directives varied by study; and the relationship between health status and completion of advance directives varied (Douglas & Brown, 2002).

Health care setting has also been associated with the use of advance directives. While evidence suggests that relatively few people in the general population have completed advance directives, studies have shown that nursing home residents have a higher documented rate of completion than in the population at large. This may be due to the availability of social workers in the facility *and* their willingness to discuss advance directives (Osman & Becker, 2003).

Conclusion

According to the Association of Oncology Social Work (2007), its members represent a diverse array of social workers serving as primary providers of psychosocial services to

cancer patients and their families (p. 2). Based on the professional responsibilities of health social workers, the potential for promoting and implementing advance directives is great. Health social workers have been trained to assist patients and families coping with acute and chronic conditions, offering a biopsychosocial approach to care (Black, 2005a; Brandsen, 2005). Oncology social workers, in particular, have been trained to provide psychosocial services to those affected with cancer (Association of Oncology Social Work, 2006). Despite the fact that the social work profession has promoted the use of advance directives as part of end-of-life care planning, patient adoption of advance directives remains surprisingly low, at less than 30 percent of Americans (Wilkinson et al., 2007). Death anxiety as an impediment to promoting or adopting advance directives by health professionals has been addressed in the literature (Reese et al., 2005), and additional training for health professionals is indicated as a need area by the professional literature (Bickel-Swenson, 2007; Connell & Mallory, 2005; Csikai & Raymer, 2005; Heyman & Gutheil, 2003; Reese et al., 2005; Wilkinson et al., 2007).

Chapter 3

Method of Study

This study utilized a survey design. The primary focus centered on the extent to which death anxiety among oncology social workers influences the completion of their personal advance directives, as well as communication with patients with whom they interact. The research design, samples, instrumentation, consistency of the study, data collection and statistical procedures utilized to study these relationships are described in this chapter. The analysis of this data is presented in succeeding chapters.

Design

This cross-sectional study utilized a survey design to elicit information from oncology social workers. This information, which included demographic data, was used to identify and compare the relationship between death anxiety scores, completion of, and discussions about advance directives. After the data was collected, variables were examined for potential cause-and-effect relationships influencing the completion and discussion of advance directives.

The dependent variables were identified as the death anxiety scores, advance directive completion, and patient centered communication about advance directives. Attempts to measure death anxiety are not new, and studies have shown that while persons do not deny feelings of uneasiness surrounding discussions of death, more studies examining the various aspects of anxiety are needed (Neimeyer et al., 2004; Wass & Neimeyer, 1995). Additionally, the rates of completion of advance directives for hospital staff members has been reported to be as low as 12 to 24 percent (Gutheil & Heyman, 2005; Schirm & Sheehan, 2005) and, for nursing home staff, 28 percent (Schirm & Sheehan, 2005). The

importance of communication in the process of advance directives and end-of-life care has recently been the focus of studies both across disciplines (Gutheil & Heyman, 2005; Huffman, 2001; Jezewski et al., 2005), and in social work (Black, 2005a, 2005b; Werner et al., 2004).

The independent variables, which possibly influence the social worker's interaction with advance directives, included (a) age, (b) race, (c) gender, (d) work setting, (e) formal education, (f) death anxiety scores, (g) work status (full-time or part-time), and (h) professional status (years of experience). A review of literature has indicated a lack of agreement as to the influence of age, race, and gender. Some studies have shown that older white women are more likely to complete advance directives, but the data is not in agreement in terms of results or reasoning across numerous studies (Gutheil & Heyman, 2005; Neimeyer et al., 2004; Wass & Neimeyer, 1995).

Target Population and Sample

The target population for this study was all oncology social workers who are registered members of the Association of Oncology Social Work (AOSW), based in the United States. The AOSW has close to 1000 members practicing in a variety of settings, including hospitals, outpatient clinics, home care agencies, community wellness programs, and patient advocacy groups. Of those members, 967 AOSW members have emails on file. The AOSW agreed to allow the membership to be contacted with an initial email and one follow-up email.

The selection of participants was based upon the results of a power analysis. This statistical procedure determined that 114 total responses were needed to detect the effects, if any existed, attributable to the independent variables (Tabachnick & Fidell,

1996). The overall former response rate, and the only current published use of the communication survey, was less than 20 percent (Black, 2005a). Assuming a 20 percent response rate, 570 surveys to members were needed (20% of 570 = 114) to obtain the desired 114 responses. A table of random numbers (Rubin & Babbie, 1989) was used to select 570 members from the 976 member list.

Instrumentation

The Revised Collett-Lester Fear of Death and Dying Scale

The Revised Collett-Lester Fear of Death and Dying Scale (Lester, 1994) was used to collect data on death anxiety. The author published permission for use of the scale to any researcher, so no additional contact was required. After reviewing the literature related to measuring death anxiety, this scale was chosen because of its ability to measure fear for self as it related to fear of death and fear of dying (Neimeyer, 1994).

The original Collett-Lester scale was revised for two reasons, as cited by the author: 1. The subscales had varying numbers of items, and 2. Inaccurate scoring was commonly noted in reports using the original scale (Neimeyer, 1994). The author revised the scale to reflect a self-administered, 36-item scale that is divided into distinctive sub-scales of eight questions: death of self, dying of self, death of other, and dying of others. For the purposes of this study, focused as it was on the social worker's personal death anxiety, only the subscales of death of self and dying of self, a total of 16 items, were analyzed. An earlier study examining the construct validity of the instrument indicated that the Cronbach alpha coefficient of each subscale was acceptable (.84 for death of self and .86 for dying of self) (Mooney, 1999) and could stand alone.

The two subscales of the Revised Scale utilized a 5-point Likert scale format and addressed the topics of: (a) Your Own Death, and (b) Your Own Dying. Subjects were asked to read an item and indicate the number that best reflected their feelings from Very = 5 to Somewhat =3 to Not =1, with 4 = between Very and Somewhat, and 2 = between Somewhat and Not.

Your Own Death. This subscale addresses how disturbed or anxious the participant is made by aspects relating to their own death. Statements in this subscale included issues of the isolation of death, shortness of life, dying young, and various aspects of feelings after death. The number of items in the scale divided the total score of items in order to obtain a mean subscale score.

Your Own Dying. This subscale addresses how disturbed or anxious the participant is made by aspects relating to their own dying. Statements in this subscale included physical changes, pain, loss of intellect and abilities, grief of others, and lack of control over the process of dying. The number of items in the scale divided the total score of items in order to obtain a mean subscale score.

The Advance Directive Communication Practices Instrument

The Advance Directive Communication Practices Instrument (ADCPI) by Black (2000) was modified and utilized, with the author's approval, to measure the social workers' communication interactions. The ADCPI is a six part, self-administered 27-item scale that used a 5-point Likert scale, dichotomous, interval and open-ended questions format. On the Likert scale subjects were asked to read an item and indicate the point that was closest to their behaviors, from All of the time = 5 to Some of the time =3 to None of the time =1, with 4 = between All and Some of the time, and 2 = between Some and

None of the time. The total score of items were divided by the number of items in the scale to obtain a mean subscale score (Black, 2005b).

Two modifications were made to the scale. The first modification included removing the term *elderly* before the word *client* so that all clients were included. The second change removed subset answers to the question asking for identification of work organization, and became a dichotomous question of private or public. This scale was selected for this study for its ability to measure communication *specifically* related to the advance directive document.

Part I: This section of the instrument provided questions addressing the initiation of the topic of advance directives by the social worker. It included client characteristics that are considered, provision of information specific to the completion of advance directives, and discussions after the topic was broached. This section contained Likert style and open-ended responses.

