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INFORMAL CAREGIVERS OF ADVANCED CANCER PATIENTS:
THE IMPACT OF GEOGRAPHIC PROXIMITY ON SOCIAL SUPPORT AND
BEREAVEMENT ADJUSTMENT

A dissertation submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy at Virginia Commonwealth University.

by

JOHN GARLAND CAGLE

Bachelor of Science Degree in Psychology & English, Mary Washington College, 1995
Master of Social Work, Virginia Commonwealth University, 1998

Director: DR. PAMELA J. KOVACS
ASSOCIATE PROFESSOR OF SOCIAL WORK

Virginia Commonwealth University
Richmond, Virginia
May, 2008

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Abstract

This research explored the social and psychological needs of caregivers of advanced cancer patients, and their subsequent bereavement adjustment. The study focuses exclusively on informal caregivers who provide assistance to patients receiving hospice care for end-stage cancer. Those individuals living furthest from the dying care recipient, the long distance caregivers, were of particular interest. This study used a prospective design to explore how a caregiver's geographic proximity impacted their social support and bereavement adjustment. A 2 x 3 repeated measures design was used to gather data from caregivers before a patient's death (using a pre-death questionnaire) as well as after the death (by post-death questionnaire). This design allowed for an examination of differences between three groups of caregivers over time: long distance caregivers (who live an hour or more from the care recipient), proximate caregivers (who live less than an hour away) and co-residing caregivers. One hundred and six ($N = 106$) caregivers were recruited to participate from Covenant Hospice, a large Gulf Coast-based palliative care organization. Validated instruments were used to measure levels of social support and bereavement adjustment.

A repeated measures MANCOVA procedure explored the impact of geographic proximity on measures of social support and adjustment. Results did not support the proposed multivariate model. However, quality of dying (as measured by the QOD-Hospice) was identified as an influential between-groups covariate within the model. Further exploration of the QOD-Hospice revealed a negative correlation with levels of emotional grief, and positive correlations with length of stay in hospice, and pre-loss and post-loss levels of social support. Overall results seem to suggest that timely referrals to

hospice, improvements in care for the dying, and increased attention to quality of dying, may have a beneficial impact for survivors during bereavement. Furthermore, findings from this study suggest that the quality of a person's final days may play an important role in how the surviving caregivers adjust to the loss. Not only can high quality end-of-life care benefit dying patients, but it may also facilitate bereavement adjustment for those who participated in their care network. However, findings were limited and further investigation of these relationships is warranted.

CHAPTER ONE

Informal Caregivers of Advanced Cancer Patients: The Impact of Geographic Proximity on Social Support and Bereavement Adjustment

“We should learn not to forget those living further away”

(Thompson & Lovestone, 2002, p. 806)

This dissertation research explores the social and psychological needs of caregivers of advanced cancer patients, and their subsequent bereavement adjustment. The study focuses exclusively on informal caregivers who provide assistance to patients receiving hospice care for end-stage cancer. Those individuals who live furthest from the dying care recipient, the long distance caregivers, are of particular interest. One hundred and six research participants were recruited from Covenant Hospice, a large Gulf Coast-based palliative care organization. The study design consisted of a 2 x 3 repeated measures design, which gathered data from caregivers before a patient’s death (using a pre-death questionnaire) as well as after the death (by post-death questionnaire). The prospective design allowed for an examination of differences between three groups of caregivers over time: long distance caregivers (who live an hour or more from the care recipient), proximate caregivers (who live less than an hour away) and co-residing caregivers. Validated instruments were used to measure levels of social support and bereavement adjustment.

This first chapter provides a general overview of the study topic, a brief discussion of key concepts, statement of significance, guiding research questions, and the study’s relevance to the social work profession.

Overview

According to the American Cancer Society (ACS, 2008) an estimated 1.4 million new cancer cases, and more than half a million cancer deaths, are expected in 2008. Currently, cancer is surpassed only by heart disease as the nation's leading cause of death (Center for Disease Control and Prevention, 2008). For those who receive a life-threatening cancer diagnosis, many will seek advanced medical treatments such as surgery, radiation, and chemotherapy. When these conventional treatment options are exhausted or declined, individuals may elect to spend their final days enrolled in a hospice or other palliative care program. Presently, there are over 4,100 hospices in the United States that provide palliative care to more than a million patients annually (National Hospice and Palliative Care Organization [NHPCO], 2007). A large majority (45.9%) of these patients are diagnosed with advanced-stage malignancy (NHPCO). In comparison, the most prevalent non-cancer hospice diagnoses are heart disease (12.2%), dementia (8.9%), and lung disease (7.1%) (NHPCO).

To qualify for Medicare funding, hospices require patients to meet two key criteria for admission. They must (1) forego curative treatment; and (2) have a physician-certified life-expectancy of six months or less. Due to these criteria and the advanced stages of their disease, many hospice patients die relatively soon after admission. Cancer patients have an average length of stay (ALOS) of less than a month and a half (42.9 days; median length of stay is 41.3 days). This is significantly shorter than the ALOS for heart disease (58.6 days), dementia (78.1 days) and lung disease (60.8 days) (NHPCO, 2006).

Under the auspices of hospice, patients and their families are provided symptom management and support from a multidisciplinary team of health professionals. This team includes home health aides, chaplains, social workers, nurses, and physicians, among others. The

overarching philosophy of hospice care is patient/family-centered, which allows individuals to direct their own care plans. For the vast majority of those admitted into hospice service, a network of family members, friends and neighbors provides the bulk of patient care. It is hypothesized that a substantial number of these networks include long distance caregivers.

Caring for a loved one from afar is a reality for millions of Americans. More so than in the past, modern families are more likely to be geographically diverse (Kosberg, 2002); and caring for a relative from out-of-town is becoming a common experience. Despite a decline in rates of geographic mobility over previous decades (Wolf & Longino, 2005) the number of long distance caregivers seems to be on the rise (National Council on Aging, 2006). This shift in caregiver demographics is due, in part, to the changing age structure of the American population (i.e., aging baby boomers, healthy aging, and increased longevity), a declining birth rate, and the rapid movement of women into the labor market (Brody, Hoffman, Kleban, & Schoonover, 1987; Stone, 2000; Tennstedt, 1999). Benefield (2005) estimates that one third of all informal caregiving occurs from a distance. Using large nationwide samples, two recent surveys report there are between 5 million (MetLife, 2004) and 7 million (Wagner, 1997) long distance caregivers in America; and those numbers are projected to double over the next 15 years (National Council on Aging, 2006). Despite these large figures, our knowledge of long distance caregivers remains limited. Both researchers and practitioners may have neglected (inadvertently perhaps) the unique needs and experiences of those providing care to loved ones from many miles away (Manthorpe, 2001; Thompsell & Lovestone, 2002). As a result, empirical evidence on the ways that proximity affects caregivers is scarce (Benefield, 2005; Koerin & Harrigan, 2002; Kosberg, 2002; Thompsell & Lovestone).

Conversely, the research on informal caregivers who live with, or near, an ailing care recipient is considerable. So, too, is the literature on the psychosocial needs of cancer patients and their families. Regardless, the needs and experiences of those who provide assistance to patients with terminal cancer are not fully understood (Nijboer et al., 1998). Caring for a dying person and then reacting to his/her death, affects survivors in very unique ways. By no means are these phenomena simple or adequately researched. On the contrary, numerous layers of social, psychological, physical, economic, political, and spiritual complexity make a study of these subjects especially challenging. Social science researchers have begun to recognize that caregiving does not occur in a vacuum; and is a very involved, intricate process. For example, recent research acknowledges that informal care is usually provided by a network of family members, friends and neighbors – rather than in an insulated caregiver/care recipient dyad (Baker, 1977; Ingersoll-Dayton, Neal & Hammer, 2003; Koerin & Harrigan, 2003; Manthorpe, 2001). Thus, focusing solely on a so-called “primary caregiver” ignores the contributions of others providing support within the network.

Because earlier research on caregivers concentrated on the needs and experiences of a single, “primary” caregiver, those providing peripheral care, such as financial support and respite, were many times erroneously identified as “non-caregivers.” This narrowly conceived definition of who caregivers are (and are not) has likely contributed to the paucity of research on long-distance caregivers. Though, as Collins, Holt, Moore and Bledsoe (2003) state “the caregiver - even at a distance – is still part of the caregiving context” (p. 315).

Coping with a critical illness, such as cancer, can be especially challenging for family members when distance is a complicating factor. Providing care from afar poses many unique challenges, especially when the care recipient has been given a life-limiting diagnosis

(Manthorpe, 2001; Parker, Call, Dunkle & Vaitkus, 2002). Previous research has shown that distance impacts social relationships, communication, and coping (Baldock, 2000; Parker et al., 2002; Schoonover et al., 1998; Thompsell & Lovestone, 2002). However, to date, little is known about how geographic proximity influences the psychosocial adjustment and support of those providing care to loved ones with terminal cancer. As a result, this study explores the effect of geographic separation on the caregiving experience and subsequent bereavement adjustment. Additionally, this investigation attempts to identify meaningful ways for practitioners to support long distance caregivers during a loved one's terminal care.

The Exclusion of Non-Cancer Diagnoses

This study focuses exclusively on those caring for a loved one with a diagnosis of end-stage cancer. This particular diagnosis was selected for several reasons. Firstly, the majority of those under hospice, or other palliative services, have a primary diagnosis that involves malignancy (NHPCO, 2006). Secondly, as of yet no studies of long distance caregivers have focused on cancer caregiving. And lastly, caring for a person with terminal cancer may be different than caring for someone with a non-cancer illness. In previous studies, cancer caregivers have been compared with caregivers of patients with AIDS (Stetz & Brown, 2004), chronic obstructive pulmonary disease (COPD), heart disease (Emanuel et al., 1999), and dementia (Clipp & George, 1993; Haley, 2001). These studies found that, while the subjective (i.e., emotional and psychological) impact of providing care is often similar, some of the objective burdens and care-related tasks tend to differ by diagnosis. For example, compared to dementia caregivers, cancer caregivers more often deal with issues of pain, loss of appetite, and constipation (Haley et al., 2001). Since the experiences of providing care can differ based on the

care recipient's diagnosis, excluding non-cancer diagnoses allows for greater homogeneity between groups, thus allowing for a more valid comparison.

The Participating Agency: Covenant Hospice, Inc.

This study was conducted in partnership with Covenant Hospice, Inc., a large palliative care organization serving southern Alabama and the Florida panhandle. Covenant is a not-for-profit agency that has provided care to terminally-ill persons since 1983. The overarching mission of the organization is "Putting life into days when days can no longer be added to life" (Covenant Hospice, 2008a). Covenant has 13 different branch offices, including a free-standing inpatient residence and an inpatient palliative care unit at the West Florida Hospital in Pensacola (see Figure1). Branch office locations in Florida include Pensacola, Milton, Niceville, Marianna, Tallahassee, Panama City, and Crestview. Alabama-based branch offices are located in Mobile, Daphne, Brewton, and Dothan. Collectively, in 2007 these Covenant Hospice branch offices and inpatient facilities provided care to more than 6,204 patients; more than 1,000 patients on a given day (Covenant Hospice, 2008b; see Table 1).

Covenant Hospice covers a large service area, extending along the Gulf Coast I-10 corridor of Florida and Alabama. This southern region covers approximately 15,000 square miles of rural, urban, and suburban residential areas (Tortorano Commissioned Publications, 2006). Notable metropolitan districts include Mobile, Pensacola, Panama City, and Tallahassee. The population in this region is highly transitional, with a large number of tourists, seasonal residents, and military families. The beaches along I-10 (and I-98) corridor are visited by more than 7 million tourists and part-time residents each year (Bouler, 2007). In recent years, this area has also seen a large amount of growth in the number of permanent residents, due in part to trends in relocations and retirements (Van Der Veer Hamilton, 2008). In addition, 22 major

military installations are located within the corridor including Air Force Bases (e.g., Eglin, Hurlburt Field, and Tyndall), Naval Air Stations (e.g., Pensacola and Panama City), an Army Post (Fort Rucker), and U.S. Coast Guard Station (in Destin, Florida) (Tortorano Commissioned Publications, 2006).

Figure 1.

Covenant Hospice, Inc. Branch Offices and Service Area



Table 1

Covenant Hospice Characteristics by Branch Office

Branch Office	Staff *	Social Workers	Enrolled Patients	Length of Stay
	<u>N</u>	<u>N</u>	<u>M</u>	<u>M days(Median)</u>
Brewton	20	2	29	83(20)
Crestview	31	2	51	97(28)
Daphne	34	3	72	67(21)
Dothan	50	3	79	88(31)
Marianna	62	7	131	116(33)
Milton	70	10	171	111(37)
Mobile	28	2	43	67(20)
Niceville	56	9	108	69(17)
Panama City	72	9	191	85(26)
Pensacola	97	11	184	70(15)
Residence	19	1	28	60(14)
Tallahassee	35	4	67	92(22)
WFH Care Center	26	1	25	31(8)

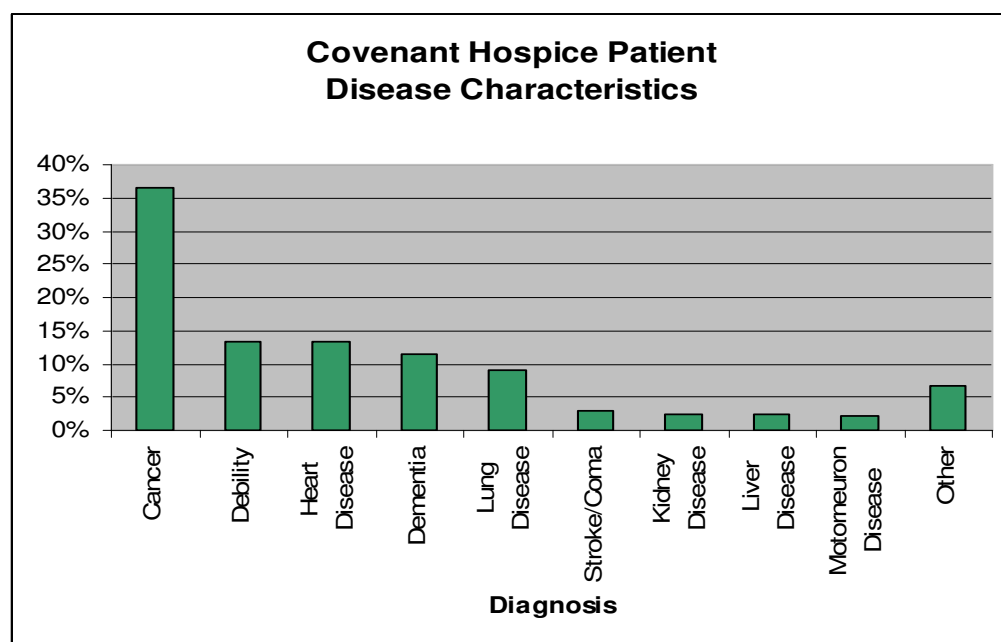
*Full- & Part-Time
(Covenant Hospice, 2008b)

Based on data from 2007, the typical Covenant Hospice patient is older, Caucasian, and has a primary diagnosis of cancer. Sixty-one percent (61%) of admitted patients are older than 75 years of age; and the vast majority is White (87%). The leading diagnosis was some form of malignant cancer (36%), followed by heart disease (13%), “debility unspecified” (13%), and

dementia (11%) (see Figure 2). As expected, most of the patients (90%) die within 6-months of admission, with nearly a third (32%) of those deaths occurring within the first week.

During the formative stages of the research, a group of Covenant Hospice leaders and directors (led by then Senior Vice President of Operations, Mr. Chuck Lee) served as the agency's institutional review panel. The group included a physician, nurses, social workers, and administrative staff. Together, they provided advice, counsel, and recommendations regarding recruitment, data collection, instrumentation, and protection of human subjects. The topic of long distance caregivers was identified as a relevant issue by both clinical team members and executive staff. Although Covenant does not keep statistics on long distance caregivers, staff members consistently agreed that exploring the needs and experiences of geographically dispersed caregivers is a much-needed and timely subject for empirical investigation. Furthermore, Covenant's bereavement professionals routinely refer long distance caregivers to bereavement groups in their own communities.

Figure 2



(Covenant Hospice, 2008b)

Key Concepts

Systematic inquiry involves the clarification of relevant terms and definitions.

Particularly, in quantitative research it is especially important to concisely operationalize a study's key variables. In this case, the research investigated psychosocial constructs such as "bereavement adjustment" and "support." These terms can take on a wide range of possible meanings. Thus, the following section provides readers with clear, succinct definitions of these concepts. Also included is a discussion about how long distance, proximate, and co-residing caregivers are defined in this study.