Part II: This section of the instrument provided questions addressing the social worker's role in the patient's appointment of a health care surrogate decision-maker and the formulation of treatment desires in the advance directive communication process. Questions addressed selection of a surrogate, and addressing future health care treatment options with clients. In addition to addressing physical aspects of care, values in living were also considered. This section contained Likert style and open-ended responses.

Part III: This section of the scale contained questions specifically regarding advance directive communication interactions with clients' family members and significant others. Questions in this part of the scale included key factors motivating the social worker to

include others, such as prognosis, expectations, other health care professional suggestions and incapacity issues. This section contained Likert style and open-ended responses.

Part IV: This section of the scale included questions addressing collaboration practices with other health care professionals specific to advance directive communication with clients. Questions in this part of the scale included frequency of contacts and variety of disciplines. This section contained Likert and open-ended style responses.

Part V: This section of the scale contained questions addressing how much time is spent engaged in advance directive communication with clients. Questions in this part of the scale included typical workday, and rating the amount of time spent communicating about advance directives with clients. This section contained interval measurement responses.

Part VI: This section of the scale contained questions addressing socio-demographic characteristics, including work settings, employment status, professional status, and demographic variables. Organizational policy influences, acting in the capacity of a health care proxy, advance directive communication practices with elderly clients versus younger clients, additional education related to death and advance directives, and the completion of their own advance directive were also addressed in this part. This section included dichotomous, interval and open-ended questions.

Internal Consistency

The reliability of this study was based on the history of the Revised Collett-Lester Fear of Death and Dying Scale and the ADCPI. The first scale's previous use of Cronbach's alpha for the two subscales was 0.91 for death of self, 0.89 for dying of self.

Pearson correlations have been reported as 0.85 for death of self, and 0.79 for dying of self (Lester, 1991). The ADCPI has produced a Cronbach alpha reliability co-efficient between .80 and .92 in a previous study (Black, 2005b).

It is assumed that the Revised Collett-Lester Fear of Death and Dying Scale measures anxiety related to death for oncology social workers. Based on a previous test for construct and concurrent validity, correlations of 0.41 for death of self, and 0.31 for dying of self, was realized with the Maudsley Personality Inventory (Lester, 1994). It is assumed that the Advance Directive Communication Practices Instrument (ADCPI) measures the behaviors of oncology social workers in relation to advance directives communication. The ADCPI has not been tested on large samples, but has shown validity in a small study (Black, 2005b).

External Consistency

The generalizability of the findings of this study is limited to oncology social workers. The generalizability could also be impacted by the lack of ethnic and gender diversity among the participants. The sample for this study was comprised primarily of Caucasian females.

Data Collection

Approval for this research project was obtained in February 2007 from the University of Missouri Campus Institutional Review Board. The combined survey instruments and potential participants emails were placed on the SurveyMonkey survey software service (Finley, 1999). Information about the survey and the consent for participation or refusing to participate without negative effects were included in the survey and the accompanying email.

The first email contact with the Association of Oncology Social Work members was made on June 1, 2007. Five hundred seventy social workers were sent emails requesting that they complete and return the survey via the internet service. Over the course of several days, 81 emails were returned as undeliverable. Continuing with the random selection of potential participants, additional emails were sent until 570 had been sent and not returned as undeliverable. Within the first two weeks, three potential participants opted-out of the survey process; one responded that due to having too much patient care the survey would not be completed; and one replied by email that due to family illness they were unable to participate. Seventy-three surveys were completed and fourteen were incomplete at this time.

On June 18, after a reminder email, an additional 30 surveys were completed, yielding 103 completed surveys. On July 24, special permission was obtained from AOSW to send one more email in an effort to obtain the 114 surveys needed as indicated by the power analysis. On July 24 a reminder email was sent requesting that the survey be completed. When the survey ended July 31, 2007, the survey service indicated that out of 140 email recipient responses, 21 partially completed the survey and 119 completed the survey. Thus, a response rate of 25% was achieved (N=570), and the power analysis goal was met. Nine email recipients opted-out of the survey process. One participant emailed the researcher and suggested that the length of the survey was asking for too much time from practitioners. Additional explanations of nonparticipation were not forthcoming so, in compliance with the original agreement with the AOSW, there were no phone calls or additional attempts to contact potential participants.

Data Analysis and Statistical Procedures

Several statistical procedures were used to analyze the data collected. The analysis began with the data being exported from SurveyMonkey to an Excel file. The researcher determined that all data was transferred accurately. The cleaning and organizing of the data then began, as the researcher visually examined each of the 140 cases on the computer screen for incomplete and missing data. As stated earlier, 114 cases were needed in the sample, based on the power analysis number required to test the hypotheses.

Missing data can reduce the credibility of the data set (Heppner & Heppner, 2004). Therefore, the researcher decided to exclude any case with more than 25% of the questions left unanswered and, using this criterion, removed 23 cases. Another case was removed because the respondent self-identified as not having any social work license or degree, although this respondent was a member of the AOSW. Two cases were removed because these social workers self-identified as academic social workers who do not engage in advance directive discussions at this point in their career. From the 140 original cases collected, then, 114 met the selection criterion for further analysis.

Within the 114 cases, missing data were again examined. For questions in the Revised Collett-Lester Fear of Death and Dying Scale that had only one data point missing in the subsections, the individual person's mean score replaced the missing value (Tabachnick & Fidell, 1996). There were six cases that required replacement of a missing value. In the ADCPI, missing data was not replaced, but coded. After the missing data issue was addressed, the data was then imported to the SPSS statistical package. Again, the researcher determined that all data was transferred accurately.

Preliminary data analyses were carried out to ensure that the assumption of normality was met, and to identify outliers, should they be present. Descriptive statistics were obtained for the continuous variables and frequencies for the categorical variables. All variables except one had a normal skew and kurtosis. Normal skew was determined using the formula of two times the standard deviation in a negative and positive direction.

Chapter 4

Results

The purpose of this dissertation was to examine the extent to which the death anxiety of oncology social workers impacts the facilitation of the completion of their personal advance directives, and communication about advance directives with patients. The justification for this study was identified in Chapter 1. The review of literature pertaining to death anxiety, advance directives, and communication was provided in Chapter 2. The methods and procedures used in conducting the study were discussed in Chapter 3. This chapter summarizes the results of statistical analyses performed in response to the three research questions.

Participants

The sample consisted of registered members of the Association of Oncology Social Work (N=570). After the data were cleaned and 23 participant responses eliminated due to missing data, the final sample consisted of 114 participants. This number represents a 25% response rate.

Demographic data collected showed that 88% of participants were female and 92% were Caucasian. Due to the lack of variance in gender and ethnicity, these two traits were not used as variables in the analysis. Selected personal characteristics of the respondents were evaluated as independent variables. Participants were between 21 and 64 years of age with a mean age of 46 years. The majority of respondents worked full-time in public, urban settings and had worked from less than one year to 34 years with a mean of 16 years. Approximately half of the participants were prepared with a masters degree (46%). More than 65% of the participants indicated that they had completed their own

advance directive. The characteristics of the participants in this study were similar to those of participants in a survey conducted by the Social Work Oncology Research Group (SWORG) (AOSW, 2006). Those results are shown in Table 1.

Insert Table 1 about here

Dependent Variables

Death anxiety, advance directive completion, and social worker communication interactions were the dependent variables in the study. Death anxiety was measured using an ordinal scale from *The Revised Collett-Lester Fear of Death and Dying Scale* (Lester, 1994). Completion of personal advance directives is a dichotomous variable, requiring a yes/no response from participants. Social work communication processes were measured using eight subscales contained in Parts 1-4 of the *Advance Directive Communication Practices Instrument* (ADCPI) (Black, 2000). Analysis was performed using SPSS for Windows Release 15.0.0.