Bereavement Adjustment

Bereavement is a multifaceted construct. Simply put, it is the reaction one experiences when a loved one dies. Grief and bereavement are similar constructs and are often used interchangeably (Center for the Advancement of Health, 2003). Some researchers attempt to differentiate the two terms. Kissane (2003), for example, describes bereavement as "the state of loss" and grief as "the emotional response associated with loss" (p. 1137). In other cases, researchers argue the two terms are more similar than different (Center for the Advancement of Health).

In this study bereavement adjustment is viewed as the complex process of recovering from a death. This includes emotional, physical and psychological healing, as well as pain. It can involve a wide spectrum of responses such as guilt, hope, anger, personal growth, resilience, depressive symptoms, longing, sleep disruption, and health changes. For the purposes of this research, bereavement adjustment was operationalized using validated, multidimensional measures and specifically formulated questions that target various aspects of coping with loss. Specifically, the bereavement adjustment dimensions of interest were self-care, hope, guilt,

anger, depression, stress, anxiety, and general well-being. These general dimensions also lend themselves to a repeated measures assessment of adjustment (e.g., comparing pre-death levels of self-care with levels of self-care after the death). The study will also include a general measure of grief.

Studies find the vast majority of bereaved persons improve without bereavement intervention (Center for the Advancement of Health, 2003; Jordan & Niemeyer, 2003). Nevertheless, bereavement is associated with numerous negative outcomes, including persistent depression, ill health, and increased mortality risk (Bondar & Kiecolt-Glaser, 1994; Kelly et al., 1999; Kurtz et al., 1997; Rodinson-Whelan et al., 2001; Schulz & Beach, 1999; Wyatt et al., 1997). A small but significant number of those grieving the loss of a loved one experience severe psychiatric morbidity (Kelly et al., 1999). The challenge is to identify predictive risk factors and effective pre- and post-bereavement interventions for these individuals.

As Aranda and Milne (2000) acknowledge, in the context of hospice and palliative care, comprehensive bereavement support begins when a patient is first referred to the organization. Few studies, however, have prospectively explored which pre-death variables predict post-death outcomes (Bass, Bowman & Noelker, 1991; Schulz et al., 2001; Singer & Bowman, 2002; Stroebe, Stroebe & Schut, 2003). What few studies have examined pre-bereavement variables suggest that pre-death interventions are more beneficial than support during bereavement (Center for the Advancement of Health, 2003; Jordan & Niemeyer, 2003; Schulz et al., 2001). Therefore, by identifying which pre-death variables affect bereavement, social workers and other health professionals can: (1) tailor interventions to address the relevant pre-death variables and in turn help foster a less problematic bereavement; (2) identify which caregivers are at a greater risk for

bereavement difficulties; and (3) specifically identify whether caregiver proximity influences bereavement reactions.

Support

Support is a general term used to describe the influential factors that sustain and strengthen a person's coping ability during a time of need. Individuals derive support from a wide variety of sources, including physical, spiritual, financial, intra-personal, and inter-personal. Support can also come from family, friends, or significant others. This type of social support seems to moderate caregiver depression; and, additionally, buffer appraisals of burden and bereavement outcomes (although this relationship is admittedly very complex) (Bass et al., 1999; Nijboer et al., 1998). Support can be measured subjectively (i.e., perceived support) or objectively (i.e., observed support). This study focuses on subjective support as reported by caregiver respondents. Specific aspects of support will include availability of friends, family, and partners as well as self-reported satisfaction with the amount of information received, and the perceived availability of health care professionals.

Long Distance Caregivers

Constructing a definition of what constitutes a long distance caregiver is a complicated task. As Koerin and Harrigan (2002) state "the definition of 'long distance' needs to be carefully considered, because both time and distance are relative concepts and previous studies have used different definitions" (p. 80). To begin, distance is a complex interplay of geographic location, accessibility, and individual circumstances (Manthorpe, 2001). Measures of distance may involve travel time, geographic distance, and/or economic feasibility. Factors related to socio-economic status may influence how distance is perceived by caregivers. For example, the

absence of telephone or internet service, lack of access to a car, and the inability to pay for gas or plane tickets can exaggerate geographic distance, making even short trips impractical.

Further complicating the issue is the possibility that long distance caregivers may not even identify themselves as a “caregiver” (Manthorpe, 2001). Previous research has acknowledged that, regardless of their location, caregivers may not self-identify (Feinberg, Wolkwitz & Goldstein, 2006; Harding & Higginson, 2001); but those living out-of-town may have a more difficult time recognizing themselves as substantial providers of care. This is unfortunate, because, as Manthorpe notes, “caring at a distance forces an examination of what is meant by ‘care’ and who can legitimately claim this as an emotion or status” (p. 593). Thus, practitioners, researchers, and care providers should endeavor to use broader definitions of caregiver, which include those beyond individuals who provide “hands on” services.

Several attempts have been made to operationally define long distance caregiving. Most focus on either the geographic distance, or length of time it takes for the caregiver to travel to the care recipient’s residence. For example, in one study caregiver focus groups defined “long distance” as “living one or more hours away” from the person receiving care (Wagner, 1997, p. 1). Other prominent studies have conceptualized long-distance caregivers using this criterion (MetLife, 2004; NAC & AARP, 2004; Thompsell & Lovestone, 2002; Wagner). Another study, however, used geographic proximity to identify long distance caregivers, defining them as persons living more than 100 miles away from the individual to whom they provided assistance (cited in MetLife, 2004).

Interestingly, the National Council on the Aging and the Pew Charitable Trust (Wagner, 1997) found that long distance caregivers averaged 4 hours (one-way) travel time to the care recipient while the Metlife (2004) study found distant caregivers reported living 7.23 hours travel

time (450 miles) from their loved one. Thus, defining distant caregiving as more than an hour away may not reflect the typical experience of those providing care from afar (Koerin & Harrigan, 2002; Parker, Church & Toseland, 2006). Additionally, “miles away” may not be the best measure of distance, as finances, traffic patterns and transportation accessibility also present distance-related barriers to those caring for a remote loved one. Because of these definitional limitations, Parker, Church and Toseland denote a long distance caregiver as:

Anyone (1) who provides informal, unpaid care to a person experiencing some degree of physical, mental, emotional, or economic impairment that limits independence and necessitates assistance; and (2) who experiences caregiving complications because of geographic distances from the recipient, as determined by distance, travel time, travel costs, personal mobility problems, limited transportation, and other related factors that affect the caregiver’s access to the care recipient (p. 391).

Some equivocation remains about who is a long distance care provider due to the transitory nature of caregiving. Many long distance caregivers are not completely stationary; they often visit and, at times, will relocate to provide direct care to their loved one (e.g., Harrigan & Koerin, 2007). A general consensus on how to best define long-distance caregivers has not yet been established. For the purposes of this study, however, long distance caregivers will be defined as caregivers living an hour or more away from the care recipient. This definition was endorsed by focus group participants during the preliminary stages of this study.

Proximate and Co-residing Caregivers

In addition to long distance caregivers, this study identifies two additional groups of caregivers with which to compare levels of support and bereavement adjustment. These are proximate caregivers and co-residing caregivers. Proximate caregivers are individuals who live

near, but not with, the care recipient. This study defines these caregivers as living less than an hour away from their loved one. Co-residing caregivers, on the other hand, live in the same domicile as the person needing care. This includes persons who have temporarily moved into a patient's home for the sole purpose of providing assistance.

Statement of Significance

The findings of this study may contribute to the current scholarship on the topics of caregivers, persons coping with cancer, end-of-life care, and bereavement. Since currently no empirical scholarship explores how support and post-death adjustment are affected by the geographic distance between a caregiver and their dying loved-one, this research addresses a significant gap in the literature. Additionally, this research is compatible with the research agendas advanced by several professional organizations. For example, the National Hospice and Palliative Care Organization (2004) summons researchers to systematically explore the following caregiver-related questions:

1. What is the experience of the family caregiver in caring for a dying individual?
2. How do pre-death interventions affect survivors post-death?
3. What is the impact of hospice/palliative care on bereavement outcomes? (p. 491)

Similarly, professional social work organizations have called for research on these topics. Since many social work practitioners find satisfying careers in end-of-life care and bereavement support, it is important that social work research explores the needs and concerns of these patients and caregivers.

The Social Work Summit on End-of-Life and Palliative Care (2002) called for social work research to focus on issues related to palliative care, end-of-life, and bereavement support. This position has been echoed by the Institute for the Advancement of Social Work Research

(IASWR, 2003) which recommended increased social work involvement in cancer-related research, particularly exploring ways to support families during the illness and subsequent bereavement. Furthermore, IASWR called for exploratory studies on the “impact and burden of cancer care on family caregivers” (p.14) as well as a systematic examination of how patient location (i.e., in-home, residential facility, or hospital) influences caregiver adjustment. Although patient location is conceptually different than caregiver proximity, it is hypothesized that the two are fundamentally related.

Not only can this research add to the few studies that have explored the support and coping needs of long distance caregivers, the findings may suggest meaningful types of psychosocial interventions for the individuals who provide care for terminally-ill cancer patients from a distance. Likewise, findings can provide some direction for those working with bereaved individuals. Conducting this inquiry also helps to uncover this “invisible” group of care providers who care from afar. Since this group has historically been overlooked, the study may also serve to further legitimize the role of those providing care from out-of-town, while acknowledging their many contributions and concerns.

Research Questions

Given the preceding concerns, several guiding research questions have been generated. These questions explore changes in social support and psychological adjustment over time, from caregiving to bereavement (i.e., pre-death status compared to post-death status). These variables are also explored across groups of caregivers based on their proximity to the patient. Specific hypotheses about the expected variable relationships are addressed in chapter 2. The overarching research questions include:

1. Do levels of pre-death adjustment differ from levels of post-death adjustment?

2. Do pre- and post-death levels of perceived support differ between long distance, proximate and co-residing caregivers?
3. Do levels of pre-death social support differ from levels of post-death social support?
4. Do levels of post-death bereavement adjustment differ between long distance, proximate, and co-residing caregivers?

Furthermore, based on an extensive survey of the literature, four areas of concern have been identified regarding the support and bereavement adjustment needs of long distance caretakers. It is assumed that compared to proximate and co-residing caregivers, long distance caregivers tend to (1) lack context regarding changes in the care recipient's status, (2) experience heightened feelings of guilt and inadequacy, (3) reap fewer care-related benefits, and (4) have unrecognized social and psychological needs.

Problem Statement: Distant Caregivers Lack Context

Because long distance caregivers rely on others to inform them about the changing health needs and status of their loved one, they are often forced to make decisions without first-hand knowledge of the situation and context (Harrigan & Koerin, 2007; Heath, 1995; Joseph & Hallman, 1998; Manthorpe, 2001). Thus, geographically separated caregivers may have a difficult time accurately assessing their care recipient's needs. Previous research suggests distant care providers are interested in receiving information related to their loved one's condition, but that this need is often not being met. In a study of family caregivers of dementia patients, long distance caregivers reported significantly higher levels of dissatisfaction with the amount of information they received compared to those living close to, or with, the patient (Thompson & Lovestone, 2002).

Subjective, biased, and sometimes ambiguous reports may further confound the caregiver/care recipient communication gap. Often times, the information caregivers receive, typically over the phone, may be vague and lack important circumstantial factors. Additionally, proximal informants may distort the patient's needs, by either exaggerating or minimizing pressing concerns (Harrigan & Koerin, 2007; Heath, 1995). This may be due, in part, because some patients do not want to be perceived as a burden (Harrigan & Koerin).

Crimmons and Ingegneri (cited in Joseph & Hallman, 1998) suggest that, since geographically distant caregivers have less direct contact with their ailing loved ones, they may be less aware of increased debility or emotional care needs - in turn, making long distance caregiving more crisis-driven. The lack of context may also contribute to increased dissatisfaction with support systems, frustration, feelings of inadequacy, and complicated bereavement adjustment.

Problem Statement: Distant Caregivers Experience Heightened Feelings of Guilt and Inadequacy

According to Collins, Holt, Moore and Bledsoe (2003) "there is a nagging realization that caregiving from a distance can be at best only partial" (p. 331). A number of caregiving researchers have echoed this assertion (Baldock, 2000; Koerin & Harrigan, 2002; Manthorpe, 2001; Scharz-Borden, 1986). Manthorpe, for example, argues that feelings of self-blame and negative self-appraisals about one's caregiving efforts are commonly experienced by those who live far away from their frail or ailing loved ones. Many remotely located family members and friends may feel they are not meeting their caregiving obligations. Falling short of one's perceived caregiving responsibilities, whether appraised by one's self or others can lead to these intense feelings of regret, remorse, and insufficiency. Those providing care to terminally ill loved

ones may be especially susceptible to guilt and self-blame. As Manthorpe writes “relatives living at a distance may face anxiety that they are not responding adequately to a person in their last weeks or days or guilt that they were not available in what turned out to be final times” (p. 598).

Problem Statement: Distant Caregivers Reap Fewer Care-Related Benefits

It is widely acknowledged that informal caregivers experience both benefits and burdens from their efforts (Amirkhanyan & Wolf, 2003; Koerin & Harrigan, 2003; MetLife, 2004; Parker, Call, Dunkle & Vaitkus, 2002; Thompsell & Lovestone, 2002). Caregivers can experience undesirable consequences such as stress, depression, and anxiety, or positive gains such as increased knowledge, a closer relationship with the care recipient, and greater self-efficacy. The blend of pros and cons gained from providing care, consequently affects the caregiver’s coping ability and bereavement adjustment (Amirkhanyan & Wolf; Bass, 1990; Brody et al., 1989). However, research suggests that geographically distant caregivers (and others who do not provide direct, hands-on care) may experience many of the negative effects associated with caregiving, but few of the rewards (Amirkhanyan & Wolf). This suggests that long distance caregivers may have a more difficult time coping with the stressors associated with providing care, or perhaps an increased risk of complicated bereavement.

Problem Statement: The Social and Psychological Needs of Long Distance Caregivers Often Go Unrecognized

The social and psychological impacts of providing care from far away are unknown. However, care-related stress often affects an entire care network, regardless of location or type of care responsibilities (Amirkhanyan & Wolf, 2003; Cicirelli, 1992; Schoonover et al., 1989). In fact, the uncertainty and lack of context about the relative’s care or health status may heighten the worry experienced by those living afar (Parker, Call, Dunkle & Vaitkus, 2002). For informal

caregivers living with or near a loved one enrolled in hospice care, support services are readily available. Similarly, after the loved one's death, bereavement follow-up is easily accessible to those living nearby. For bereaved persons at a distance on the other hand, the availability, or initiation, of grief support networks may be overlooked by palliative care social workers or bereavement specialists (Manthorpe, 2001).

Relevance to Social Work

As a profession, social work has flourished in a variety of health care settings; and has an especially strong presence in end-of-life care environments, including palliative care centers, nursing homes, hospices, and oncology clinics. Because of the wide array of social, psychological, and economic needs of the clients and families who seek assistance in these settings, social workers are often viewed as integral members of interdisciplinary team practice. In addition, social work practitioners, especially those working in hospice and palliative care programs, are playing prominent roles in the area of bereavement work (Walsh-Burke, 2000). To assist grieving individuals during this taxing time, grief counselors and bereavement support personnel provide a wide range of clinical services. Caring for a loved-one with cancer, and then grieving the loss after they die, are often two of the most stress-inducing life events. In the context of palliative care, social workers are charged with providing social and psychological support to patients and their caregivers, regardless of their geographic location. As Manthorpe (2001) points out, social workers can acknowledge the less visible long distance caregivers, recognize their concerns, and serve as a local liaison or familiar voice.

Social work, along with other health disciplines, should be involved in discussions about research, meaningful interventions, and multidisciplinary collaboration to improve support for long distance caregivers (Benefield, 2005). Thus, it is instrumental for practitioners in these

fields to be knowledgeable about caregiver support, loss, grief reactions and bereavement, as well as means to effectively intervene when needed (Gwyther et al., 2005). Social workers in end-of-life care settings also acknowledge the importance of understanding the needs of caregivers. When asked about what content areas they needed most, the workers indicated education on (1) “the psychological and social needs of patients and families,” (2) “psychosocial interventions to ameliorate distress,” and (3) “the influence of dying on family dynamics” (Csikai & Raymer, 2005, p. 62). Perhaps by providing adequate support and information to those living at a distance, practitioners can reduce stress and allow those offering care from a distance to do so more effectively (Thompson & Lovestone, 2002). Social workers can also help by connecting distant loved ones with proximate caregivers (Manthorpe, 2001); “however, relatives at a distance are not so readily labeled as carers and their needs and circumstances lie outside the remit of social workers, who generally have discrete geographical responsibilities and of course heavy demands on their time” (p. 594).