Death Anxiety. Participants identified their death anxiety on the *Your Own Death* (YOD), and *Your Own Dying* (YD) subscales. Each subscale consists of eight questions. Participants indicated their anxiety using a Likert-type scale (1 = Not very anxious; 5 = Very anxious), within the context that the minimum accepted alpha coefficient is generally .70 or higher (Heppner & Heppner, 2004). The Cronbach's Alpha coefficient for the subscales were .83 (YOD) and .84 (YD), and the coefficient for the total death anxiety scale was .89, indicating high internal consistency. Those results are shown in Table 2.

Insert Table 2 about here

Advance Directives. Advance directives were measured as a dichotomous variable with the respondents indicating *yes*, they have completed an advance directive, or *no*, they have not completed an advance directive. A total of 113 participants responded to this question, with 68% indicating that they have completed an advance directive. A summary of items is presented in Table 3.

Insert Table 3 about here

Social Work Communication Interactions. The following subscales of five communication processes were used to measure social worker advance communication practices: initiation of advance directive topic, disclosure of information, surrogate appointment, treatment options, values in living, frequency of family member/significant other interactions, family member/significant other interactions factors, and collaboration with other health care professionals. A Likert-type scale was used to collect data on the communication processes (1 = None of the time; 5 = All of the time). The Cronbach's Alpha for the subscales ranged from .80 to .90, indicating high reliability. The mean scores and standard deviations for each item subscale and a total communication score are presented in Table 4.

Insert Table 4 about here

Hypotheses

Three hypotheses were tested in this study. The first hypothesis is that the personal characteristics of oncology social workers will predict their death anxiety scores.

Hypothesis two holds that oncology social workers with higher death anxiety scores will be less likely to have completed a personal advance directive, i.e. the Death Anxiety Score will be higher for those who answer *no* to whether they completed an advance

directive than for those who answered *yes*. Finally, hypothesis three states that oncology social workers with higher death anxiety scores will be less likely to communicate with patients about advance directives. The correlation between death anxiety scores and the willingness to communicate with patients about advance directives will be negative. To begin addressing these questions, interval level variables were tested using correlation analysis, and dichotomous variables were tested using t-tests.

A correlation matrix established the degree of a relationship between variables and among variables. Bivariate correlation analysis determined the strength and direction of the relationship between variables, the amount of variation in values between variables, and the probability of sampling error (Weinbach & Grinnell, 2004). Independent t-tests were used to compare the mean differences between interval level variables and dichotomous variables.

Hypothesis 1

The personal characteristics of oncology social workers will predict their death anxiety scores.

Correlations were established among age, years of experience, education, setting (public/private), and employment (full/part time), and the subscale and total scores of death anxiety. Years of experience was positively correlated with the YOD subscale ($r = .299$, $p = .001$) and the total death anxiety score ($r = .209$, $p = .026$). The positive correlations indicate that respondents having more years of experience had higher death anxiety scores both on the subscale of your own dying and the total death anxiety score. There were no significant correlations between the other independent and dependent variables. Those correlations are shown in Table 5.

Insert Table 5 about here

T-tests were conducted to test for differences in the variance in ratings on death anxiety by work setting (rural/urban), work status (full/part time) and advance directive completion (yes/no), and no significant differences were found.

A regression analysis was performed to determine the extent to which years of experience, age, employment (full/part time), setting (rural/urban), and education explained the variance in ratings on death anxiety. This was completed to examine the relative importance of the independent variables in predicting the dependent variable. The value of $R^2 = 16.4$ identifies the percent of variance in the death anxiety score explained collectively by all of the independent variables. Table 6 summarizes this analysis. This hypothesis was partially supported by the data. Results indicated that as the personal characteristic of years of experience increased, the death anxiety score increased. Death anxiety scores and the personal characteristics of age, education, setting (public/private), and employment (full/part time) were not significantly related.

Insert Table 6 about here

Hypothesis 2

Oncology social workers with higher death anxiety scores will be less likely to have completed a personal advance directive. The Death Anxiety Score will be higher for those who answer “no” to whether they completed an advance directive than for those who answered “yes.”

Logistic regression was used to analyze the extent to which your own death anxiety, your own dying anxiety, and total death anxiety scores were risk factors for not completing an advance directive. This type of regression is frequently used in social work

research to predict the outcome of a dichotomous dependent variable with interval level independent variables (Weinbach & Grinnel, 2004). This hypothesis was not supported at the $p < .05$ level of significance.

As noted earlier, 68% of participants (N = 113) indicated that they had completed an advance directive. Fifty-six of seventy-six participants reported why they *did* complete a document and gave a variety of explanations, with professional experience as a motivating factor. One social worker indicated that s/he had “seen and know too much; have strong feelings about what I do and don’t want.” Others indicated peace of mind, control over decisions, and the desire to not have family members make decisions.

For those participants who *did not* have a completed advance directive (N= 37), 26 provided additional explanations including laziness, denial, and “I don’t know.” Lack of time, too afraid, and not sure of wishes, were also reasons mentioned. Two participants indicated they have had verbal discussions with loved ones, but have not completed the document.

Hypothesis 3

Oncology social workers with higher death anxiety scores will be less likely to communicate with patients about advance directives. The correlation between death anxiety scores and the willingness to communicate with patients about advance directives will be negative.

Correlation analyses showed that on the subscale and total scores of death anxiety and communication, the total subscale of *your own death* was negatively correlated to the total subscale of *disclosure of information* ($r = -.19$, $p = .049$) and to the total subscale of *values in living* ($r = -.19$, $r = .046$). These negative correlations indicate that respondents

having higher *your own death* scores had lower communication scores related to disclosure of information and values in living. Those correlations' coefficients are shown in Table 7.

Insert Table 7 about here

Hypothesis 3 was partially supported by the data, inasmuch as the death anxiety scores increased, the communication scores related to disclosure of information and values in living decreased. Death anxiety scores and the communication scores of initiation, appointment of a health-care surrogate, treatment options, interaction with family, interaction with others, and collaboration were not significantly related.

Additional Findings

The following findings are related to individual questions on the communication survey instrument, though they were not included in any of the previous analyses.

Communication

Related to *initiating* the discussion of advance directives, 48% of participants (N = 55) indicated that a diagnosis of cancer always prompts a discussion. Additional prompts included metastatic diseases, physician request, HIV, and patients with multiple admissions to hospital. Socially based prompts included lack of family support, divorce, or domestic partner; comments from the patient, such as "I don't want to linger," and mental health issues. One participant pointed out that her/his discussions also included the patient's right to decline an advance directive. Nearly 18% (N = 20) noted that they discuss advance directives with *all* patients as a routine part of their interactions.

The *role* of the social worker was addressed related to assisting the patient in appointing a surrogate and formulating treatment desires. Almost three-fourths of

participants (N = 114) indicated that they were involved some or none of the time with helping patients select surrogate decision makers, as opposed to all of the time. Ten participants (9%) made a point to note that the patient directed their level of involvement.

Additional discussion focused on the following topics (N = 114): comfort measures only (61%), artificial respiration (60%), cardiopulmonary resuscitation (58%), artificial nutrition/hydration (56%), and hospice (42%) were reported as always being discussed with the patient. One respondent stated that they address “all of the above, all the time.” Values in living, or quality of life discussions related to the consequences of treatment options were reported as some or all of the time for impact on self-care abilities (79%), dependency on others for care (78%), and nursing home placements (62%). Five respondents made a point of mentioning that the *patient’s definition* of quality of life was the key in those interactions. The costs related to treatment options were discussed none of the time or some of the time by the almost three quarters (75%) of participants.