Issues of social and economic justice are two of the foremost concerns of the social work profession. A brief examination of the literature on issues of caregiving, access to health care, and other care disparities reveal numerous social justice concerns. For example, a pervasive, albeit inequitable, societal expectation continues to exist - namely that women should attend to the direct, hands-on care needs of care recipients, rather than men. Although the numbers of male and female long distance caregivers are nearly equivalent, noteworthy gender gaps remain (Joseph & Hallman, 1998; MetLife, 2004; Wagner, 1997). For example, women tend to miss more work, provide more personal care, and are willing to travel further and more often (MetLife).

Other important social justice issues have been identified in the literature. According to Kosberg (2002) the social work profession should also explore the needs of the less prosperous individuals who are separated from their loved ones needing care (e.g., rural elderly who require health services located out of town). Social workers also need to identify policy initiatives and strategic programs which can ensure the long-term care needs are met and that geographically separated families are supported (Kosberg). Benefield (2005) similarly recommends macro-level advocacy by informing legislators and key decision makers about the often unrecognized plight of the distant caregiver. Given the increasing multicultural richness in America, these strategies may also include collaboration with immigrant and first-generation populations who provide care and support for loved ones in other countries (United Nations Social and Economic Council, 2004).

Typically, health care entities which provide services to patients at the end of life, such as renal dialysis clinics, home health agencies, cancer care facilities, and hospices, often provide support services to local informal caregivers. However, the support needs of concerned individuals who provide care from a distance often go unacknowledged. Health care professionals should consider the needs and contributions of caregivers living at a distance (Koerin & Harrigan, 2002), especially since distance is known to complicate care, communication and relationships (Bladock, 2000; Joseph & Hallman, 1998; Parker et al., 2006; Schoonover et al., 1989). Unfortunately, the social, psychological, and financial demands on distant caregivers have generally remained unexplored by researchers (Parker et al., 2002). But as Brody and colleagues (1987) note, “it is important to strengthen the family’s caregiving capabilities and reduce strains that may impede that care” (p. 529). This research may contribute to our understanding of caregivers, particularly those living at a distance. More specifically, the

purpose of this study was to identify how the social support and bereavement adjustment of cancer caregivers are influenced by geographic proximity.

Conceptual/Theoretical Framework

Theoretical frameworks help explain and describe complex relationships and social interactions. They also provide guidance to practitioners, researchers, and educators. Although a more explicit discussion of this study's theoretical orientation can be found in chapter 2 (page 53), this study draws on two broad-based social theories to help explicate the intricacies involved in providing care to a loved one. These are (1) the ecological perspective and (2) family systems theory. The premise of the ecological approach to social work practice is that individuals are best understood within the context of the complex social and political systems within which they exist (Germain, 1984; Greene, 2000). This perspective is congruent with the person-in-environment approach which views individuals within the larger context of their physical and social surroundings. Family systems theory views family groups as self-regulating systems which strive to maintain equilibrium (Rolland, 1994). Being diagnosed with a life-threatening illness can have serious ripple effects extending throughout a number of important social spheres such as family, friends, neighborhoods, work, and spiritual communities.

When caregiving networks form in response to the needs of a terminally-ill individual, the networks (and the processes by which they work) are dynamic, interdependent systems which change and evolve over time. Carpentier and Ducharme (2003) characterized the many complexities involved in understanding care networks, including: (1) shifts from informal to formal services; (2) interdependence among network members; (3) changes over time; (4) changes in function; (5) changes in individual perceptions; (6) conflicts within the network; (7) reciprocity among members; (8) overlapping roles; (9) family culture, i.e., collective vs.

individualistic; (10) responses to crises; (11) maintenance and regulation of the network; and, (12) outside obligations. When issues of geography and distance are included in the mix, it is easy to recognize that an inclusive model is needed in order to capture the *gestalt* of the entire care network. To account for these various factors, the ecological approach, coupled with family systems theory, help provide a holistic person- and family-centered perspective to account for the interconnectedness and uniqueness of individual care networks.

CHAPTER TWO

A Review of the Literature

This chapter provides a review of scholarly literature pertaining to long distance caregivers of persons with terminal cancer. The purpose of this review is manifold. A thorough examination of the research base allows for: (1) a general understanding about the current state of knowledge on long distance caregiving; (2) an evaluation of the quantity and quality of the existing empirical research; (3) the identification of known or theorized relationships among salient variables; and (4) the formulation of specific research hypotheses. The literature review begins with a general overview of caregiving in the United States, including discussions of cancer care, end-of-life care, and bereavement. This is followed by a thorough exploration of what is currently known about long distance caregivers and a critical examination of the designs and methods utilized by those studies. The chapter concludes with a description of the study's theoretical orientation and specific research hypotheses and sub-hypotheses.

Caregiving in the United States

Research on long distance caregiving is couched within a larger body of research on informal caregiving. Scholarship on the experience of unpaid caregivers has grown extensively over the past five decades. Studies of caregiving began in the 1950s with small descriptive studies investigating the relationship dynamics of family systems (Tennstadt, 1999). Over the years, researchers have greatly refined their empirical methods and instrumentation. Recent research on informal caregivers (see Table 2 for definitions of key terms) includes a number of large national probability samples (e.g., NAC & AARP, 2004; National Long Term Care Survey of Informal Caregivers, 1989) and qualitative inquiries that provide detailed insight into the caregiver's world (e.g., Ingersoll-Dayton et al., 2003). The care recipients are a diverse group of

individuals with unique needs. Those receiving care include children with chronic disabilities, patients with traumatic brain injuries, and persons with mental health diagnoses, to only name a few. Although research on these populations have made important and considerable contributions to the caregiving literature, the scholarship used to inform this study has been restricted to previous research pertaining to informal caregivers of frail or seriously ill adults. A large number of caregiver studies have focused primarily on caregivers of individuals with progressive dementias, especially of the Alzheimer's type. As Tennstedt (1999) states, however, "we must be careful not to generalize to all caregivers what we have learned about dementia caregivers" (p. 12). Similarly, Haley and colleagues (2001) question the applicability of the dementia research to caregivers of cancer patients.

The number of Americans currently providing informal care to an ill or disabled adult is estimated between 44.4 million (NAC & AARP, 2004) and 54 million (Health and Human Services, 1998). The time and effort spent by these uncompensated caregivers is valued at nearly \$200 billion (a conservative estimate), which translates to roughly 20% of the overall U.S. health care budget (MetLife, 1999). Those who assume the role of unpaid caregiver often experience a number of physical, emotional, social, and financial consequences. For instance informal caregiving has been associated with heightened levels of anxiety, depression, social isolation, and economic pressure (Ferrario, 2004; George & Gwyther, 1986; Harding & Higginson, 2003; Jensen & Given, 1991; Rose, 1998; Schulz, Visintainer & Williamson, 1990). Providing care is not without its benefits, however. Many caretakers report stronger relationships with the patient, an increased sense of personal accomplishment, and improved self-esteem (Boerner, Schulz & Horowitz, 2004).

Table 2

Definitions of Key Terms

Term	Definition
Care Recipient:	The person who requires care or assistance; a patient.
Direct Care:	Providing personal assistance routine activities of daily living (ADLs), such as eating, bathing, toileting and mobility; hands-on care.
Indirect Care:	Secondary support, i.e. assisting with instrumental activities of daily living (IADLs) such as paying bills, preparing meals, transportation, and household maintenance.
Informal Caregivers:	Unpaid caregivers, usually family or friends of the care recipient.
Formal Caregivers:	Paid providers of care; hired services.
Co-residing Caregivers:	Informal caregivers who live with the care recipient.
Proximate Caregivers:	Informal caregivers who live near the care recipient; local caregivers.
Long Distance Caregivers:	Informal caregivers who provide assistance from afar; the out-of-town caregivers.

Although the current literature on caregivers is large and diverse, one recurring topic is the aging of America. There is a particular interest in how changing demographics (e.g., the Baby-Boomer generation) will alter the face of informal caregiving in the United States.

Cancer Caregiving

The few existing studies suggest this group experiences high levels of caregiver burden (Emanuel et al., 2000; Emanuel et al., 1999; Ferrario, 2004; Given et al., 2004; NAC & AARP, 2004). Cancer caregivers also tend to report lower quality of life (McMillan et al., 2002), greater

relationship strain (Kissane et al, 1994), a decreased sense of mastery (Moody, Lowery & Tarandi cited in McMillan, 2005), and diminished mental and physical health (Haley et al., 2001; Nijober et al., 2000; Nijober et al., 1998; Payne, Smith & Dean, 1999). And perhaps most disconcertingly, Schulz and Beach (1999) report that caring for terminally-ill loved one increases one's risk of mortality.

At the end of life, informal caregivers of patients with cancer tend to be spouses (reported between 54% and 65%) (Emanuel et al., 1999; Given et al., 2004; McMillan, 2005). Even so, Givens and colleagues report that those who provide informal assistance to parents with terminal cancer (~26%), and are employed, are most likely to report depressive symptoms. Some studies report that after a loved one's death, survivors tend to recover quickly from the detrimental effects of caregiving (Jordan & Niemeyer, 2003; Schulz et al., 2001). Schulz and colleagues (2001) found improved indicators of health and depression in a sample of bereaved caregivers who reported high levels of care-related strain prior to the death. It is hypothesized that during the course of bereavement, former caregivers may experience a "relief effect" in the absence of care-related demands. In addition, several other factors may contribute to the relief effect during bereavement: (1) the patient is no longer suffering, (2) caregivers can begin to emotionally prepare themselves for the loss during the caregiving period, and (3) caregiving allows for the formation of a support network, which could continue to support the survivor after the loss (Schulz et al.).

Conversely, some researchers argue that increased caregiver strain can lead to a greater risk of complicated bereavement outcomes, in other words a "depletion effect" (e.g., Ferrario, 2005; Schulz et al., 2001). Some studies suggest caregivers continue to experience lingering physical and psychological consequences long after the death of their loved one. For example, a

number of studies have reported that some family care providers maintain a persistent depressive state for as long as a year or more into bereavement (Bondar & Kiecolt-Glaser, 1994; Kelly et al., 1999; Kurtz et al., 1997; Rodinson-Whelan et al., 2001; Wyatt et al., 1997).

Several factors seem to moderate the strains of caregiving and negative impacts of a loved one's death. For example, a caregiver's self-care routine and perceptions about social support appear to foster coping and adjustment, during the illness and afterward during post-death adjustment (Aranda & Milne, 2000; Brewer, 2002; Powers & Wampold, 1995). In fact these two variables may have direct rather than moderating effects. As Aranda and Milne (2000) state "it appears that the extent of self-care during bereavement, rather than the bereavement itself, may contribute to post-morbid health" (p. 53). Similarly, social support may be a mediator of health outcomes for cancer caregivers (Nijboer, 1998).

Providing care can also be a very rewarding experience (e.g., Amirkhanyan & Wolf, 2003; Boerner, Schulz & Horowitz, 2004), even when the care recipient has a life-limiting diagnosis (Aranda & Milne, 2000; Brown & Stetz, 1999; Nijboer et al., 1999; Salmon, 2005; Stein et al., 1997). Positive outcomes include feelings of personal growth, a sense of accomplishment, increased knowledge, reciprocity, increased self-efficacy, preparedness, and increased empathy (Amirkhanyan & Wolf; Stein et al.). Other positive changes may occur within the family system or caregiving network, as relationships may strengthen during the care process (Aranda & Milne, 2000; Brown & Stetz, 1999). Stein and colleagues (1997) hypothesized that these sorts of positive appraisals can foster adjustment beyond the death of the care recipient.

In this context, another important aspect to consider is that care is often provided through a network of both formal and informal caregivers. Previous literature has focused more on the "primary caregiver" rather than the dynamic tapestry of family, friends and professional service

providers who together participate in the caregiving process (Amirkhanyan & Wolf, 2003; Ingersoll-Dayton et al., 2003). Furthermore, the unique dynamics of a particular caregiving network can influence survivor outcomes (Bass, Bowman & Noelker, 1991).

End-of-Life Care

The end-of-life (EOL) care movement in America is still relatively young. In fact, it was just over 25 years ago that the first hospice opened its doors in Branford, Connecticut. This momentous event was precipitated by the work of two prominent women - Dr. Elisabeth Kübler-Ross, the author of *On Death & Dying* (1969); and Dame Cicely Saunders, who pioneered the hospice movement in London, England. Today, hospice organizations provide comfort care and support services to more than a million individuals coping with terminal illness annually (NHPCO, 2007). The primary goal of hospice and other palliative care organizations is to maximize an individual's *quality* of life, rather than to extend their *quantity* of life. In general, the philosophy of palliative care is patient and family-centered, interdisciplinary, and holistic.

Hospice care is often confused with palliative care. This confusion is due, in part, to the ambiguous and still evolving concept of "palliative care." For instance, the phrase can mean a philosophy of care which is patient-centered and focuses on ways to supply pain and symptom management. In this sense, hospice agencies provide palliative care. On the other hand, "palliative care" is also referred to as a distinct type of care program. By this designation, palliative care organizations are those which provide comfort care to individuals whether or not they meet the prognostic requirements used by hospice of a life expectancy of six-months or less; or patients can simultaneously benefit from comfort care while also undergoing curative therapies (NHPCO, 2007).

The body of scholarship on EOL issues has grown rapidly in recent years. The large majority of the research (more than 90%) in this area has been published in the last 15 years (George, 2002). Certain trends in end-of-life care resonate throughout the literature. These include (1) attempts to expand the current prognostic criteria for hospice care (i.e., beyond a prognosis of six months or less); (2) the emergence of the palliative care facilities and specialists in freestanding hospitals; (3) improved recognition of, and care for, those dying with non-cancer illnesses (especially dementia); and, (4) efforts to improve access for minority populations.

Grief and Bereavement

Over the past century, multiple theories about grief and bereavement have been advanced. Since Freud's publication of *Mourning and Melancholia* in 1917, counseling professionals and academics have conjectured about the nature and process of how survivors react to a loved one's death. Notable conceptualizations include psycho-relational (e.g., Freud, Bowlby, Parkes), cognitive-behavioral (e.g., Lazarus & Folkman, Stroebe, Kavanagh), staged process models (e.g., Kubler-Ross), systems approaches (e.g., Walsh, Kissane, Shapiro), and task-oriented models (e.g., Worden). Despite a plethora of theoretical orientations, few of these bereavement theories have convincingly withstood empirical testing (Bonanno & Kaltman, 1999; Robak, 1999; Wortman & Silver, 1989).

Recent studies have called into question the benefits of bereavement support (Center for the Advancement of Health, 2003), with some finding that post-death support may actually do more harm than good (Jordan & Niemeyer, 2003). For the most part, grieving the loss of a loved one is not a manifestation of psychiatric morbidity. As a group, caregivers tend to be very resilient, and the vast majority recovers without a need for professional intervention. Based on these concerns, bereavement researchers have called for a focus on (1) measurable outcomes, (2)

the identification of risk factors for problematic bereavement, and (3) an exploration of which pre-death variables and interventions affect post-death adjustment (Center for the Advancement of Health, 2003). Although it is difficult to characterize the entire bereavement research community, the trend seems to be that the larger explanatory theories are being abandoned in favor of more discrete, testable hypotheses (e.g., Schulz et al., 2001; Stroebe et al., 2001).

Informal Care Networks

Negotiating Caregiving Responsibilities

The process of sharing caregiving responsibilities among the members of a care network is complex. Proximity and gender are two significant factors when families consider how caregiving responsibilities are divided among relatives. Stern and Neuharth (2002) found that proximity was a key determinant in deciding caregiver responsibility. Similarly, in the 2004 MetLife survey, relatives who lived closer to the patient shared a greater portion of the responsibilities. These results support Stern's (1996) earlier finding that the closest sibling usually assumes the role of caregiver regardless of work status.

Even though proximal family members are more likely to take on the bulk of the responsibilities, a surprising number of long distance caregivers play a principal role in their loved one's care. In the study commissioned by NCOA, 11% of long distance caregivers indicated they were the only caregiver, another 14.5% identified themselves as the primary caregiver, another 31% said they were sharing the responsibilities equally, and 49% indicated they were providing support to a primary caregiver (Wagner, 1997). Koerin and Harrigan (2002) made a similar discovery in the 1997 NAC & AARP survey, noting that more than one third of respondents were providing either half or a majority of the caregiving load. "Between one-third

and one-half of long distance caregivers are *not* secondary helpers, as might be assumed given the distance between them and the care receiver” (Koerin & Harrigan, p. 79; emphasis retained).

As Koerin and Harrigan (2002) note, it is likely that at least one member of a caregiving network is a long distance caregiver. The following reviews what is known about the needs of these geographically dispersed caregivers and how their experiences affect social support and bereavement.

Current Knowledge on Long Distance Caregivers

Based on data from the preceding studies, it appears that a substantial number of people extend physical, emotional, social, and financial assistance from a distance. The MetLife (2004) survey estimated that there are as many as 5 million long distance caregivers in the United States. Earlier, Wagner (1997) estimated as much as 3.5% (7 million) of the adult population provides care from a distance. Although little is known about this sizable group, the available evidence suggests long distance caregivers are both similar to, and different from, their proximal counterparts in a number of key ways.

Gender

Previous studies have shown that gender is known to be a large determinate when deciding which adult members within a family network will provide informal care (e.g., Joseph & Hallman, 1998; Neuharth & Stern, 2000). In general, women are expected to take on the role of informal care provider when a family member becomes critically ill or injured. Interestingly though, nearly half of long distance caregivers are men. Two of the large nationwide surveys found that women were only a slight majority (56% and 54 %) (Wagner, 1997 and Koerin & Harrigan, 2002 respectively), while a third found more men (58%) than women (42%) provided care from a substantial distance (MetLife, 2004).

Men, therefore, make up a larger proportion of long-distance caregivers. In her qualitative study, Baldock (2000) also noticed that gender-based differences among caregivers appear more equitable as distance increases. As she explains, “a simple gendered construct of caring from a distance cannot be maintained” (p. 221). She discovered that when geographically separated from a parent who requires care, both women and men play instrumental roles in maintaining close communication, as well as providing social and emotional support to local caregivers. In addition, members of both genders make frequent visits home, during which they provide physical assistance to the patient and respite to proximal caregivers.

Although a nearly equal number of women and men provide assistance from afar, numerous gender inequalities remain. As Parker, Church and Toseland (2006) phrase it, women are unfortunately confronted with a “triple-bind,” which includes the demands of career, raising children, and elder care (p. 393). This socially constructed dilemma can result in career sacrifices, family conflict, and intense emotional distress for women living at a distance. Among groups of caregivers, men report fewer negative consequences (i.e., guilt, subjective burden, role engulfment, family conflict, depression, and anxiety) related to the care (Brody et al., 1987; Joseph & Hallman, 1998; Schoonover et al, 1988). For women, distance may exacerbate these negative consequences. Given the spatial separation from their loved one, women may fall short of the expectations they have of themselves in the caregiver role (Brody et al.). Thus, the disparity between what women feel they *should* do, and what they *can* do, may further contribute to distance-related caregiver strain.

Also of interest, women tend to view geographic separation differently than men. For example, Brody et al. (1987) found that even when brothers and sisters live the same approximate distance from their parent(s), the women perceive the distance is more of a barrier

than do male siblings. Even so, female caretakers are more likely to travel farther and more frequently than male caregivers (Joseph & Hallman, 1998).

Other Demographic Characteristics

In addition to an almost even split in gender, the vast majority of long distance caregivers are adult children who provide assistance to a parent, parent-in-law or step parent (Koerin & Harrigan, 2002; MetLife, 2004; Wagner, 1997). Less than one percent of distant caregivers provide care for a spouse. Long distant care providers also tend to be middle aged, with the reported average age somewhere between 42 (NAC & AARP, 2004) and 51 (MetLife). Parker and colleagues (2002) reason that the midlife convergence of established careers, family life, and “the increased probability of parental illness and parent care responsibilities” are the reason most long distance caregivers are middle aged (p. 271). In addition, a large majority are Caucasian (MetLife) and well educated, with between 23% (NAC & AARP) and 70% (MetLife) having obtained a college degree or reaching graduate school. The majority is employed and half report an annual income of \$75,000 or more, well above the national average (MetLife). Nearly two-thirds of long distance caregivers are married (MetLife; NAC & AARP; Wagner) with more than a quarter reporting to have at least one child under the age of 17 living with them (MetLife).

Using aggregate information from these large nationwide surveys, the long-distance caregiving population appears relatively educated, of a higher socio-economic status, and married. Lower socio-economic and minority groups may have been under-represented due to design limitations and biased sampling strategies (e.g., the use of internet-based surveys in MetLife). Also, since these surveys were conducted in English, non-English speaking individuals, or those with lower literacy levels, may have been systematically excluded from the pool of potential respondents. Some studies have recognized these shortcomings, and have

attempted to off-set them by over-sampling racially and ethnically diverse populations (e.g., NAC & AARP)

The Care Recipient

Individuals who receive care from a long distance caregiver have an average age ranging from 78 (Koerin & Harrigan, 2002; Wagner, 1997) to 89 (MetLife, 2004). Approximately two-thirds of the care recipients are female (MetLife; Wagner). In terms of living arrangements, 21-35% of care receivers live alone, while somewhere between 37-56% live with a spouse, relative or friend (Koerin & Harrigan; MetLife; Wagner). Among those providing care to someone over 50, cancer is the third most reported reason that care is required, behind aging and diabetes (NAC & AARP, 2004). Given the subject of this study, it is especially important to note that those providing long distance care for a loved one with cancer tend to report higher levels of care-related burden (NAC & AARP).

Caregiving Tasks from Afar

Long distance caregivers conduct a myriad of supportive activities to ensure the needs of their loved ones are met. Although the specific care-related tasks and responsibilities vary from family to family, the long distance caregiver's role can include social and emotional support, advanced care-planning, financial assistance, care-coordination, and respite for local caregivers (Baldock, 2000; Harrigan & Koerin, 2007; MetLife, 2004; Parker et al., 2002). Other important tasks may be the coordination of social events and the preservation of the honor, dignity, and worth of the beloved care receiver (Harrigan & Koerin). To do this, long distance caregivers often rely on local support from nearby friends, family, or hired formal care services (cited in Collins, Holt, Moore, & Bledsoe, 2003). Orchestrating local services, however, can be difficult (Harrigan & Koerin; Heath, 1995).

To ensure that adequate care is being provided, long distance caregivers not only coordinate care, but provide follow-up as well. The challenge from afar is to stay knowledgeable about changes in the care recipient's health status and aware of available resources (Collins, Holt, Moore, & Bledsoe, 2003). Active communication and proactive planning can help negotiate these obstacles. This can involve broaching issues about advanced health care plans, such as power of attorney, do-not-resuscitate orders, living wills, funeral arrangements, and quality of life concerns (Collins, Holt, Moore & Bledsoe, 2003; Harrigan & Koerin, 2007). Practical, prevention-based care coordination may also include establishing what Heath (1995) describes as "care partnerships" with service providers in the ill person's community (p. 48). This may involve hiring the services of a geriatric care manager living in the elder's community, enlisting the help of friends and neighbors, and perhaps even using a remote controlled medical emergency alarm device (such as FirstAlert or Med-Alert) to alert local support services when assistance is needed (Heath, 1995; Koerin & Harrigan, 2002; Roff et al, 2003).

The recent MetLife (2000) study found that one half of distance caregivers spent time arranging care services for the patient, or checking to see that care is adequately being provided. Similarly, Koerin and Harrigan (2002) report that 56.9% of long distance caregivers made arrangements for professional support services. Surprisingly, three fourths of long distance caregivers helped with instrumental activities of daily living (IADLs) such as managing economic assets, assisting with medicines, arranging transportation, preparing meals, and cleaning around the house.

Out-of-town caregivers also make significant financial contributions to ensure their loved one's care needs are being met (MetLife, 2004; Parker et al., 2002; Wagner, 1997). According to Manthorpe (2001) these monetary contributions are expressions of concern and emotional

closeness. On average long distance caregivers provide approximately \$200 out-of-pocket per month for goods and services for their care recipients (MetLife, 2004). This is in addition to another \$200 per month for travel expenses. In total, long distance caregivers spend an average of \$400 a month on care-related services and travel.

Furthermore, those who live further away spend more per month. The MetLife (2004) study found geographic distance adds to caregiver expenses. It not only costs more to travel farther, but greater distances can make it difficult to manage responsibilities at work and with family. Unfortunately, these care-related expenditures may increase dramatically after a terminal diagnosis. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT, 1995) suggests that providing for someone at the end of life may force some families to the brink of financial impoverishment. SUPPORT investigators reported that although their sample was relatively well-insured, 31% of respondents reported “loss of most or all of the family savings” (SUPPORT, 1995, p. 1632).

Employment

Many informal caregivers maintain outside employment. Survey results from the NAC/AARP (2004) study found that caregivers living further away are more likely to be employed (68%) than those living nearby (57%). Neuharth and Stern (2000) also found a positive relationship between caregiver distance and employment status. In the MetLife (2004) study, a large majority (80%) of respondents reported being employed either full or part-time. As one might expect, employment is a key concern for geographically distant caregivers. Many need allowances for time off, phone access, and benefit information from their employer to face the unique challenges of providing support from a distance (Manthorpe, 2001).

Data on whether employers are considerate of the needs of those providing care are mixed. The MetLife (2004) study found the majority of long distance caregivers described their employer as accommodating, allowing for time off, flexible hours, tardiness and missed days. It also appears that caregivers take advantage of these allowances. For example, 68% of caregivers living at a distance report more work-related adjustments than those living within an hours' travel time from the care recipient (57%) (NAC & AARP, 2004). Similarly, caregivers living further from their elderly relatives are more likely to take sick leave and relocate to assist the frail care recipient (Joseph & Hallman, 1996 cited in Joseph & Hallman, 1998).

Despite some evidence that employers are considerate of the needs of distance caregivers, a number of studies have concluded that few employers provide benefits to assist their workers who are also family caregivers (Scharlach cited in Parker, Church & Toseland, 2006). These seemingly unsupportive work environments may pressure informal caregivers to resign, elect an early retirement, or forego further career advancement. As many as 64% of long distance caregivers report their caregiving situation has adversely impacted their employment (Koerin & Harrigan, 2002). Long-distance caregivers are often put in the difficult position of prioritizing family, career and the care of their remote loved-one (Roff et al., 2003). Unfortunately individuals in this position may be forced to choose between two "jobs," one as paid employee and the other as an unpaid caregiver. Clearly these career disruptions further contribute to gender inequalities, since the majority of persons who accept the role of unpaid caregiver are women.

Contact with the Care Recipient

Long distance caregivers reportedly live an average of 450 miles, and more than 7 hours travel-time, from the person receiving help (MetLife, 2004). Even so, adult children who move away are still expected to maintain contact with their frail or ailing parent(s) (cited in Collins,

Holt, Moore, & Bledsoe, 2003). Unfortunately, distance can be a barrier to regular contact and interaction with the care recipient (MetLife, 2004). Of course, living far apart affects the frequency and nature of interactions between family members (Frankel & Dewit, 1989). Even though proximity changes the nature of the contact, relationships such as those between a parent and child can remain strong over long distances (Dewit, Wister, & Burch, 1988; Schoonover, Brody, Hoffman & Kleban, 1988). Climo (1992), for example, challenged the assumption that geographically distant children are emotionally disconnected from their parents. In other words, physical closeness is not a prerequisite for preserving emotional attachments. As Manthorpe (2001) argues, even though distance complicates contact between family members, “older people generally derive immense emotional support from their relatives regardless of distance” (p. 600). Likewise, Baldock (2000) found that frequent contacts (by phone or mail) between children and parents helped maintain these close relationship ties when separated from loved ones.

Compromised mobility and distance from those needing care can, and do, greatly restrict the contact and care arrangements that caregivers can make. This often elicits a great deal of stress, worry and anxiety (Parker et al., 2002). Similarly, Crimmons and Ingegneri (cited in Joseph & Hallman, 1998) suggest since geographically distant children have less direct contact with their parents, they may be less aware of increased debility or emotional care needs, making long distance caregiving by children more crisis-driven than proximate care. This may be especially true when caring for a loved one with a terminal diagnosis.

While long distance caregivers are known to make fewer face-to-face contacts with their care recipients compared to proximally located caregivers (Joseph & Hallman, 1998), contacts by phone, mail, and computer are frequent. In a group of military officers who identified themselves as living a long distance from an elderly parent or parents, Parker et al. (2002)

explored how the frequency of parent contact (by mail, phone, or e-mail) was influenced by parent-child characteristics. They found that, overall, parental contact is frequent, with the vast majority of officers writing or calling their parents almost weekly, whether they are worried or not (Parker et al.). A similar study discovered that the primary forms of contact are by telephone or e-mail (Roff et al., 2003). The internet and other forms of electronic communication will likely change the nature and extent of contact between geographically distant caregivers and those they care for (Parker et al., 2002).

Although distance, employment and finances often make travel difficult, long distance caregivers do make frequent face-to-face visits with the loved one needing care. For example, as many as 16% of those living more than an hour away visit their loved one once a week or more (NAC & AARP, 2004). Parker et al. (2002) suggest during a health crisis or emergency, long distance caregivers are especially likely to visit care recipients and provide more direct, hands-on care or other assistance. They also hypothesize that these abbreviated visits may only heighten the psychological worry and distress of a sustained long distance separation.

The number of long distance caregivers who eventually move in with, or near, the care recipient is unknown; however, it is not uncommon. Several qualitative accounts reveal that some caregivers have the means and flexibility to successfully relocate closer to their loved one (Baldock, 2000; Brewer, 2002; Harrigan & Koerin, 2007). Given their propensity to visit for extended periods and, in some cases, change residence, long distance caregivers should not be seen as an entirely stationary population.

Social Support

The presence of social support is often viewed as a moderator for caregiver distress and bereavement complications (Given et al., 2004). In general, studies seem to confirm that

perceived social support fosters coping and resilience, both during caregiving and afterward during post-death adjustment (Aranda & Milne, 2000; Brewer, 2002; Powers & Wampold, 1994). As Nijboer et al. (1998) note, social support is a likely mediator of mental and physical health outcomes for cancer caregivers as well. These sources of social support can include intimate partners, family, friends, health professionals, and resources.

A caregiver's perception about her or his level of support is significant. Just because others are present does not mean that one feels appreciated or adequately supported. Perceptions of social support affect bereavement outcomes. Simply put, a lack of perceived support seems to predict complications during bereavement (Parkes, 2002; Walsh-Burke, 2000). Similarly, subjective appraisals about professional support (e.g., hospice) during caregiving can influence bereavement adjustment (Bass, Bowman & Noelker, 1991).

Spirituality

Issues of religion and spirituality should be considered during care management discussions especially for caregivers providing support from a distance (Crowther, Baker, Larimore, Koenig & Parker, 2003). Faith-based communities can be an instrumental form of support for both long distance caregivers and their care recipients (Crowther et al.). Local churches, mosques, synagogues, temples, and other spiritual communities can provide local support to frail or infirm individuals, while keeping distant caregivers informed of their needs. It is believed that feeling spiritually supported can mediate the stressors of caregiving (Crowther et al.), as well as problems during bereavement (Kissane, 2003). Although empirical evidence about the type and level of spiritual support received by long distance caregivers is virtually non-existent, Crowther and colleagues argue that many Americans, including geographically distant caregivers, turn to religion and spirituality during stressful life events. The importance of

spirituality among long distance caregivers was also exemplified in a recent case by Collins et al. (2003). In their case study examining the experience of a long distance caregiver, they found that spiritual retreats, prayer, and interactions with other members of the spiritual community, were instrumental sources of strength and inspiration (Collins et al.).

Military Families

Armed service personnel and their families are a significant sub-population of long distance caregivers. The job often requires extended tours away from home and frequent changes in station assignment (Kosberg, 2002). As a group, military families may represent the most stable group of long distance caregivers (Roff et al., 2003). Previous studies on military populations found that more than 90% of senior military officers lived greater than 300 miles from their parents (cited in Roff, Toseland, Martin, Fine, Parker, 2003). The needs and experiences of long distance caregivers who are active duty military are likely similar to those of civilians (Roff et al.); and, thus, it is likely that findings from studies using samples of military families providing long distance care (e.g., Parker et al., 2002) are applicable to non-military families as well.

Costs and Benefits of Long Distance Caregiving

The struggles and opportunities involved in providing quality care to a distant loved one is something that researchers are just beginning to explore (Parker et al., 2002). As Harrigan and Koerin (2007) describe it, long distance caregiving is “both painful and rewarding” (p. 13). Many of those researching long distance caregivers concur that providing care, even at a lengthy distance, offers many challenges, as well as many rewards (Baldock, 2000; Brody et al., 1987; Koerin & Harrigan, 2002; MetLife, 2004; Parker et al., 2002; Thompsell & Lovestone, 2002). Some of the rewards include fulfilling a personal obligation, ensuring adequate care for the loved

one, a sense of personal satisfaction, and time spent together (Koerin & Harrigan; Wagner, 1997).