Respondents indicated that *interaction* with patient’s family members primarily occurred some or all of the time with the spouse (93%), child (89%), children and other family (73%), and significant other/non-family (71%). Eighty-one (71%) noted client incapacity would prompt them some or all of the time to interact with others; ten participants (9%) noted that they only interact at the patient’s request. Encouraging patients to involve family members was also noted as part of routine interactions for four participants.

Collaboration with other health care professionals some or all of the time was primarily with physicians (97%), nurses (84%), and other social workers (72%). Legal counsel, administrators, and ethics committees were not routinely part of collaboration

practices. Participants were asked to address the amount of *time* they spent engaged in advance directive communication with their patients. Fifty-six percent of participants indicated that they spend about the right amount of time needed, though 40% spent not enough time. One respondent noted that too much time was spent on advance directive communication.

Advance Directives and Client's Age

The social workers that participated in this study were 53 years of age, on average. Almost 70% of the social workers (N = 110) indicated that they interacted with patients differently based on the patient's age. In explaining their behavior, social workers indicated the language used with clients of different ages changed based on different social norms. Advance directive discussions were reported as "more complicated with younger clients . . . parents, siblings, and spouses [were] all involved." One participant noted that reassurance was needed with younger patients, as they were afraid a "jinx" might occur once the document is completed. There was also a comment made that older patients were "more aware" and "receptive" to advance directives while at the same time deferring decisions to their children.

Organizational Policy and Additional Training

As one respondent noted, "policy underlies all that we do in social work." In relation to organizational policy impacting advance directive communication, almost 60% indicated their actions are guided by policy. Policies mentioned included the Patient Self Determination Act and agency protocol of asking every new patient about her/his advance directive status. For two social workers in this study, advance directives were not in the scope of their current practice expectations.

Additional training related to death or advance directives issues was reported by less than 30% of social workers (N = 31). Of those indicating they had additional training, the majority involved continuing education units (CEUs). End-of-life care, advance directives, death/dying, and hospice courses were the most common. Training by Hospice staff was the second most mentioned source of instruction. Formal programs such as *Disseminating End of Life Education to Cancer Centers* and *Respecting Choices* were also noted as sources of training. Graduate and post-graduate course work was also cited as the basis for additional training.

Summary

In summary, there were data partially supporting *Hypothesis 1*, indicating that the personal characteristics of oncology social workers will predict their death anxiety scores. These characteristics were found to explain slightly more than 16% of the variance in scores. *Hypothesis 2* was not supported. There were data partially supporting *Hypothesis 3*, that oncology social workers with higher death anxiety scores will be less likely to communicate with patients about advance directives. Chapter 5 will discuss these results and the implications of the findings for social work practice, policy and research.

Chapter 5

Discussion

This final chapter discusses the implications of the results of the dissertation. The focus of this study was to examine issues related to low advance directive completion rates and to determine if death anxiety and communication practices by oncology social workers might be affecting completion rates. While the significant results of the study were small, the findings are worthy of additional discussion relative to future research, policy, and practice.

Results of hypotheses

This study explored the relationship between social workers' personal level of death anxiety, the completion of their own advance directive, and communication with patients about advance directives. Age, work setting, work status, and years of experience were examined to determine if these variables had any effect on the death anxiety scores. Communication was measured looking at initiation, role, interaction, collaboration, and time related to death anxiety. Death anxiety was measured using the Revised Collett-Lester Fear of Death and Dying Scale (Lester, 1994). Communication interactions were measured using Black's (2000) Advance Directive Communication Practices Instrument. A summary of the relevant findings for this study is as follows.

Hypothesis 1 postulated that there would be a significant relationship between social workers' death anxiety scores and their personal characteristics. The sample bias prevented analysis of gender, ethnicity, and professional status. The lack of results for these characteristics adds no new information to previously scarce data.

A significant relationship was noted between the social worker's death anxiety score and years of experience. Respondents having more years of experience reporting higher death anxiety scores explained approximately 16% of the variance in death anxiety scores. Sixteen years of experience was the average for the respondents.

Increased death anxiety with increased years of experience may speak to this group of respondents' experiences over the years. Terror Management Theory suggests that the reality of death is held at a distance by an individual in order to function. Social workers' education and training addresses the death of their patients, not their own death, so thoughts about death of self are usually not primary. Building on the Terror Management Theory, the social workers are thinking about their patients' deaths rather than their own deaths.

Personal Construct Theory suggests that belief and value structures are built over time and anxiety may be present if the current situation does not fit into an existing construct. Social workers have built belief and value structures related to their patients' deaths through education and training related to end-of-life issues. But structures may not be present related to her/his own death. When confronted with thinking about her/his own death through this study, the respondents may have encountered ideas that do not fit their current constructs. This, combined with the reality of his/her own death, may have challenged base belief and value structures and, as a result, increased the anxiety levels as reported in this study. Increased death anxiety examined from the perspective of the two theories supports previous literature, suggesting "as individuals and professionals, we must engage in self-exploration about what death and dying means to us" (Hobart, 2001,

p. 182). An increase in death anxiety may be due to lack of thinking about death as related to self versus others.

There was no significant difference between death anxiety and work setting, employment status, or age. The lack of significance related to age is in agreement with more recent studies (Neimeyer et al., 2004), which suggest that as age *increases* from mid-life to old age, death anxiety *decreases*. Mid-life is considered to be the ages between 35 and 60 years of age (Ashford, LeCroy and Lortie, 2006). The respondents of this study had an average age 46 years, or middle age, which may explain this finding.

Hypothesis 2 postulated that oncology social workers with higher death anxiety scores would be less likely to have completed a personal advance directive. There was no significant relationship between these two variables. There was also no significant difference between social workers who had completed an advance directive and those who had not completed an advance directive and their death anxiety scores. However, the percentage of the sample which has completed an advance directive (68%) is of interest when compared to the completion rates of various other groups from previous studies. Previous studies by several authors have shown low rates of completion by both professionals and the lay community (Cohen, 2007; Ditto et al., 2005; Douglas & Brown, 2002; Galambos, 1998; Heyman & Gutheil, 2003). Based on the comments of the respondents, it is possible that the experiences of oncology social workers prompt the completion of advance directives. One study (Roff, Simon, Klemmack, & Butkeviciene, 2006) suggested that witnessing death in healthcare systems without palliative care and good pain control might increase death-related fears. The higher rates of advance

directive care for the respondents may be an attempt to have better control over their own end-of-life situations.

Hypothesis 3 postulated that oncology social workers with higher death anxiety scores would be less likely to communicate with patients about advance directives. Results indicated that as the death anxiety scores increased, the communication scores related to disclosure of information and values in living decreased. These findings support previous research indicating that higher death anxiety by professional staff members has negative impacts on staff interactions with patients related to death (Neimeyer et al., 2004).

The findings of this study add to the existing literature by supporting a major premise of Terror Management Theory (TMT). TMT suggests that perceived worldview differences between individuals, including values, might cause an increase in anxiety (Brown, 2005). This finding may imply that oncology social workers, by virtue of being exposed to more reminders of death, may perceive a difference between themselves and their patients. This perceived difference may increase the social workers' anxiety, which could explain the lower communication scores. As Katz & Genevay (2002) pointed out, "When personal feelings triggered by professional encounters go unacknowledged or unmanaged, we risk compromising care: We may find ourselves avoiding patients and families who activate these feelings in us" (p. 335).

This study also adds to the findings related to the Personal Construct Theory (PCT), which suggests individuals strive to "make sense of the world and successfully anticipate events" (Holland et al., 2007) and then respond according to the constructs. Participants that had completed advance directives stated desire for control over decisions and knowledge gained through professional experience as motivating factors. Participants that

did not complete directives reported that they could not determine their [future] wishes, and they were not sure why they had not completed advance directives. They also cited patient beliefs [constructs] of an advance directive as a “jinx” which prevented completion of the document. These explanations can all be related back to how the individual has created, or constructed, meaning in the reality of her/his life that is reflected in their actions related to advance directives.