The burdens of long distance caregivers are also noteworthy. In fact, Collins et al. (2003) caution about underestimating negative effects, such as stress and depression, on long distance caregivers. Distance can create unique stressors for distance caregivers (Wagner, 1997). Wagner found approximately one third of long distance caregivers report their role is either stressful or very stressful. Furthermore, she found that 79% of geographically distant caregivers report being adversely affected by caregiving, and a quarter are substantially affected, noting declining health, significant social impairment, or extraordinary levels of anxiety. Similarly, the NAC and AARP (2004) survey found a larger percentage of caregivers who lived furthest away reported emotional distress (47%) more so than those living with the care recipient (43%), or those residing an hour or less away (28%). This lends support to Thompsell and Lovestone's (2002) earlier findings when they compared perceptions of support between near and distant relatives of dementia patients, they found that both groups experienced equally high levels of subjectively reported stress. Those living afar may withdraw, feeling helpless and unable to offer adequate support. Climo (cited in Parker et al., 2002) suggests the social expectation for children to provide care for their parents and the "unavoidable realities of time, distance, and resources produce family strain, guilt, and increased worry" (p. 262). Geographically distant caregivers may simply feel that their contributions to the patient's care are inadequate (Collins et al., 2003; Joseph & Hallman, 1998). Thompsell and Lovestone (2002) add that "the question of how far distant relatives experience burden is worthy of a more detailed study" (p. 806).

A Systematic Review of the Literature: Long Distance Caregivers

A systemic review of the current literature on long distance caregiving resulted in the identification of fourteen academic articles (Baldock, 2000; Climo, 1992; Collins et al., 2003; Harrigan & Koerin, 2007; Joseph & Hallman, 1998; Koerin & Harrigan, 2002; MetLife, 2004; NAC & AARP, 2004; Neuharth & Stern, 2000; Parker et al., 2002; Schoonover et al., 1988; Thompsell & Lovestone, 2002; Wagner, 1997; Watari et al., 2006). Each of these articles specifically addresses the subject of providing care across extensive geographic distances. Additionally, with the exception of Climo (which is published in an edited text), all are published in refereed journals. Eight of the fourteen are primarily quantitative studies, two incorporate mixed methods (Watari et al., 2006; Schoonover et al.), while the remaining four (Baldock; Climo; Collins et al; Harrigan & Koerin) are qualitative analyses.

It should be noted that several other scholarly publications have addressed the topic of long distance caregiving, but do not necessarily contribute to the empirical evidence about the experiences or current state of caregiving from a distance. Instead the substance of these articles vary from providing prescriptive advice (Harvard Women's Health Watch, 2004), advocacy (Benefield, 2005; Heath, 1995; Manthorpe, 2001), general discussion (Carton, 2000; Weaver, 2001) to model/intervention development (Parker et al., 2003; Parker et al., 2001; Roff et al., 2003).

Critique of Empirical Research

The following section provides brief descriptions and evaluations of the quality of evidence provided by the 14 studies identified during the literature review. The assessment of the methodological and scientific merit of published academic studies poses an interesting challenge. The preferred approach to knowledge-building depends upon one's philosophical orientation.

Different research paradigms espouse different methodological approaches. The strategy used here is straightforward: (1) to identify the type of research design, the methodology (including systematic strategies of observation - if any); (2) provide a description of the participants; and, (3) the relative strengths and weaknesses of using that particular approach. In other words, studies are judged based on how well they achieve their own stated objectives.

Watari and her colleagues (2006) evaluated a Los Angeles-based program designed to support long distance caregivers of dementia patients. The support program consisted of five main components: (1) an over-the-phone consultation with a professional care liaison; (2) receipt (either by mail or internet) of a community resource guide and care-plan worksheet; (3) the creation of a web-site to connect long distance caregivers with local resources; (4) phone-based legal consultations to assist with advanced care-planning and financial assessments; and, (5) the use of a monitoring system to help locate, and safely return, persons with dementia who have wandered off or become lost. The satisfaction, service use, and needs of long distance caregivers were explored using a cross-sectional survey. The study was primarily quantitative, although some open-ended questions were included. A non-probability sample of 90 long distance caregivers was compared to 187 local caregivers. To gather data, researchers used a combination of e-mail and post mail surveys. Response rates were low, with a return rate of 29% for surveys sent by post and 19% for surveys sent by e-mail. This study was limited in a number of ways. First, the use of non-probability sampling techniques and low response rates weaken the generalizability of the results. Additionally, the sample of long distance caregivers was largely White and well-educated, suggesting a need to actively require minority respondents - and further calling into question the sample's representativeness. Despite these limitations, this study

does provide some much needed descriptive information about the needs and experiences of those providing care to a person with dementia from far away.

The joint study by the National Alliance for Caregiving and the American Association of Retired Persons (2004) was a nationwide survey to gather information about the state of caregiving in the United States. The survey used random digit dialing and telephone interviews to recruit a sample of 1247 self-identified caregivers. Caregivers were operationally defined as persons 18 years or older who provided one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to an individual 18 years of age or older. Over-sampling techniques were used to include sufficient numbers of African American, Hispanic and Asian-American participants ($N = 200$ per minority group). Of the total caregiver sample, 15% ($N = \sim 187$) were identified as long distance caregivers. Given this study's rigorous probability sampling, the findings have good external validity and generalizability to the larger population of caregivers. However, since the focus of this study was on caregivers in general, rather than long distance caregivers specifically, the information on distance caregivers is limited.

MetLife (2004), in conjunction with the National Alliance for Caregiving (NAC), conducted an on-line survey of long distance caregivers. Out of 79,851 initial e-mail invitations to participate in the study 8,438 accepted the invitation. Of those, 1,130 met the inclusion criteria of "helping someone 55+ during the past year, who has 'chronic physical, cognitive, or mental health problems' and who lives more than an hour away" (p. 4). The large sample size and use of probability sampling techniques makes the study sample highly representative of the larger population (with an estimated margin of error of ± 2.8). However, using an exclusively online survey format may have excluded individuals with limited internet access; which might have been a potential source of error, possibly compromising the generalizability of the findings.

Koerin and Harrigan (2002) conducted a secondary data analysis of the 1997 NAC/AARP caregiver study to explore the characteristics and activities of long distance caregivers. In this case, long distance caregivers were defined as living two or more hours away. The original study employed nationwide probability sampling, with over-sampling of three minority groups, consisting of caregivers who were Black, Asian, and Hispanic. Surveys were administered via phone-based interviews. The initial sample included 1,509 identified caregivers, with a sub-sample of 109 respondents meeting the definition of long distance caregiver. Based on the use of probability sampling techniques and (recognition of the margin of error), the findings from this study can be inferred to the larger population of long distance caregivers. However, because the primary study did not focus on providing care from a distance, Koerin and Harrigan were limited in the scope of research questions they could explore.

Parker and his co-investigators (2002) explored the concerns of senior male military officers regarding their geographic separation from their parents or parent. Two cohorts of students enrolled in the United States Air War College (USAWC) were surveyed, one in the summer of 1997 and the other in the summer of 1998. A total of 277 individuals participated in the surveys. Because researchers used convenience sampling, the findings and conclusions drawn from this study cannot be considered representative of the experiences of the larger population of military personnel. Furthermore, the sample did not include women or non-married individuals and the respondents were not specifically identified as providing care or support to the parent(s) in question, thus, were not reflective of the larger population of long distance caregivers. Another concern is that the analytic strategy employed in this study (Structural Equation Modeling or SEM) presupposes causal pathways over time. Since data were collected using cross-sectional surveys, the directionality of the predictive relationships demands

additional scrutiny. While acknowledging these methodological weaknesses, the findings of this study may provide some indication about how geographic separation from elderly parents contributes to worry, anxiety, and the need for proactive care planning. Implications are targeted, in part, toward long distance caregivers.

Joseph and Hallman (1998) explored the effects of distance on involvement in care by using a secondary data analysis of the 1991 Work and Family Survey originally conducted by the Canadian Aging Research Network (CARNET). The primary study enlisted a Canada-wide probability sample of employed persons. The sample included 5496 participants, 1149 of whom had provided assistance to an elderly relative, or relatives, within the past six months. The researchers used travel-time to split caregiver respondents into one of three categories: 1-30 minutes ($n = 703$), 31-120 minutes ($n = 297$), and > 120 minutes ($n = 149$). These categories were used to test a hypothesis of a *distance-decay* effect on the amount of care provided (p. 631). This study has sufficient generalizability, albeit to employed persons living in Canada. Another concern is that these data are potentially outdated (based on findings from a 1991 survey). In addition, caregivers who were not formally employed at the time of data collection were excluded from this sample. Overall, this research contributes to our understanding of caregiving from afar, but the findings must be considered with respect to these limitations.

Thompson and Lovestone (2002) conducted a case-controlled comparison of two groups of relatives, one group living less than an hour from the care recipient, the other living more than an hour away. Participants were from the United Kingdom and recruited using a community-based registry of dementia cases. The final sample included 29 distant relatives and 35 local relatives. Data were collected using structured phone interviews with both the patient and their relative(s). In this case the samples were small, and recruited by convenience. These factors limit

the generalizability of the findings. However, the matching process minimized the overall variance between the two groups of relatives, thereby strengthening the study's internal validity. In other words, the authors could more confidently assert that the independent variable (distance) was the determining factor when group differences were identified. Conversely, because the data were gathered at one point in time, the direction of causal inferences cannot be established. Another point to consider is that neither of these groups was identified as "caregivers" per se, although respondents were involved in providing care to varying degrees.

Neuharth and Stern (2000) investigated how caregiving responsibilities are negotiated among siblings when an elderly parent requires care. They used data from the 1982 and 1984 National Long Term Care Survey (NLTC) to conduct a secondary data analysis. From an original sampling frame of 25,401, only 2,635 elderly persons met the criteria for study inclusion in 1982, and 2,426 in 1984. The authors found that distance from the parent was a key variable when care-related responsibilities are being delegated among siblings. Although the exact sampling strategy is not clearly described in the article, the large sample sizes suggest adequate external validity. However, given that these surveys were conducted nearly a quarter century ago (prior to widespread use of cell phones and the internet), the generalizability of these findings to contemporary care networks is dubious at best.

Sponsored by the National Council on the Aging (NCOA), Wagner (1997) conducted a cross-sectional survey of long distance caregivers. Using a representative sample of the U.S. population, researchers paneled nearly 1,000 individuals, of which 200 were considered to be long distance caregivers. The study defined long distance caregivers as individuals living more than an hour away from the person receiving care. Respondents were included if they provided or managed some aspect of "care, services, or legal, assistance" for a person 55 years of age or

older. Given the representativeness of the samples, findings may be generalized (with caution) to other long distance caregivers. However, the use of a phone-based survey may have overlooked a significant group - persons who do not have access to a residential landline.

Schoonover and colleagues (1988) use mixed-methods to compare siblings (local and distant) who were providing care and support to a widowed mother. The sample was derived from a previous study involving 150 families. In all, 100 families were interviewed, most of which had been in the original sample. Seventy-one local siblings and 55 distant siblings were involved in this investigation. A cross-sectional questionnaire was delivered in a personal interview format for local siblings and by mail for distant siblings (response rate 82%). Of course, sample representativeness is compromised by the use of non-probability recruitment strategies. Also, the use of two different data collection strategies for local and distant siblings may have systematically biased the results. Furthermore, even though the samples included siblings from the same family, kin-effects were not controlled. With these shortcomings in mind, the high response rate would have limited non-response error; and the inclusion of open-ended questions, allowing for methodological triangulation (Padgett, 1998).

Climo's (1992) book calls attention to the challenges of maintaining relationships with, and providing assistance to, parents over long distances. Using a questionnaire-based interview process, he explored the experiences of adult children who were living substantial distances from their parents (or parent). The sample included 40 couples, of which at least one partner was a university professor at Michigan State University. All respondents lived at least 200 miles from her or his parent(s). The author divided participants into one of three groups: (1) those longing to be reunited, (2) those who have accepted the distance, and (3) those who are estranged. This book provides a substantial amount of raw data in the form of direct quotes from participants.

Baldock's (2000) study entitled *Migrants and their Parents: Caregiving from a Distance* is a qualitative exploration of the experiences of long distance caregivers. Twelve individuals living in Australia were interviewed about providing care and support to a parent living overseas. All participants were employed by the author's home institution, Murdoch University. Four of the interviewees worked in administration, and the remaining eight were instructors. The author did not explain her process of analysis, although interviews were recorded and transcribed. Because the method of analysis is unclear, it is difficult to evaluate the quality of evidence from this study. However, the findings were organized using themes that were observed in the data, and several direct quotes were provided to further illustrate the idea. Baldock describes her study as an exploratory analysis, which provides readers with "important insights in the richness of extended family relations and obligations across space and time" (p. 221).

Harrigan and Koerin (2007) share their personal stories of becoming long distance caregivers and offer practice implications based on these experiences. The authors' narrative accounts are juxtaposed against a review of the literature on providing care from afar; and, in particular, their findings from the NAC/AARP caregiver study (see Koerin & Harrigan, 2002). This joint presentation of the authors' lived experiences, in tandem with an overview of empirical research, provides readers with a pseudo-mixed-methods description of long distance caregiving, offering both breadth and depth. Of course, the biographical information provided by the authors cannot be translated to caregiver populations in general. However, this study does provide an interesting contrast between findings from large-scale studies and the unique stories shared by the authors.

Collins and her co-authors (2003) provide a personal, first-hand account of the trials and travails of being a long distance caregiver within an African American family. This personal

reflection is a case-study steeped in the literature on providing care from far away. As a case exploration, this study cannot speak to the unique and varied experiences of other long distance caregivers. However, as the authors state, the article captures “the many small but important ongoing negotiations and strategies that will be useful to both social workers and caregivers engaged in the process of linking the caregiver to appropriate resources” (p. 315).

Theoretical Orientation

This research was not designed to formally test an established theory. However, theory provides a useful contextual backdrop for formulating hypotheses and understanding the results. A number of models have been advanced in an attempt to describe the transition from caregiving to bereavement; however, many of these models lack the adequate empirical evidence to support their claims (Aranda & Milne, 2000; Bonanno & Kaltman, 1999; Center for the Advancement of Health, 2003; Wortman & Silver, 1989). The cognitive stress theory described by Lazarus and Folkman (1984) centers around caregiver perceptions and how cognitive appraisals of stress affect individual outcomes. Two hypothetical extensions of this theory have been proposed to explain how the caregiving experience affects bereavement (Schulz et al., 2001). The first is the *depletion hypothesis* which posits that increased stress and burden during bereavement leads to vulnerability and problems during bereavement. Under this assumption, a caregiver’s coping ability is compromised (i.e., depleted) due to the strains associated with providing care; and, therefore, she/he becomes more susceptible to complications after the loved one’s death. The second hypothesis is the *relief hypothesis*, which assumes negative bereavement outcomes are attenuated by the death because the caregiving stressors have ended. Under the relief hypothesis a caregiver may experience relief from care-related stressors after the death of the loved one, which in turn, may facilitate bereavement adjustment (e.g., Bass, Bowman & Noelker, 1991).

The type of care that a caregiver provides, whether direct (i.e., hands-on) or indirect, may also influence perceptions about the care experience. These perceptions may have positive and negative consequences into bereavement. As Thompsell and Lovestone (2002) observed, “an assumption underlying much of this literature is that it is the act of physically caring that induces ‘burden.’ This assumption, however, is largely untested” (p. 806). Amirkhanyan and Wolf (2003) hypothesized, the psychological well-being of caregivers is influenced by the combination of (1) stressors and (2) rewards of providing direct care. The positive aspects of caregiving, such as sense of accomplishment or developing a closer relationship with the patient, may buffer the negative effects of care-related stressors. And those who do *not* provide direct, hands-on care (e.g., those living at a distance) may *not* experience the benefits that are gained by meeting the immediate physical needs of the individual receiving care (Amirkhanyan & Wolf, 2003).

Study Hypotheses

Research hypotheses provide clear, testable statements of anticipated relationships between variables. Based on the preceding literature review, the following research hypotheses and sub-hypotheses were formulated:

H₁ - Post-death bereavement adjustment will differ among long distance, proximate, and co-residing caregivers.

H₂ - Levels of pre-death social support will differ from levels of post-death social support.

H₃ - Levels of pre-death adjustment will differ from levels of post-death adjustment.

H_{3 Sub 1} - Co-residing caregivers will show greater improvement on adjustment measures overtime.

H_{3 Sub 2} - Co-residing caregivers will have more depressive symptoms.

H_{3 Sub 3} - Long distance caregivers will report higher levels of guilt.

H_{3 Sub 4} - Long distance caregivers will report higher levels of anger

H₄ - Pre- and post-death levels of perceived support will differ between long distance, proximate and co-residing caregivers.

H_{4 Sub 1} - Long distance caregivers will report higher levels of dissatisfaction with the amount of information received.

CHAPTER THREE

Methodology

This study explores the effects of geographic distance on informal caregiver support and bereavement adjustment. Informal caregivers are those who provide assistance to patients receiving hospice services for end-stage cancer and do not receive monetary compensation for their efforts. These caregivers are often family members, friends, and neighbors. The caregivers who live furthest from the dying care recipient, the long distance caregivers, are of particular interest.

Research Design

This is a prospective bereavement study, which utilizes a 2 x 3 repeated measures design (see Appendix A) to gather data from caregivers before the patient's death (using a pre-death questionnaire) as well as after the death (via post-death questionnaire). This design allows for an examination of differences between the three previously discussed groups of caregivers: long distance caregivers (who live an hour or more from the care recipient), proximate caregivers (who live less than an hour away) and co-residing caregivers. Furthermore, the prospective design was developed based on the recommendations of leading bereavement researchers (e.g., Bass, Bowman & Noelker, 1991; Schulz et al., 2001; Stroebe, Stroebe & Schut, 2003). Validated instruments were used to measure the dependent variables: social support and bereavement adjustment. Additional data, such as length-of-stay in hospice, patient diagnosis, and Palliative Performance Scale score (Appendix B), were gathered from the patient's hospice chart. These methods were constructed to address the following research questions:

1. Do levels of pre-death adjustment differ from levels of post-death adjustment?

2. Do pre- and post-death levels of perceived support differ between long distance, proximate and co-residing caregivers?
3. Do levels of pre-death social support differ from levels of post-death social support?
4. Do levels of post-death bereavement adjustment differ between long distance, proximate, and co-residing caregivers?

Pilot Study

Prior to the main study, a brief pilot study was conducted to evaluate the appropriateness, sensitivity, and wording of the pre- and post-death surveys. Conducting a pilot study with focus group participants involves the inductive process of gathering and analyzing group feedback for the purpose of assessing needs, refining measures, and modifying research protocols (Center for the Advancement of Health, 2003; Rubin & Babbie, 2001). Twelve pilot study participants were recruited from members of a Covenant Hospice bereavement support group. Members of this support group had experienced the death of a loved one, typically a spouse or partner. The support group is ongoing and has an open enrollment (persons can join or leave the group at any time).

Informed, voluntary consent was obtained from all participants prior to initiation of the pilot study. None of the group members' names were recorded, and confidentiality will be protected during any future dissemination activities. All participants were over the age of 18 years and functionally literate in English.

The pilot study took place on December 12, 2006 and lasted approximately one and a half hours. Seven of the participants were female, and five were male. They had an average age of 73 years and the majority (78%) was Caucasian. One subject was Native American, and another identified as "other." All had provided care to a spouse, with one exception, a person who had

been the caregiver for a relative other than a spouse/partner, parent, sibling, or child. Data from the pilot study were collected from the two questionnaires drafts (Pre-Death and Post Death) and a short group discussion (lasting approximately 30 minutes). Detailed, handwritten research notes recorded comments from the group discussion. Iterations of the pilot study questionnaires were based on an extensive literature review, input from hospice professionals, and scholars with knowledge on the topics of caregiving and bereavement. Participants were asked to pilot test the draft versions of the study questionnaires, and to provide feedback on content, syntax, ambiguities, and appropriateness of the overall survey process. Additionally, the group members were asked to give general critique and feedback about the proposed research protocols for the main study. This was done in accordance with Stroebe, Stroebe, and Schut (2003), who recommend that bereavement researchers utilize focus groups and pilot studies to assess the emotional sensitivity and appropriateness of the selected measures.

Feedback from the pilot study participants included a variety of useful comments and recommendations. A number of participants remarked that, for a few of the questions, there was a need to clarify the person to whom the question was referring. For example, in response to a question which asked participants to rate their self-care, one person stated: “But I wasn’t the one who was sick.” Other comments addressed some temporal ambiguities. The instructions for an instrument designed to evaluate respondent well-being directs readers to answer based on “how you have been feeling over the past two weeks.” One of the pilot study participants found this confusing and asked: “When is this two-week period?” And regarding a question which asked about the number of hours that the respondent devoted to the patient’s care, one person queried: “Are these waking hours?” Several other subjects expressed concern that future respondents may not understand the acronyms “ADLs” and “IADLs.” Additionally, those who had been co-

residing caregivers expressed confusion about the questions exploring distance from the care recipient. These comments, questions, and concerns were used to revise and clarify the final versions of the study questionnaires.

Group members were also asked how soon after the loved one's death would be appropriate for the distribution of the post-death questionnaire. The original protocol called for the bereavement surveys to be distributed within one to two months after the death. In general, participants felt that this proposed time-frame for sending the second survey was "too soon" after the death, but that between three and four months would be more acceptable. Based on this feedback, the timing of the post-death questionnaire was revised to be sent out three months after the date of death. Additionally, the wording of the accompanying post-death survey correspondence was revised to say: "Filling out a survey after the death of a loved-one can be a difficult task. We want to be sensitive to your needs, so please take your time and return the survey whenever possible. Thank you."

Main Study

As previously described, this research involved a quantitative, repeated measures study of bereavement adjustment and support as experienced by informal caregivers of terminally-diagnosed cancer patients. The primary focus was on the caregivers who live lengthy distances from the patient.

Data Sources

Data were collected from respondents at two points in time, once before the loved one's death, and again after the death. The study's structure allows for an analysis of how variables of perceived social support and adjustment change over time. Study data were collected using three

sources, the hospice medical chart and two self-report surveys (one pre-death, one post-death) which were completed by the informal caregiver.

1. Pre-Death Questionnaire: A self-report instrument mailed to the identified caregiver approximately one week after the patient's admission into hospice care. This survey assessed the caregiver's expectations about the patient's care and measured the caregiver's current physical, social, and emotional status (Appendix C).
2. Post-Death Questionnaire: The second questionnaire is a bereavement survey which evaluates the caregiver's adjustment after the death, including their physical, social, and emotional status, perceptions about the quality of the patient's dying, and a self-assessment of their caregiving involvement (Appendix D).
3. Patient Medical Chart: Collecting data from the medical chart helped reduce respondent burden, by minimizing the amount of information that caregivers needed to provide on the questionnaires. This approach also allowed for greater data consistency. The chart provided specific data regarding the patient's primary diagnosis, location, gender, pain-level upon admission, Palliative Performance scale score, and length-of-stay in hospice (see Appendix E).

Study participants were given the option to complete their questionnaires online. The hard-copy (i.e., pencil and paper) surveys remained the primary source of data collection; however, the intent was to maximize response rates by providing an internet survey alternative. The cover page of the hard copy surveys reads: "If you would prefer to complete this survey online, please log on to: [survey link] and enter the log-in code: [survey code]." The online survey used software from Inquisite, Inc. Web-Survey Systems. The development and maintenance of the web-survey was provided by the Virginia Institute for Social Services

Training Activities (VISSTA), in conjunction with the VCU School of Social Work. An evaluator associate from VISSTA helped to administrator the online survey.

Data Collection Procedure

Since primary data collection involved self-administered surveys delivered by mail, non-response error was a significant concern. To minimize non-response error, the administration of questionnaires followed the basic tenets of Dillman's (2000) tailored design method. Hence, questionnaires were distributed in the following manner:

Pre-Death Survey

1. An initial pre-death questionnaire sent by mail (Appendix C).
2. A thank you postcard sent seven days later by mail (Appendix F).
3. A duplicate survey packet mailed to the respondent's residence approximately two weeks after the distribution of the initial pre-death survey.

Post-Death Survey (only sent to respondents who returned the pre-death survey)

1. A pre-notification postcard by mail (Appendix G).
2. Respondents received an initial post-death survey packet (3 months after the death), including a pre-addressed postage-paid return envelope (Appendix D).
3. Sent a thank you card one week later (Appendix H).
4. Mailed a duplicate post-death survey three weeks after the initial bereavement survey.

Data collection began on February 19, 2007 and ended on February 19, 2008 - precisely one year after it began. Scheduled mailings for the initial questionnaire (the pre-death survey) concluded on January 21, 2008.

Self-Administered Survey Format

One potential limitation of the self-administered format is that, since surveys were not administered by an interviewer (over-the-phone, for example), respondents could not be actively encouraged to complete the questionnaire. This may also contribute to non-response error (Dillman, 2000). However, a possible strength of this design is that self-administered surveys provide a sense of anonymity (compared to an interview format), and respondents may feel less pressured to give “socially appropriate” responses; thereby reduce the likelihood of social desirability bias (Stroebe, Stroebe & Schut, 2003).

Length of Questionnaires

The length of the two questionnaires may have influenced response rates. The final version of the pre-death survey included a total of 74 questions, and the post-death survey was 93 questions long. It took respondents an estimated 20 minutes to complete a survey. Potential respondents may have opted out of participation due to the length of these surveys. However, a literature review by the U.S. Bureau of the Census (Bogen, 1996) concluded that, while a negative relationship seems to exist between survey length and response rates, the strength of this relationship is surprisingly weak.

Sample

Sample Recruitment

Study participants were recruited from Covenant Hospice, a large Gulf Coast-based palliative care organization that provides comfort care to terminally ill persons. Participants were identified based on their admission into care (usually home-based service) at one of the 13 Covenant Hospice branch office locations. This network of branch offices has a collective service area spanning two states and an estimated 15,000 square miles. Together the hospice

branches provide palliative care to more than 1000 families on a given day (see Chapter 1 page 6 for a more detailed description of Covenant Hospice, Inc.). Potential participants were recruited from this patient pool.

Hospice social workers were enlisted to help recruit potential study participants. This includes workers at each of the 13 Covenant Hospice branches. Hospice policy requires social workers to complete a psychosocial assessment for all newly admitted families within 48 hours. During this assessment visit, a social worker identified potential study participants using the following inclusion/exclusion criteria: (1) the patient had a primary diagnosis of cancer; (2) the patient meets Covenant's admission criteria and has been admitted into hospice care; and, most importantly (3) the family is willing to receive a phone call from the study's author to gather the names and contact information of the various informal caregivers. An informal caregiver was defined as any person the patient (or proxy decision maker) identified as someone who is usually unpaid (i.e., not an agency employee) who provides physical, mental, emotional, or financial assistance to the care recipient – *regardless of geographic location*. Once a social worker identified a willing patient and family meeting the inclusion criteria, the informed consent process began (see Appendix I & J).

Although no study data were collected directly from patients, they were asked to provide signed consent since data from their medical chart was used to minimize the length of the caregiver questionnaires. Social workers asked the patient (or proxy decision-maker) for their permission to contact the family by phone and to collect contact information for those involved in the patient's care network. To qualify for participation, caregivers had to be over 18 years of age and functionally literate in English. These conditions for participation were evaluated during the initial phone contact. Once a patient granted permission to contact his or her caregiver(s), the

author collected the mailing addresses of those persons who were identified as an informal caregiver and met the inclusion criteria. The selected respondents were then sent a pre-death survey by United States Postal Service with an attached consent cover letter (Appendix K), study brochure (Appendix L) and a pre-addressed, stamped envelope for return by mail.

Since social workers employed by Covenant Hospice assisted with study recruitment and consent procedures, all social workers were trained to ensure that informed, voluntary consent was established. Social workers were given a consent script (see Appendix J), and had weekly contact with, and supervision by, the student investigator (Mr. Cagle).

Participants

Recruitment for this study began on February 19, 2007 and lasted an entire year. During this time, a total of 116 hospice patients were referred to the study. The author attempted to contact new referrals as soon as possible, usually within 24 hours. Even so, nine (9) patients died prior to initial contact. Similarly there were two cases in which family members asked the author to postpone survey distribution until further notice because the patient's death was considered imminent. In both situations, the referred patient died within several days and questionnaires were never sent. Additionally, one patient stated that he did not have any informal caregivers and thus did not meet the inclusion criteria for the caregiver survey portion of the study. The remaining 104 hospice patients were contacted (or in some cases, their proxy decision-makers) and, together, they identified a total of 253 informal caregivers to whom surveys were sent. Patients identified which individuals they considered caregivers. They also provided names and mailing addresses for those within the care network. Of the 253 pre-death surveys that were mailed out, 126 surveys were returned eliciting an initial response rate of 50%.

Table 3

Participation Rates

Group	Number of Participants
Patient Participation	
Patients Included:	<i>N</i> = 104
Pre-Death Surveys	
Caregivers identified/Surveys mailed out:	<i>N</i> = 253
Surveys returned:	<i>N</i> = 126 (50% response rate)
Surveys included in the final analysis:	<i>N</i> = 106
Number of Co-residing Caregivers:	<i>n</i> = 54
Number of Proximate Caregivers:	<i>n</i> = 27
Number of Long Distance Caregivers:	<i>n</i> = 25
Post-Death Surveys	
Num. of caregivers who qualified:	<i>N</i> = 66
Surveys returned:	<i>N</i> = 53 (80% response rate)
Surveys included in the final analysis:	<i>N</i> = 36
Number of Co-residing Caregivers:	<i>n</i> = 16
Number of Proximate Caregivers:	<i>n</i> = 12
Number of Long Distance Caregivers:	<i>n</i> = 8

Inclusion/Exclusion Criteria

Questionnaires were administered to the identified caregiver within one week of the patient's admission into hospice service and, again, three months after the death of the patient. The first two questions on the pre-death survey explore whether respondents meet the inclusion criteria for the study. Question #1 asks if the patient in question (i.e., the care recipient) has a cancer diagnosis. Question #2 asks if the person with cancer is currently under hospice care. A "no" response to either question #1 or question #2 indicates that the person filling out the questionnaire does not qualify for participation in the study. Based on answers to these two

questions, a total of nine (9) respondents did not meet inclusion criteria. Three (3) respondents indicated that the patient does not have cancer while six (6) reported that their loved one was not currently enrolled in hospice. Regarding these first two questions, the survey prompted respondents: “If ‘NO,’ you are finished with the survey. Please return it using the envelope provided. Thank you.”

Further examination of the nine surveys failing to meet the inclusion criteria revealed one anomalous case. In that situation, a person indicated that her/his loved-one did not have a diagnosis of cancer; however, this respondent ignored the prompt (i.e., to stop and return the survey) and, instead, answered the remaining questionnaire questions. In this particular case, data from the patient’s chart revealed that the patient did, indeed, have a primary diagnosis of cancer. Because a diagnosis of cancer was confirmed *and* the respondent elected to complete the entire questionnaire, data from this survey were included in the subsequent analyses. Thus, the total number of surveys which did not meet the inclusion criteria was revised to eight (8); and these were excluded from the final analysis.

In addition to the questionnaires that did not meet the inclusion criteria, eleven (11) other surveys were also eliminated from further examination. Four (4) of these questionnaires were returned entirely blank; and seven (7) were completed after the death of the patient. Additionally, one respondent did not answer either of the two questions regarding geographic proximity (i.e., miles away and travel time), which is the key independent variable in this study. Therefore, a total of 106 pre-death surveys were included in the main analysis.

Bereavement Surveys

Among the caregivers who responded to the initial pre-death survey, 66 caregivers qualified for, and were sent, the post-death survey. Participants qualified if their care recipient

died on, or before, November 19, 2007, precisely 3 months prior to the conclusion of data collection. Fifty-three (53) post-death surveys were returned for a response rate of 80%. This relatively high response rate was buffered by an overall attrition rate of 66% (see Chapter 4, page 93 for an in-depth analysis of attrition). To ensure that the person completing the post-death survey is the same person who filled out the pre-death survey, researchers matched survey codes along with the respondent's birth month and year. When these data were analyzed, in two cases the respondent's birth information reported on the pre-death survey did not correspond with the birth information reported on the post-death survey. These two post-death surveys were removed from the final analysis. In three cases, post-death surveys were returned, but left entirely blank. These were also eliminated from further analysis. All totaled, of the 53 post-death surveys that were returned, only 48 (91%) were included in the final data analyses (Note: because many of the analyses used in this study resolve missing data by using case-wise exclusion, this approach further diminished the number of useable bereavement surveys, and, hence, the actual number varied depending on which tests were used and which variables were being analyzed).

Caregiver Characteristics

As in many studies on caregivers, a large majority of respondents in this sample were female ($n = 69, 68\%$) and approximately a third ($n = 33, 32\%$) were male. Regarding geographic proximity to the patient, 50.9% ($n = 54$) of respondents co-resided with the care recipient, while 25.5% ($n = 27$) of respondents qualified as proximate caregivers, and 23.6% ($n = 25$) meet the operational definition of long distance caregiver – living an hour or more away. The majority of respondents ($n = 88, 87\%$) had a high school education or better. A third of respondents, 33% ($n = 32$), were providing care to a parent, while 31% ($n = 30$) were caring for a partner or spouse, 14% ($n = 14$) were caring for a sibling. Eighty percent ($n = 82, 80\%$) of respondents were Euro-

American/White, 10% ($n = 10$) were African-American/Black, 6% ($n = 6$) identified themselves as Native-American/Alaskan Native, 2% ($n = 2$) indicated they were Bi-racial/Multi-racial, and 2% ($n = 2$) responded “other.” Interestingly, 11% of respondents did not identify themselves as caregivers, even though they were all identified as such by the patient, or patient’s proxy.