Policy

The participants of this study reported that policy strongly influences their practice, and that the Patient Self-Determination Act continues to be the guiding federal policy, as it is tied to funding. This policy has been in place for almost two decades, it provides guidelines for the provision of information, and it is the educational mandate for advance directives (Douglas & Brown, 2002). The findings of this study add to the growing research and literature suggesting that knowledge of federal and state laws is vital to ensuring the provision of accurate information to patients (Hobart, 2001).

The respondents of this study indicated a high level of collaboration among physicians, nurses, and other social workers. Collaboration impacts not only practice but also policy. An earlier study (Daka-Mulwanda, Thornburg & Klien, 1995) provides a two-part model for collaboration. The first part improves the provision of services that stem from the federal government and extend to the individuals in a community. The example, as it relates to advance directive communication, would include the vertical, or multi-level, actions that occur as federal and state laws coordinate to meet requirements and citizen mandates. As noted earlier, most states have some form of law supporting advance directives (Ditto et al., 2005).

Collaborations involving physicians, nurses, and social workers that partner to provide care to patients as they make end-of-life care decisions would be considered horizontal actions. This second aspect of the collaboration model would extend the partnership from the professional staff to include the family, significant others, and community resources (Daka-Mulwanda et al, 1995) that are important to the patient. This study found that 93% of the time, social workers are engaged with spouses, and 71% of the time with non-family supports when discussing advance directives. Social workers have expertise that combined with this collaboration model can help fill any gaps that might exist in coordinating the technical, legal, and emotional needs that are present in advance directive communications (Hobart, 2001).

Practice

This study found that the respondents initiated communication about advance directives when a cancer diagnosis was present. This supports the AOSW (2006) survey that showed oncology social workers reported high degrees of competence related to end-of-life issues and advance directives. However, the majority of oncology social workers also reported practicing in settings that do not provide end-of-life care to the majority of cancer patients. This finding highlights a need for *all* social workers to be educated and competent in the delivery of end-of-life and advance directive communications, since the need for this type of communication may arise in many settings.

The need for all social workers to be competent in the delivery of end-of-life and advance directive care is similar to the current interest in the profession related to social work education in gerontology. Capitalizing on lessons learned from the gerontology movement could prove helpful for advancing end-of-life and advance directive

communications. Increasing student and faculty interest would be low cost at the BSW and MSW levels. Students could benefit from interactions with skilled mentors and guest speakers and assignments related to advance directive communications as they are infused across a curriculum. Faculty could be encouraged to add content across the curriculum without rewriting the curriculum, and be encouraged to do research related to advance directive communications (Rosen and Zlotnik, 2001). Research has begun to identify future textbook needs and research agendas (Brandsen, 2005). Recently, *Health and Social Work* featured a special issue dedicated to end-of-life care (Taylor-Brown & Sormanti, 2004). The *Journal of Palliative Medicine* also introduced a special social work series focused on end-of-life and palliative care issues, including collaboration and interdisciplinary work (Christ & Blacker, 2005).

Future Research

Future research investigating the impact of death anxiety on oncology social workers' communication interactions with patients related to advance directives would contribute to the professional literature. Social workers are actively involved in advance directive communications. There is a need to explore other aspects of death-related anxiety with social workers in other practice areas. Studies could explore social workers' stories of experiences related to end-of-life care as they impact their own views of care.

Sixty eight percent of the social workers in this study reported having a completed advance directive document. The national average is approximately half that number. Future studies could examine social worker's end-of-life competency based on completion of their own advance directive. Further analysis using the Terror Management

Theory and Personal Construct Theory paradigms could further the knowledge base related to understanding differences in advance directive rates of completion.

Research related to social work education could help identify end-of-life communications specialty training needs. The Advance Directive Communication Practices Instrument could be used to replicate this study with social workers in other fields of practice. Studies looking at the belief and value constructs of students and social workers with field experience could contribute to the literature on advance directives. Additional studies could provide answers to needs for additional training or introspective exercises dealing with death anxiety. Questions related to electives, knowledge, and skills could help guide curriculum changes that better prepare students for the field.

Limitations

The results of this study should be interpreted with caution and the following limitations considered. First, the use of a self-reporting survey has advantages and disadvantages. The advantage is the ease of collecting data with respondents having anonymity. Disadvantages include the danger that self-reported behavior may not actually be what transpires in practice; that even with anonymity assurances, bias in responses may have occurred; and that there may have been different interpretations of questions by respondents. As one researcher (Werth Jr., 2005) noted, a caution to consider is the use of statistics absent the context that produces the statistics. It is possible that the discussion and results of this survey would be viewed in a different light if full disclosure were possible.

Second, the results of this study are limited to oncology social workers and may not be generalizable to other social work professionals. Given the non-random sample of

oncology social workers that had current memberships in AOSW the results cannot be generalized beyond the study sample and any results must be viewed carefully in relation to any other group.

Third, it is possible that social workers specializing in oncology for years may have already considered various aspects of death anxiety and advance directives prior to this study. This may have affected the identification of relationships in this study.

Finally, the response rate for this study was 25%. This number is relatively low when one considers the generally accepted guidelines. Although not statistically determined, the guidelines range from an *adequate* 50% to a *very good* 70% response rate (Rubin & Babbie, 2007). The power analysis that was utilized to determine the responses needed for this study does have a statistical basis. One hundred fourteen responses were needed to adequately test the population for an effect, and they were realized. Additional studies with a more traditional response rate should be undertaken to validate these findings. Perhaps a more traditional survey approach would have yielded better response rates than the web-based survey methodology.

Conclusions

This study examined oncology social workers' death anxiety, advance directive completion, and advance directive communication. In spite of limitations, the study's findings contribute to the furthering of understanding oncology social workers in this context. The combined use of Terror Management Theory and Personal Construct Theory has seldom been used to study oncology social workers, and the statistically significant findings suggest future research may be warranted. Perhaps the use of different measures of death anxiety and communication would help discover that indeed there are other

facets of this topic to consider. Much of this study was exploratory; yet, significant results were realized. Those findings suggest future research is warranted.

Table 1

Demographics of Independent Variables

Measure	n	M	SD	Range
Age	112	46.19	10.25	21-64
Years of experience	114	15.76	8.75	0-34
Death Anxiety	114	2.69	2.69	1-4.6

Measure	n	%
Educational level		
BSW	4	3.5
MSW	52	45.6
Ph.D.	4	3.5
Missing	54	47.4
Work Setting		
Rural	23	20.2
Urban	88	77.2
Missing	3	2.6
Work Status		
Full time	90	78.9
Part time	21	18.4
Missing	3	2.6

Table 2

Death Anxiety Dependent Variables

Measure	n	M	SD
<i>Your Own Death</i>			
The total isolation of death	114	2.69	1.249
The shortness of life	114	2.68	1.208
Missing out on so much after you die	114	2.73	1.345
Dying young	114	2.71	1.387
How it will feel to be dead	114	1.85	1.206
Never thinking or experiencing	114	2.09	1.307
The possibility of pain and punishment during life-after-death	114	1.59	1.112
The disintegration of your body after you die	114	1.60	1.002
TOTAL <i>Your Own Death</i>	114	2.24	.834
<i>Your Own Dying</i>			
The physical degeneration involved	114	3.07	1.315
The pain involved in dying	114	3.32	1.164
The intellectual degeneration of old age	114	3.57	1.064
That your abilities will be limited as you lie dying	114	3.43	1.182
The uncertainty as to how bravely you will face the process of dying	114	2.60	1.274
Your lack of control over the process of dying	114	3.03	1.300

Measure	n	M	SD
The possibility of dying in a hospital away from friends and family	114	2.54	1.345
The grief of others as you lie dying	114	3.52	1.305
TOTAL <i>Your Own Dying</i>	114	3.13	.862
TOTAL DEATH ANXIETY	114	2.69	.764

Note. Death anxiety was determined on a 5-point scale (1= Not very anxious; 5= Very anxious). TOTAL DEATH ANXIETY= the grand mean of Your Own Death and Your Own Dying.

Table 3

Own Advance Directive Completion

Measure	n	%
Advance Directive		
Yes	77	67.5
No	36	31.6
Missing	1	.9

Table 4

Communication Dependent Variables

Measure	M	SD
<i>Social worker's initiation of the topic of advance directives</i>		
Initiation of advance directives	3.48	1.243
<i>Social worker's disclosure of information related to advance directives</i>		
Purpose of the specific advance directive	4.55	.942
Patient's right to formulate the document	4.48	1.006
Parameters of the specific directive	4.38	1.025
Patient's right to modify or rescind	4.36	1.040
Assumption that proxy aware of Tx desires	4.21	1.265
Copy required for client file	4.39	1.259
TOTAL Disclosure	4.39	.923
<i>Social worker's addressing patient's appointment of surrogate</i>		
Help them consider choices	2.69	1.298
Geographical proximity	2.66	1.369
Phone access availability	2.74	1.476
Emotional stability	2.87	1.442
Awareness of patient's wishes	3.42	1.545
Notify proxy of client's desire to appoint	1.61	1.101
Obtain surrogate's confirmation to serve	1.61	1.060
TOTAL Surrogate	2.51	1.025

Measure	M	SD
<i>Social worker's addressing patient's formulation of treatment desires</i>		
Cardiopulmonary resuscitation	4.05	1.413
Artificial nutrition/hydration	4.02	1.433
Artificial respiration	4.03	1.508
Comfort measures only	4.20	1.277
Hospice	3.67	1.491
TOTAL Treatment	3.99	1.218
<i>Social worker's helping patient's reflect on values in living</i>		
Impact on self-care abilities	3.43	1.370
Probability of resuming prior lifestyle	3.33	1.418
Likelihood for dependence on others for care	3.37	1.365
Need for rehabilitation	2.74	1.433
Likelihood for nursing home placement	2.89	1.423
Costs of treatment option	2.42	1.395
TOTAL Values	3.03	1.232
<i>Social worker's interactions with client's family members and significant others</i>		
Spouse	3.54	.997
One adult child	3.28	.991
Two or more adult children	2.89	1.084
Other family relative	2.79	1.076

Measure	M	SD
Significant other/non-family	2.85	1.083
Lawyer	1.36	.730
TOTAL Family	2.78	.756
<i>Factors motivating social worker's to interact with client's family members and significant others</i>		
Poor client prognosis	3.39	1.424
Unrealistic client expectations	2.87	1.347
Unrealistic family expectations	3.03	1.353
Multiple family contacts	2.85	1.365
Polarized positions among family	2.81	1.522
Other health care professional suggestion	2.89	1.425
Client incapacity (questionable mental status)	3.27	1.495
TOTAL Factors	3.01	1.175
<i>Social worker's collaboration practices with other health care professionals</i>		
Physician	3.68	1.346
Psychiatrist	1.75	1.063
Nurse	3.74	1.402
Social worker	3.33	1.718
Clergy	2.19	1.247
Administration	1.64	.988

Measure	M	SD
Legal counsel	1.54	.933
Ethics committee	1.64	1.023
TOTAL Collaboration	2.44	.864
TOTAL Communication	3.21	.681

Note. Communication was determined on a 5-point scale (1= None of the time; 5= All of the time). TOTAL Communication= the grand mean of initiation, disclosure, surrogate, treatment, values, family, factors and collaboration.

Table 5

Personal Characteristics and Death Anxiety Correlations

Measure	1	2	3	4	5	6
1. Age	-					
2. Years Experience	.515**	-				
3. Education	.031	.230	-			
4. Total YOD	-.088	.074	-.007	-		
5. Total YD	.103	.299(**)	-.012	.625*	-	
6. Total Death	.010	.209(*)	-.011	.898*	.905*	-

Note. YOD=Your Own Death, YD=Your Own Dying.

** p < 0.01 (2-tailed)

* p < 0.05 level (2-tailed)

Table 6

Summary of Regression Analysis for Variables Predicting Death Anxiety Scores

Variable	Model 1		
	<i>B</i>	<i>SE B</i>	β
Age	-.026	.012	-.320
Years Experience	.055	.014	.606
Education	-.268	.304	-.112
Employment	-.117	.259	-.055
Setting	-.068	.245	-.035
R^2		.164	
F		3.242	

Table 7

Death Anxiety and Communication Correlations

Measure	1	2	3	4	5	6	7	8	9	10	11	12
1. Total YOD	-											
2. Total YD	.625**	-										
3. Total Death Anxiety	.898**	.905**	-									
4. Initiation	-.014	-.073	-.049	-								
5. Total Disclosure	-.185*	-.166	-.195*	.355**	-							
6. Total Surrogate	.078	.092	.094	.327**	.249**	-						
7. Total Treatment	-.014	-.020	-.019	.366**	.275**	.275**	-					
8. Total Values	-.187*	-.183	-.205*	.214*	.037	.451**	.433**	-				
9. Total Family	-.035	.033	-.018	.298**	.249**	.403**	.363**	.327**	-			
10. Total Factors	.051	.130	.101	.166	-.017	.400**	.248**	.473**	.351**	-		
11. Total Collaboration	-.034	.056	.013	.316**	.156	.516**	.410**	.568**	.533**	.628**	-	

Measure	1	2	3	4	5	6	7	8	9	10	11	12
12. Total Communication	-.065	-.036	-.055	.607**	.423**	.693**	.672**	.700**	.640**	.637**	.784**	-

Note. Death anxiety includes measures 1-3. YOD=Your Own Death, YD=Your Own Dying. TOTAL DEATH ANXIETY= the grand mean of Your Own Death and Your Own Dying. Communication includes measures 4-12. Disclosure=Disclosure of information, Surrogate= Surrogate appointment, Treatment= Treatment options, Values= Values in living, Family= interactions with family members and others, Factors= Factors motivating interactions with family members and others, Collaboration= Collaboration with other health care providers. TOTAL Communication= the grand mean of initiation, disclosure, surrogate, treatment, values, family, factors and collaboration.

** p< 0.01 (2-tailed).

* p< 0.05 (2-tailed).