Table 4

Demographic Characteristics of Sample - Caregiver Respondents (N = 106)

Variable	Category	<i>n</i>	%	<i>M</i>	<i>SD</i>
<u>Caregiver Data</u>					
Age (years)				56.9	13.9
Gender	Female	69	32.4		
	Male	33	67.6		
Race/Ethnicity	African American	10	9.8		
	Latino/Hispanic	0	0		
	Asian/Pacific-Islander	0	0		
	Native-American	6	5.9		
	Caucasian	82	76.6		
	Bi-racial/Multi-racial	2	2		
	Other	2	2		
Relationship to Patient <i>The patient is my...</i>	Spouse/Partner	30	29.4		
	Child	6	5.9		
	Parent	32	31.4		
	Sibling	14	13.7		
	Other Relative	10	9.8		
	Friend	2	2		
	Other	8	7.8		
Caregiver Proximity	Co-residing	54	50.9		
	Proximate	27	25.5		
	Long Distance	25	23.6		

Patient Demographics

One hundred and four recently admitted hospice patients agreed to participate in the study. On average patients were 76 year old ($SD = 14.3$) and a slight majority (53%) were male versus female (47%). At the time of admission, the vast majority of patients were being cared for at home ($n = 96, 92%$) compared to those in a nursing facility or other inpatient care environment ($n = 8, 8%$). The most prevalent diagnosis was Lung Cancer ($n = 15, 14%$) followed by Prostate Cancer ($n = 7, 7%$). Upon admission into hospice service, patients are asked to report their pain level using a 0 - 10 continuum, zero indicating “no pain” and ten indicating “the worst pain imaginable.” Patients in this sample reported an average pain level of 2 ($SD = 2.6$). Similarly, during admission patients are evaluated by a nurse using the Palliative Performance Score (PPSv2), a measure of functionality. Ratings from the PPSv2 are percentage-based, with 100% indicating completely healthy and 0% indicating death. For patients in this sample, the average PPSv2 score was 43.5% ($SD = 11.4%$). On average, patients identified between 2 and 3 informal caregivers ($M = 2.4, SD = 1.3$) participating in their care-network.

Referrals by Hospice Branch Office

Ten of the 13 Covenant Hospice branch offices referred patients/families to the study. The majority of referrals came from the Milton office (21%, $n = 22$), followed by the Panama City office (19%, $n = 20$), and Niceville (15%, $n = 15$). No study participants were referred by Tallahassee, Pensacola, or Daphne. Interestingly, the Pensacola office provides care to a large number of patients. The average daily census for the Pensacola office in 2007 was 184 patients, the second largest branch office. This may be evidence of “gate-keeping” (Ross & Cornbleet, 2003) and an additional source of sample bias.

Table 5

Demographic Characteristics of Sample - Hospice Patients (N = 104)

Variable	Category	<i>n</i>	%	<i>M</i>	<i>SD</i>
Patient Data					
Age (years)*				76	14.3
Gender	Female	49	47		
	Male	55	53		
Cancer Diagnosis**	Lung	15	14		
	Prostate	7	7		
	Breast	4	4		
	Colon	4	4		
	Liver	4	4		
	Pancreas	3	3		
	Ovarian	3	3		
	Melanoma	3	3		
	Myeloma	3	3		
	Other	59	56		
Location at Admission	Home	96	92		
	Nursing Facility	4	4		
	Palliative Care Unit	4	4		
Pain Level (0 - 10)				2	2.6
Palliative Performance Score				43	11.3
Length of Stay (days)***				55.5	46.9

*Data for age was not available for case-wise analysis

** Percentages do not equal 100% due to rounding

*** Length of Stay is measured from the date of admission until the date on which the patient was discharged from hospice (usually due to death or revocation). These statistics do not include patients still under hospice at the time of data collection

Non-Response Error

In this study, the response rates were 50% for the caregiver (pre-death) survey, and 80% for the bereavement (post-death) survey. According to Rubin and Babbie (2005) a response rate of 50% is generally considered “adequate for analysis and reporting” (p. 289). For samples involving informal caregivers of hospice patients, response rates are notoriously low, both before the patient’s death and after (Fowler, Coppola & Teno, 1999; McLaughlin, Sullivan & Hasson, 2007). Similarly designed studies of hospice caregivers that used mailed, self-report surveys have also reported relatively poor rates of return, ranging between 28% - 54% (Casarett, Crowley & Hirshman, 2003; McLaughlin, Sullivan & Hasson, 2007; Salmon et al., 2005). To investigate the presence of response bias in this sample, differences between respondents and non-respondents were explored. Caregiving networks in which at least one caregiver returned the survey were compared to those networks in which no one responded. No statistically significant group differences were identified on any of the patient characteristics, including gender, length of stay, admission location, pain level, and Palliative Performance Score (PPSv2).

Sample Size

Based on a preliminary power analysis, the author sought an initial sample size of more than 300 participants. However, the participating agency, Covenant Hospice, Inc. recommended an overall *N* of 300 or less to minimize staff burden (Chuck Lee, personal communication April 25, 2006). Recruitment rates declined over time, despite sustained efforts to generate awareness of, and interest in, the study. It was determined that a recruitment period of one year was sufficient for the purposes of this dissertation. The resulting sample included 106 caregiver participants, far less than initially proposed. At the 95% confidence level, a power analysis of a sample size of 106 participants produced a confidence interval of +/-9.52 (Creative Research

Systems, 2006). Additionally, the relatively high attrition rate (66%) may adversely impact the study's overall validity (Rubin & Babbie, 2005).

Human Subjects Protection

This research was approved by the Institutional Review Boards at Virginia Commonwealth University (VCU) and Florida State University (FSU). (Dual approval was required because the author is a doctoral student at VCU and a faculty member at FSU). A panel of research experts and executive staff from Covenant Hospice, Inc. provided additional guidance and oversight. All patient medical information was handled in accordance with the Health Insurance Portability and Accountability Act (HIPAA) requirements; and efforts were made to ensure that all survey data remained confidential (see consent forms in Appendices I, J, and K).

Any summative data that were collected during this study may be used for purposes of academic publication and presentation, political advocacy, caregiver service development, or for further study. To preserve respondent confidentiality, data are reported in a group format with identifying information omitted. Furthermore, at no point will these data be used for marketing purposes. All information gained from survey responses will remain confidential and specific question responses will remain anonymous.

Consent Issues

“As a researcher, one is potentially an intruder into the world of the bereaved, and one must, for example, fully respect the decision of a bereaved person not to participate in a research project” (Stroebe, Stroebe & Schut, 2003, p. 239). All potential participants (whether involved in the pilot study or main study) were given either a written consent form or cover letter informing them about the nature of the study, their responsibilities as participants, as well as the potential

risks and benefits. Additionally, hospice patients were asked for their consent to release information in their hospice medical chart. The consent forms and cover letters were worded at 10th grade reading level. The author's name and contact information were printed on the consent form and cover letter. Questions about the consent process, focus group content and the overall research goal were encouraged.

Potential Risk to Human Subjects

“How – and how soon – can we approach bereaved people to participate in research?” (Stroebe, Stroebe & Schut, 2003). This study met the Federal standards of “minimal risks” to study participants. However, it was conceivable that some respondents could suffer psychological anxiety, depression, or distress while answering questions related to a terminally ill or deceased loved one (Balk, 1995; Bonanno & Kaltman, 1999). It is unlikely that participation in this study placed any subjects in harms way, beyond what they might encounter in day-to-day interactions or during a routine psychological exam. However, to address any possible hazards to those who agreed to participate, the study protocol included several precautions designed to minimize potential harm.

It is believed that the inclusion of a web-based survey option does not expose participants to any greater risks relative to the administration of the hard-copy surveys. The content of the internet survey mirrored the content of the hard-copy survey. Thus, the internet survey did not include any identifying, or especially sensitive, information. Furthermore, this research does *not* involve data that might place subjects at risk of criminal or civil liability. Additionally, the likelihood of a security breach was (and is) low. However, if security of the web-based survey data were compromised, the impact would be comparable to potential compromises in postal delivery (e.g., mail-tampering or misdelivery). Since the surveys did *not* ask for any personally

identifying information it would be highly unlikely that anyone would be able to identify the name or location of a respondent using survey data alone.

Risk Reduction

In studies with bereaved participants, it has been recommended that professional help should be made available in the event an individual becomes distressed as a result of study involvement (Balk, 1995; Stroebe, Stroebe & Schut, 2003). Covenant Hospice, Inc. provided bereavement follow up from licensed bereavement counselors for study participants who felt they needed to talk to a professional. Bereavement counselors provide a number of support services including, support groups, one-on-one counseling, over-the-phone consultation, and/or working to connect individuals with the desired supportive resources in her/his locale. The informed consent letters included the contact information of the principal investigator, the VCU School of Social Work, and Covenant Hospice's toll free on-call support service. These contact sources were made available to assist anyone with questions about the study or who experienced emotional or psychological distress due to participation in the research.

All identifying information provided by study participants was confidentially protected and coded according to de-identification procedures outlined in Health Insurance Portability and Accountability Act (HIPAA) regulations governing clinical research in medical settings (refer to the National Institutes of Health's guide at http://privacyruleandresearch.nih.gov/clin_research.asp). At no point were the names and addresses of respondents connected to the data from questionnaires. The participants' contact information and questionnaire codes were kept secure in a key-locked filing cabinet in the project director's office at FSU. Completed questionnaires were collected by a hired graduate research assistant at VCU. The research assistant was a Master-level social work student who

had successfully completed VCU's Human Subjects Research Ethics training. At no point was the research assistant privy to any information which could identify respondents. Questionnaire codes allowed the author and the research assistant the ability to communicate regarding which surveys have been collected and which respondents qualified for a post-death questionnaire. The names of the patients and/or respondents were not used during these discussions.

To clarify further, the pre- and post-death questionnaires were linked using a coding process. The codes appeared on the lower, left-hand corner of each questionnaire. This author maintained the master list, linking questionnaire codes with the name and address of all potential participants. As completed pre-death questionnaires were returned by mail to the research assistant (at VCU), the research assistant then communicated their receipt to this author (Mr. Cagle/at FSU) by identifying which questionnaires had been returned using the code. Returned pre-death and post-death questionnaires with the same code were linked together during data entry. All data collection forms will be mechanically shredded after the conclusion of the study (estimated date of destruction 9/1/2008). Additionally, six months after the conclusion of the study, all web-based electronic survey data will be deleted and overwritten.

Web-based Survey Option

According to Inquisite, Inc. their data protection measures are considered guarded, proprietary information. Thus, information on specific security protocols is not available to the public. However, company representatives have assured that: (1) to date, Inquisite has not experienced a breach of its security; (2) Inquisite continues to provide the highest possible level of security; (3) all survey data are firewall protected; (4) Inquisite ensures data integrity by using "advanced security and scalability features;" and, (5) access to survey data is restricted to administrators by user ID and password security (Inquisite, 2007, p. 1).

Also noteworthy, according to Dr. Ann Nichols-Casebolt (Chair of the VCU's Committee on the Conduct of Human Research – Panel B), VCU researchers have used Inquisite, Inc. services in the past without incident. Participants were consented in the same manner, regardless of whether they chose to complete the paper and pencil or internet version of the survey. However, those who elected to complete the survey online encountered the consent letter on two occasions, once in the mailed-out survey packet, and again when they logged-on to the survey website. The internet consent document mirrored, verbatim (Note: In the online consent document the phrase “...complete the attached questionnaire and return it by using the enclosed, stamped envelope” was replaced with “...complete and submit the following survey.”) the hardcopy version of the consent cover letter (see Appendix K). The final consent line stated, “By completing the survey, you are agreeing to participate in the research.” Respondents were prompted to select one of two click buttons, either to agree or not agree. If a subject selected “agree,” the survey began. The web-based survey was designed to allow participants to skip questions they do not wish to answer. And, at the conclusion of the online survey, respondents were presented with two options, a button to submit the data and another button to discard the data.

Compensation

Study participants were given a small token gift to encourage participation. Each potential survey participant received a custom designed refrigerator magnet valued at \$1, which was mailed along with the initial questionnaire packet. The theme of the magnet is “Honoring the Efforts of Caregivers” (see Figure 2). For the bereavement survey, respondents were given an ink pen (a Pilot G-2 .07), valued at \$1, as a token gift.

Figure 2

Respondent Incentive – Refrigerator Magnet*Risk/Benefit*

It is likely that the majority of respondents enjoyed completing the survey as it may give voice to their caregiving experience and highlight unidentified service needs. It may have also provided some therapeutic benefit by giving participants a private forum to share information about their experiences. Other potential benefits of this research include the identification of previously unmet needs which may, in turn, influence political advocacy, practice interventions, service delivery, and resource allocation.

Instrumentation

A variety of validated measures were used to operationalize and evaluate key variables within the study. The majority of the instruments were selected to assess changes in a respondent's psychological adjustment or social support over time. Others were used to examine,

and control for, potentially confounding variables. The following section includes detailed descriptions of the scale variables involved in the study:

The Depression Anxiety Stress Scale-21

The short form of the Depression Anxiety Stress Scale (DASS-21) is a 21 item multidimensional questionnaire designed to assess negative emotional states (Lovibond & Lovibond, 1995). The questionnaire consists of three, seven-item subscales which measure depression, anxiety, and stress. The instrument uses a 4-point, Likert-style response set to investigate a respondent's affect over the previous week. Response options range from zero - "does not apply to me at all" to 3 - "applied to me very much, or most of the time." Previous psychometric evaluations of the DASS-21 suggest that each of the three subscales maintain good reliability and validity (Henry & Crawford, 2005). One such study calculated the internal reliability coefficient for each sub-dimension using Cronbach's alpha, resulting in a 0.94 for depression, 0.87 for anxiety, and 0.91 for stress (Antony, Bieling, Cox, Enns & Swinson, 1998). A more recent study using a large sample of non-clinical respondents produced reliability estimates of 0.88 for depression, 0.82 for anxiety, 0.90 for stress, and 0.93 for the entire DASS-21 (Henry & Crawford). Additionally, the available evidence supports both the convergent and discriminate validity of the DASS-21. When compared to other independent measures of emotional status (i.e., the Hospital Anxiety and Depression Scale, the Personal Disturbance Scale) the DASS-21 was also determined to have good overall construct validity. However, Henry and Crawford conducted a confirmatory factor analysis on the instrument and found the stress sub-scale may also measure an additional construct - general negative affectivity. Sample questions for the DASS-21 include:

"I felt that life was meaningless" (Depression)

“I felt I was close to panic” (Anxiety)

“I tended to over-react to situations” (Stress)

The Texas Revised Inventory of Grief – Part 2

The Texas Revised Inventory of Grief (TRIG) is a two part, 21-item scale, which measures behavioral and emotional responses to loved one’s death (Faschingbauer, Zisook & DeVaul, 1987). The instrument employs a 5-point response scale ranging from “completely true” to “completely false.” The first section of the TRIG (the TRIG1) is eight items in length and evaluates how the death has disrupted the respondent’s life. The second portion of the scale (the TRIG2) uses 13 items to assess a bereaved individual’s present state of emotion. As a number of recent bereavement studies have done, the present study does *not* use the former portion of the TRIG (the TRIG1), given its limited sensitivity (Stroebe, Hansson, Stroebe & Schut, 2001). Instead, it incorporates only the use of the TRIG2. Prior research suggests that the latter half of the TRIG is an internally consistent instrument, with which to measure bereavement outcomes. In a study exploring the bereavement experience of spouse caregivers of cancer patients, Gilbar and Hasida (2002) reported the TRIG2’s reliability coefficient (Cronbach’s alpha) of 0.95. During the original development of the instrument, Faschingbauer et al. (1987) reported a lower alpha of 0.86 and an acceptable split-half reliability of 0.88.

The TRIG2 is also known to have adequate predictive, divergent, and construct validity (Faschingbauer et al., 1987). Sample statements from the TRIG2 include:

“I still get upset when I think about the person who died.”

“I cannot accept this person's death.”

The Herth Hope Index

The Herth Hope Index (HHI) is a modified 12-item version of the Herth Hope Scale used to evaluate levels of hope and psychosocial-spiritual optimism (Herth, 1992). The HHI includes a 4-point Likert-type response set ranging from 1 - “Strongly Disagree” to 4 – “Strongly Agree.” Higher scores indicate greater levels of hope. The Brown University *Toolkit of Instruments to Measure End-of-Life Care* ([TIME]Roach, 2000) tested the psychometric properties of the HHI using a sample of family caregivers of terminally ill persons and reported a Cronbach’s alpha of 0.88. Herth’s (1992) initial study yielded a much higher alpha coefficient of 0.97, in addition to a test-retest reliability of 0.91. Both Herth and TIME (Roach) assert that the HHI has adequate construct, criterion, convergent, and discriminatory validity. The following are selected statements from the HHI:

“I have a positive out look toward life.”