References

- American Cancer Society. (2007). *Cancer facts and figures*. Retrieved January 10, 2008, from <http://www.cancer.org/downloads/STT/caff2007PWSecured.pdf>
- Association of Oncology Social Work. (1998).
- Association of Oncology Social Work. (2006). *The AOSW member survey report*. Retrieved January 10, 2008, from <http://www.aosw.org/docs/MemberSurvey.pdf>
- Association of Oncology Social Work. (2006). *Position papers*, from www.aosw.org
- Association of Oncology Social Work. (2007). *ONS & AOSW joint position paper on end of life care*. Retrieved September 18, 2007, from <http://www.aosw.org/html/prof-position.php>
- Association of Oncology Social Work. (2008). *About us*. Retrieved January 30, 2008, from <http://www.aosw.org/html/about.php>
- Arndt, J., Routledge, C., & Goldenberg, J. L. (2006). Predicting proximal health responses to reminders of death: The influence of coping style and health optimism. *Psychology and Health, 21*(5), 593-614.
- Arndt, J., & Vess, M. (2008). Tales from existential oceans: Terror management theory and how the awareness of our mortality affects us all. *Social and Personality Psychology Compass, 2*(2), 909-928.
- Ashford, J., LeCroy, C. W., & Lortie, K. (2006). *Human behavior in the social environment: A multidimensional perspective* (3rd ed.). Belmont: Thomson Brooks/Cole.
- Becker, E. (1973). *The denial of death*. New York: The Free Press.
- Bickel-Swenson, D. (2007). End-of-life training in U.S. medical schools: A systematic

- literature review. *Journal of Palliative Medicine*, 10(1), 229-235.
- Black, K. (2000). *Advance directive communication with hospitalized elderly patients: Disciplinary practices*. Unpublished Dissertation, Rockefeller College of Public Affairs and Policy.
- Black, K. (2004). Advance directive communication with hospitalized elderly patients: Social workers' roles and practices. *Journal of Gerontological Social Work*, 43(2/3), 131-145.
- Black, K. (2005a). Advance directive communication practices: Social workers' contributions to the interdisciplinary health care team. *Social Work in Health Care*, 40(3), 39-55.
- Black, K. (2005b). Social workers' personal death attitudes, experiences, and advance directive communication behavior. *Journal of Social Work in End-of-Life & Palliative Care*, 1(3), 21-35.
- Bradley, E., & Rizzo, J. (1999). Public information and private search: Evaluating the patient self-determination act. *Journal of Health Politics, Policy and Law*, 24(2), 239-273.
- Brandsen, C. K. (2005). Social work and end-of-life care: Reviewing the past and moving forward. *Journal of Social Work in End-of-Life & Palliative Care*, 1.
- Brown, C. (2005). *Death anxiety and attitudes toward the older adult among psychotherapists*. Unpublished Dissertation, Walden University, Minneapolis, MN.
- Bullock, K. (2006). Promoting advance directives among African Americans: A faith-based model. *Journal of Palliative Medicine*, 9(1), 183-195.
- Chen, Y.-C., Del Ben, K., Fortsen, B., & Lewis, J. (2006). Differential dimensions of

- death anxiety in nursing students with and without nursing experience. *Death Studies*, 30, 919-929.
- Christ, G., & Blacker, S. (2005). Series introduction: The profession of social work in end-of-life and palliative care. *Journal of Palliative Medicine*, 8(2), 415-417.
- Christ, G., & Blacker, S. (2006). The helping relationship: Beyond the best of intentions. *Journal of Palliative Medicine*, 9(1), 182.
- Christ, G. H., & Sormanti, M. (1999). Advancing social work practice in end-of-life care. *Social Work in Health Care*, 30(2), 81-99.
- Clark, E. (2006). *Preparing for the aging boom*. Retrieved January 8, 2008, from <http://www.socialworkers.org/pubs/news/2006/03/clark.asp>
- Cohen, B. (2007). Advance directives: Know what you want, get what you need. *Mayo Clinic Proceedings*, 82(12), 1460-1462.
- Cohen, B., McGuinnis, S., & Wing, P. (2006). *Licensed social workers serving older adults, 2004*, from http://workforce.socialworkers.org/studies/health/health_chap7.pdf
- Connell, B. E., & Mallory, J. L. (2007). Advance directives: Curriculum content and preparation of nursing students. *MEDSURG Nursing*, 16(3), 163-168.
- Cote, R. (1995). *George Kelly: The theory of personal constructs and his contribution to personality theory*. Spruce Grove: Alberta.
- Csikai, E., & Raymer, M. (2005). Social workers' educational needs in end-of-life care. *Social Work in Health Care*, 41(1), 53-72.
- Daka-Mulwanda, V., Thornburg, K., Filbert, L., & Kline, T. (1995). Collaboration of services for children and families: A synthesis of recent research and

- recommendations. *Family Relations*, 44(2), 219-223.
- Ditto, P. H., Hawkins, N. A., & Pizarro, D. A. (2005). Imagining the end of life: On the psychology of advance medical decision making. *Motivation and Emotion*, 29(4), 481-502.
- Douglas, R., & Brown, H. (2002). Patients' attitudes towards advance directives. *Journal of Nursing Scholarship*, 32(1), 61-65.
- Emanuel, L., & Emanuel, E. (1993). Decisions at the end of life. *Hastings Center Report*, 23(5), 6-14.
- Evans, J. W., Walters, A. S., & Hatch-Woodruff, M. L. (1999). Deathbed scene narratives: A construct and linguistic analysis. *Death Studies*, 23(8), 715-734.
- Finley, R. (1999). *SurveyMonkey*, from www.surveymonkey.com
- Forsythe, C. D. (2005). Protecting unconscious, medically-dependent persons after Wendland & Schiavo. *Constitutional Commentary*, 22, 475-495.
- Foster, L. W., & McLellan, L. J. (2002). Translating psychosocial insight into ethical discussions supportive of families in end-of-life decision-making. *Social Work in Health Care*, 35(3), 37-51.
- Fulton, G., & Saunders Jr., D. (2001). *Who speaks for Robert Wendland? The latest chapter in the law of life-sustaining medical treatment decisions*. Retrieved from <http://ipspr.sc.edu/ejournal/medicaltreatdec.asp>
- Galambos, C. M. (1998). Preserving end-of-life autonomy: The patient self-determination act and the uniform health care decisions act. *Health & Social Work*, 23(4), 275-277.
- Go, R., Hammes, B., Lee, J., & Mathiason, M. (2007). Advance directives among health care professionals at a community-based cancer center. *Mayo Clinic Proceedings*,

82(12), 1487-1490.

Gockel, J., & Morrow-Howell, N. (1998). Advance directives: A social work initiative to increase participation. *Research on Social Work Practice, 8*, 520-529.

Goldenberg, J. L., Pyszczynski, T., Greenberg, J., & Solomon, S. (2000). Fleeing the body: A terror management perspective on the problem of human corporeality. *Personality & Social Psychology Review, 4*(3), 200-219.

Gutheil, I. A., & Heyman, J. C. (2005). Communication between older people and their health care agents: Results of an intervention. *Health & Social Work, 30*(2), 107-117.

Heppner, P. P., & Heppner, M. J. (2004). *Writing and publishing your thesis, dissertation & research: A guide for students in the helping professions*. Belmont, CA: Brooks/Cole-Thomson Learning.

Heyman, J. C., & Gutheil, I. A. (2003). Attitudes of social work students toward end-of-life planning. *Educational Gerontology, 29*, 313-326.

Hinkka, H., Kosunen, E., Metsanoja, R., Lammi, U. K., & Kellokumpu-Lehtinen, P. (2002). Factors affecting physicians' decisions to forgo life-sustaining treatments in terminal care. *Journal of Medical Ethics, 28*, 109-115.

Hobart, k. (2001). Death and dying and the social work role. *Journal of Gerontological Social Work, 36*(3/4), 181-192.

Hoffman, M. (1994). Use of advance directives: A social work perspective on the myth versus the reality. *Death Studies, 18*, 229-241.

Holland, J., Neimeyer, R. A., Currier, J., & Berman, J. (2007). The efficacy of personal construct therapy: A comprehensive review. *Journal of Clinical Psychology, 63*(1),

93-107.

Huffman, G. B. (2001). Benefits of discussing advance directives with patients. *American Family Physician, 64*, 319-321.

Hui, V., Bond, M., & N G, W. T. (2006-2007). General beliefs about the world as defensive mechanisms against death anxiety. *Omega: Journal of Death & Dying, 54*(3), 199-214.

Jezewski, M. A., Brown, J. K., Wu, Y.-W. B., Meeker, M. A., Feng, J.-Y., & Bu, X. (2005). Oncology nurses' knowledge, attitudes, and experiences regarding advance directives. *Oncology Nursing Forum, 32*(2), 319-327.

Katz, R., & Genevay, B. (2002). Our patients, our families, ourselves. *American Behavioral Scientist, 46*(3), 327-339.

Kramer, B., Christ, G., Bern-Klug, M., & Francoeur, R. (2005). A national agenda for social work research in palliative and end of life care. *Journal of Palliative Medicine, 8*(2), 418-431.

Lester, D. (1994). The Collett-Lester fear of death scale. In R. Neimeyer (Ed.), *Death Anxiety Handbook* (pp. 45-60). Washington, D. C.: Taylor & Francis.

Luptak, M. (2004). Social work and end-of-life care for older people: A historical perspective. *Health & Social Work, 29*(1), 7-15.

Luptak, M. (2006). End-of-life care preferences of older adults and family members who care for them. *Journal of Social Work in End-of-Life & Palliative Care, 2*(3), 23-44.

Mooney, D. C. (1999). *Construct validity of the revised Collett-Lester fear of death and dying scale.*, Griffith University, Queensland, Australia.

Mooney, D. C. (2005). Tactical reframing to reduce death anxiety in undergraduate

- nursing students. *American Journal of Hospice & Palliative Medicine*, 22(6), 427-432.
- National Association of Social Workers. (2003-2006). *Social Work Speaks: NASW policy statements* (6th ed.). Washington, D.C.: National Association of Social Workers.
- Neimeyer, R. A. (Ed.). (1994). *Death anxiety handbook: Research, instrumentation, and application* (Vol. 1). Washington, D.C.: Taylor & Francis.
- Neimeyer, R. A., & Bridges, S. (2004, February 15). *Personal construct theory*. Retrieved January 10, 2008, from <http://www.pcp-net.org/encyclopaedia/pc-theory.html>
- Neimeyer, R. A., Wittkowski, J., & Moser, R. P. (2004). Psychological research on death attitudes: An overview and evaluation. *Death Studies*, 28, 309-340.
- Nyatanga, B., & de Vocht, H. (2006). Towards a definition of death anxiety. *International Journal of Palliative Nursing*, 12(9), 410-413.
- O'Neill, D. (2001). Present, rather than advance directives. *Lancet*, 358, 1921-1922.
- Osman, H., & Becker, M. (2003). Complexity of decision-making in a nursing home: The impact of advance directives on end-of-life care. *Journal of Gerontological Social Work*, 42(1), 27-40.
- Payne, S. A., Dean, S. J., & Kalus, C. (1998). A comparative study of death anxiety in hospice and emergency nurses. *Journal of Advanced Nursing*, 28(4), 700-706.
- Perkins, H. S. (2007). Controlling death: The false promise of advance directives. *Annals of Internal Medicine*, 147(1), 51-57.
- Pyszczynski, T. (2004). What are we so afraid of? A terror management theory perspective on the politics of fear. *Social Research*, 71(4), 827-848.

- Reese, D. J., Chan, C. L. W., Perry, D. C., Wiersgalla, D., & Schlinger, J. M. (2005). Beliefs, death anxiety, denial, and treatment preferences in end-of-life care: A comparison of social work students, community residents, and medical students. *Journal of Social Work in End-of-Life & Palliative Care, 1*(1), 23-47.
- Roff, L., Simon, C., Klemmack, D., & Butkeviciene, R. (2006). Levels of death anxiety: A comparison of American and Lithuanian health and social service personnel. *Death Studies, 30*, 665-675.
- Roscoe, L. A., Osman, H., & Haley, W. E. (2006). Implications of the Schiavo case for understanding family caregiving issues at the end of life. *Death Studies, 30*, 149-161.
- Rosen, A., & O'Neill, J. (1998). *Social work roles and opportunities in advanced directives and health care decision-making*. Retrieved January 30, 2008, from <http://www.socialworkers.org/practice/aging/advdirect.asp>
- Rosen, A., & Zlotnik, J. (2001). Demographics and reality: The "disconnect" in social work education. *Journal of Gerontological Social Work, 36*(3/4), 81-97.
- Rubin, A., & Babbie, E. (1989). *Research methods for social work*. Belmont, CA: Wadsworth Publishing Company.
- Rubin, A., & Babbie, E. (2006). *Essential research methods for social work*. Pacific Grove, CA: Wadsworth Publishing Company.
- Russac, R., Gatliff, C., Reece, M., & Spottswood, D. (2007). Death anxiety across the adult years: An examination of age and gender effects. *Death Studies, 31*(6), 549-561.
- Salmond, S., & David, E. (2005). Attitudes toward advance directives and advance

- directive completion rates. *Orthopaedic Nursing*, 24(2), 117-129.
- Schirm, V., & Sheehan, D. K. (2005). Conversations about choices for end-of-life care: Knowing and understanding preferences. *Journal of Hospice and Palliative Nursing*, 7(2), 91-97.
- Servaty, H. L., Krejci, M. J., & Hayslip Jr., B. (1996). Relationships among death anxiety, communication apprehension with the dying, and empathy in those seeking occupations as nurses and physicians. *Death Studies*, 20, 149-161.
- Smieja, M., Kalaska, M., & Adamczyk, M. (2006). Scared to death or scared to love? Terror management theory and close relationships seeking. *European Journal of Social Psychology*, 36, 279-296.
- Tabachnick, B. G., & Fidell, L. S. (1996). *Using Multivariate Statistics* (3rd ed.): Northridge: Harper Collins.
- Tammelleo, A. D. (2000). Protecting patients' end-of-life choices. *RN*, 63, 75-78.
- Taylor-Brown, S., & Sormanti, M. (2004). End of life care. *Health & Social Work*, 29(1), 3-5.
- Tierney, W., Dexter, P., Gramelspacher, G., Perkins, A., Zhou, X.-H., & Wolinsky, F. (2001). Patients' satisfaction with primary care. *Journal of General Internal Medicine*, 16, 32-40.
- Vandecreek, L., & Frankowski, D. (1996). Barriers that predict resistance to completing a living will. *Death Studies*, 20, 73-82.
- Volker, D. (2003). Assisted dying and end-of-life symptom management. *Cancer Nursing*, 26(5), 392-399.
- Wass, H., & Neimeyer, R. A. (Eds.). (1995). *Dying: Facing the facts* (Third ed.).

Washington, D.C.: Taylor & Francis.

Weinbach, R., & Grinnell, R. (2004). *Statistics for social workers* (6th ed.). Boston:

Pearson/Allyn and Bacon.

Werner, P., Carmel, S., & Ziedenberg, H. (2004). Nurses' and social workers' attitudes and beliefs about and involvement in life-sustaining treatment decisions. *Health & Social Work, 29*(1), 27-35.

Werth Jr., J. L. (2005). Becky's Legacy: Personal and Professional Reflections on Loss and Hope. *Death Studies, 29*(8), 687-736.

Wilkinson, A., Wenger, N., & Shugarman, L. (2007). *Literature review on advance directives*: U.S. Department of Health and Human Services.

VITA

Marlys R. Peck was born February 7, 1964 in Windsor, Missouri. She grew up in Cole Camp, Missouri and graduated from Benton County R-1 High School. She attended State Fair Community College for one year, and then transferred to the University of Missouri in Columbia. She obtained her Bachelor of Social Work in 1992, Master of Social Work in 1993 and Doctor of Philosophy in Social Work in 2008. Marlys is again residing in her hometown of Cole Camp. She is in her second year as an assistant professor at the University of Central Missouri in Warrensburg, Missouri.