“I believe that each day has potential.”

The WHO-5 Well-Being Scale

The World Health Organization’s five-item Well-Being Scale (WHO-5) was developed from an original 10-item scale (Bech, 2004). The WHO-5 is used to measure positive levels of a respondent’s psychological well-being. The scale consists of five statements about general well-being and 6 point response continuum, spanning from 0 - “At no time” to 5 - “All of the time.” Bech evaluated the psychometric properties of the WHO-5. Using a nonparametric Mokken analysis, Loevinger coefficients of 0.50 or higher were produced, suggesting sufficient internal homogeneity and scalability (Bech). In further support of the WHO-5’s internal validity, Gröpel (2001) calculated its reliability coefficient, reporting an acceptable Cronbach’s alpha of 0.85. Furthermore, the instrument maintains adequate sensitivity and unidimensionality (Bech)

The WHO-5's divergent validity was supported in studies comparing the measure with other conventional instruments for evaluating depressive symptoms (Henkel et al., 2003). Surprisingly, in these studies, the WHO-5 performed better at discriminating clinically depressed individuals from non-depressed persons (Henkel et al.) than the other validated assessment tools. Bech (2004) reported that a raw score of 13 overall, or a one on any of the five items, may indicate a clinically depressed state.

The Lubben Social Network Scale - 6

The Lubben Social Network Scale - 6 (LSNS-6) is a six item instrument designed to measure perceived social support from friends and relatives (Lubben & Girona, 2003). The LSNS-6 is an abbreviated version of an original 10 item scale. This shorter version of the scale was created for use in clinical settings, which often require use of brief assessment instruments. The LSNS-6 contains two subscales, each consisting of three items. Subscales are titled "Family" and "Friendships" to distinguish social support received from kin and non-kin. Lubben and his colleagues (2006) evaluated the validity and reliability of the LSNS-6 on a population of European older adults from England, Germany, and Switzerland. They consistently found acceptable reliability coefficients ($\alpha = 0.83$) for the entire scale and both subscales. For the Family subscale Cronbach's alpha ranged from 0.84 to 0.89 and the non-kin subscale ranged from 0.80 to 0.82. The study also provided evidence supporting the scale's discriminant validity.

The Victoria Hospice Palliative Performance Scale - Version 2

The Victoria Hospice Palliative Performance Scale version 2 (PPSv2) is a clinical measure used to assess a patient's functional status (Anderson et al., 1996). The tool evaluates a patient's performance based on five observed domains: ambulation, ability to do activities, self-care, food/fluid intake, and consciousness level. These domains are rated using deciles

(percentage increments of 10%), with 100% indicating healthy and 0% indicating death. When patients are admitted into the care of Covenant Hospice the admitting nurse evaluates the patient using the PPSv2. As a result, data from this scale were collected from the patient's medical chart.

The Palliative Performance Scale was originally adapted from the Karnofsky Performance Scale (Anderson et al., 1996). Previous studies have found that the PPSv2 has good inter-rater reliability and construct validity (Morita, Tsunoda, Inoue & Chihara, 1999; Virik & Glare, 2002). It correlates well with other indicators of functionality such as the original Karnofsky scale (Anderson et al., 1996). Additionally, the PPSv2 has been found to have good prognostic ability (Head, Ritchie & Smoot, 2005; Morita, Tsunoda, Inoue & Chihara, 1999; Virik & Glare, 2002), particularly with cancer patients (Harrold et al., 2005).

The Quality of Dying - Hospice

The Quality of Dying - Hospice (QOD-Hospice) is a 21-item instrument used to measure perceived quality of dying. It is designed for bereaved individuals whose deceased loved one was under hospice care prior to the death. It was constructed to be used as a retrospective proxy-report instrument, asking respondents to reflect on their loved one's final days. The QOD-Hospice was developed specifically for the purposes of this study, and thus requires further psychometric evaluation. Some face validity and content validity are assumed because the instrument and its questions were adapted from the Quality of Dying - Long Term Care ([QOD-LTC]; Munn et al., 2007) and, by extension, the QUAL-E (see Steinhauser et al., 2002 and Steinhauser et al., 2000). The final 23-item version of the QOD-LTC (available at www.eol.unc.edu) resulted in a reliability coefficient of $\alpha = .85$. In this study, the QOD-Hospice elicited the same internal reliability statistic (Cronbach's $\alpha = .85$; see chapter 4 for additional descriptive statistics), suggesting very good consistency between items. The QOD-Hospice

presents subjects with a series of statements regarding various aspects of the deceased's quality of dying, accompanied by a 5-point Likert-style response set, ranging from 1 (Not at all) to 5 (Completely). A "don't know" response option is also provided since respondents are asked to rate specific statements regarding the quality of dying of their loved one, information which they may not know, or be able to recall. Examples of statements from the QOD-Hospice include:

"My loved one was free from pain."

"His/her dignity was maintained."

"There was someone from hospice whom he/she trusted."

Items are calculated to produce scores that range from 0 - 100, with higher scores indicating a better quality of dying.

Ordinal-Level Measures

A number of variables were operationalized using ordinal-level measures. Repeated measures assessments of a respondent's guilt, anger, self-care, health status, and satisfaction with the care, information, and availability of hospice were evaluated using rank-level data. For the variables health status and self-care, respondents rated themselves using a zero to ten continuum, zero indicating "extremely poor" and ten indicating "Excellent." The remaining variables of guilt, anger, and satisfaction with hospice care used a Likert-type response set.

Table 6

Description of Study Measures

Instrument	Description	N of Items	Data Source
DASS-21 ¹	General psychological distress using subscales for depression, anxiety, and stress	12	Pre-Death & Post-Death
WHO-5 ²	Global well-being	5	Pre-Death & Post-Death
HHI ³	Self-assessed optimism and hopefulness	12	Pre-Death & Post-Death
LSNS-6 ⁴	Perceived social support from family and friends	6	Pre-Death & Post-Death
TRIG2 ⁵	Current state of grief-related emotion	13	Post-Death
QOD-Hospice ⁶	Retrospective proxy assessment of a decedent's quality of dying	21	Post-Death
PPSV2 ⁷	Patient functionality using assessments ambulation, ability to do activities, self-care, food/fluid intake, and consciousness level	5	Medical Chart

¹Depression Anxiety Stress Scale - 21 (Lovibond & Lovibond, 1995)²World Health Organization's Well-Being Scale (Bech, 2004)³Herth Hope Index (Herth, 1992)⁴Lubben Social Network Scale - 6 (Lubben & Gironde, 2003)⁵Texas Revised Inventory of Grief - Part 2 (Faschingbauer, Zisook & DeVaul, 1987)⁶Quality of Dying - Hospice (developed for this study)⁷Victoria Hospice Palliative Performance Scale version 2 (Anderson et al., 1996)

Data Analysis

Quantitative Data

This study employed a variety of univariate, bivariate, and multivariate analyses. Prior to analyses, quantitative data were pre-screened to resolve missing data and outliers. To determine

whether study measures met the requisite assumptions for multivariate analysis, the principal study variables (DASS-21, LSNS-6 and QOD-Hospice) were evaluated for normality, linearity, homoscedasticity, and multicollinearity. Similarly, the properties of all scaled instruments were explored, including assessments of central tendency (mean, median, and mode), dispersion (standard deviation and range), and internal reliability (Cronbach's α). Based on these evaluations, data transformations were made accordingly. For example, a finding of non-normality on two of the DASS subscales resulted in a simple square-root transformation for the depression subscale and the elimination of the anxiety subscale from any analysis apart from its parent scale, the DASS-21.

Tests exploring group differences (e.g., *t*-tests, ANOVAs and MANOVAs) rely on an assumption of group equivalency. Thus, the similarities and differences between co-residing caregivers, proximate caregivers, and long distance caregivers were explored (Healey, 2002). Notable differences in group size were observed. There were nearly twice as many participants in the co-residing group than in either the proximate or long distance group. (In response to this, the sum-of-squares model utilized during the main multivariate analysis was adjusted to accommodate for the imbalance in group size.) Comparability among groups was also examined using simple cross-tab analyses of the three caregiver groups. For dependent variables measured at the interval/ratio level, this involved a one-way analysis of variance (ANOVA) with a subsequent post hoc analysis (Bonferroni's correction) used to locate statistically significant differences. Group differences on rank-ordered variables were evaluated using the non-parametric equivalent, a Kruskal-Wallis test. And, a simple chi-squared analysis was employed to explore differences among nominal variables. For all tests, a critical *p*-value (alpha) was set at 0.05.

The demographic variable, *relationship-status*, was identified as a potentially confounding factor between groups; thus, an in-depth assessment of *relationship-status* was performed. To accomplish this, the variable was transformed into a dichotomous variable, with one category indicating (1) the patient was the respondent's spouse/partner. The remaining category signified that (2) the patient was *not* the respondent's spouse/partner. Independent samples *t*-tests were used to explore mean differences between these two groups on variables of social support and adjustment. The variable *gender* was also identified as an important control variable and a similar series of independent samples *t*-tests were used to investigate the impact of *gender* on outcome variables. Another important control variable, *quality-of-dying* as measured by the QOD-Hospice, was also examined using bivariate correlations (Pearson's *r*) with each of the dependent variables.

An additional series of bivariate analyses were conducted to examine associations between patient characteristics and caregiver outcomes. Correlations among *pain-level* and *length-of-stay* and measures of psychological adjustment and social support were performed using Pearson's correlation coefficient. Additionally, two simple linear correlations were computed between (1) distance and bereavement adjustment, and (2) distance and social support. Non-parametric tests were also used to explore differences between caregiver groups (co-residing, proximate, and long-distance) on rank-ordered data. A Kruskal-Wallis test was used to identify group differences on measures of self-rated health, self-care, guilt, anger, and satisfaction with hospice. Paired samples *t*-tests (with unadjusted means) were employed to analyze changes in repeated measures across combined caregiver groups. This explored general differences over time on combined groups (involving the entire sample).

The central analysis of this study involved a doubly repeated measures multiple analysis of covariance (MANCOVA) to examine differences over time (within groups) and between groups of co-residing, proximate, and long distance caregivers (McNeil, Newman & Kelly, 1996; Mertler & Vannatta, 2005). The MANCOVA procedure allows for a comparison of adjustment and social support scores between the three caregiver groups, while controlling for variables known to influence bereavement (e.g., gender and quality of patient death) (Center for the Advancement of Health, 2003). Caregiver proximity was used to evaluate differences on the dependent variables of perceived social support and bereavement adjustment). Since the study seeks to explore group differences based on one independent variable and multiple dependent variables, while controlling for potential mediating variables (*gender* and perceived *quality-of-dying*), the multivariate design can be characterized as a multiple criterion, multiple predictor design with adjustments for covariance. And, thus, the repeated measures MANCOVA is an appropriate analytic model (McNeil, Newman & Kelly; Mertler & Vannatta). In order to account for the impact of *relationship-status* in the multivariate model, the MANCOVA was repeated a second time, with the second iteration including *relationship-status* as a covariate.

Before conducting any statistical procedures, null-hypotheses were established indicating, that among the predictor variables, there will be no differences in the scores of the criterion variables. Alternatively, the author explored the previously stated research hypotheses about expected differences between the various test variables.

Follow-up Analysis

Once the MANCOVA was computed, a follow-up ANOVA was used to locate statistically significant differences (Healey, 2003; Mertler & Vannatta, 2005). Based on these findings any appropriate null hypotheses were subsequently rejected (or not). Also, a thorough

discussion, couched in the context of related research and relevant theory, follows the statistical results. This includes measured statements of whether the results seem to confirm, refine or altogether contradict the current literature on caregiver support, bereavement or proximity.

Qualitative Analysis

The pre-death and post-death questionnaires gave respondents an opportunity to provide a brief (1 to 1½ page) narrative response. On both questionnaires, participants were prompted by the following statement: “Please use the space below to make any additional comments about how you could have been better prepared/supported during the care of your loved one.” The data gleaned from these prompts were analyzed for their qualitative content. An inductive and systematic process was used to identify recurrent and emergent themes within these written data. Responses to the two open-ended questions were analyzed for thematic content using the general tenets of the constant-comparison method developed by Glaser and Strauss (1967) and Strauss and Corbin (1998). Raw data was unitized using open (or axial) coding. Coded excerpts with similar themes were grouped together. Themes from pre-death responses were separated from post-death responses and tagged for further comparison. Additionally, since long distance caregivers have been a particular focus for this research, the comments provided by out-of-town caregivers were also tagged to explore, in-depth, the similarities and differences of their content. After the initial round of coding, clustering, and categorization, these findings were peer-reviewed by an expert in qualitative methodology and analysis, Dr. Kovacs. Many of the preliminary themes were corroborated by the reviewer; however, a number of new themes emerged during the process of peer oversight. These new themes were, again, compared and contrasted with the raw data to identify any contrary or conflicting evidence within the responses.

The purpose of this approach was to provide readers with additional depth, perspective, and context about the caregivers' lived experiences; and to complement the quantitative findings. This use of mixed methodology allows for a "triangulation-by-method strategy," which can help corroborate results and enhance qualitative rigor (Padgett, 1998, p. 97). Additionally, the open-ended nature allowed respondents to identify salient factors that the quantitative measures may have failed to capture. Direct quotes that encapsulated the identified themes were selected and reported as exemplars in the analysis; of course, any identifying content was removed to preserve respondent anonymity.

CHAPTER FOUR

Results

In this chapter the study's quantitative and qualitative findings are discussed. The first section describes data prescreening, including the management and resolution of missing data and outliers. The subsequent section presents the assumptions involved in conducting an inferential analysis; and is followed by an assessment of the variable prerequisites regarding normality, linearity, homoscedasticity, and multi-collinearity. The third section presents the results from an analysis of study instruments, including measures of central tendency, variability, and internal reliability for all scale measures. The fourth section is a univariate analysis of the three caregiver groups of interest: co-residing, proximate, and long distance. This is followed by an assessment of group equivalency. The fifth segment presents bivariate analyses and an evaluation of the control variables. Findings from the main multivariate analysis, a MANCOVA procedure, are then described in the sixth section. The seventh and final section summarizes results of the qualitative analysis.

Data Prescreening

Missing Data

Missing data were analyzed to identify patterns of non-response. The majority of missing responses were found on question #71 of the pre-death survey, which inquired about the respondent's income level. Eleven percent ($n = 12, 11\%$) of respondents did not answer this question. Individuals who did not reply to the question of income were, on average, older (62 years old compared to 56 years old; a simple t -test of mean differences revealed a test statistic of $t = -1.119, df = 8.278 (p > .05)$ and the majority (75%) were retired. This may indicate that on the variable *Income*, values are not missing at random and, thus, replacing these missing values by

list-wise substitutions would be ill-advised. Six percent ($n = 6$, 6%) of the responses to the questions regarding *Age* and *Frequency of Visits* were missing. However, for these two variables, no identifiable patterns of non-response were discovered. For all demographic variables, missing values were not replaced.

Six respondents did not complete any of the demographic questions (questions #65-#73 on the pre-death survey). Three respondents did not complete the DASS-21 and one person did not fill out any questions on the Herth Hope Index. These cases were excluded from analyses involving these variables.

Cases in which three or more questions were left blank on a given measure were withheld from analyses involving the respective variable. However, when one or two questions on a validated instrument (i.e., the WHO-5, DASS-21, Herth Hope Index, LSNS-6, or TRIG2) were left blank, mean values were calculated case-wise and inserted to replace the missing values. This is a conservative approach, since the overall mean values of a variable remains the same (Mertler & Vannatta, 2005); however, a variable's variance will be somewhat reduced by this process. According to Mertler and Vannatta, "this is usually not a serious problem unless there are numerous missing values" (pp. 26-27). In these data, the number of missing values found on validated measures was relatively small. The instrument with the most missing values was the pre-death version of the DASS-21, in which a total of twelve questions were left blank, only 0.5% of the total number of DASS-21 questions posed to respondents. Furthermore, this approach (mean substitution by case) is justified given the relatively high levels of internal reliability found for each instrument and related subscales (see Tables 8 and 9).

Outliers

Data were also prescreened to identify any outliers. Outliers are extreme values which can skew the distribution of scores on a given variable, and in turn, distort the mean (Mertler & Vannatta, 2005). Outliers are often the result of errors, which, if identified can be easily resolved. In these data, several extreme or anomalous values were identified. In a number of instances the unusual values were determined to be errors occurring during data entry. For example, a value of “8” was identified as a response to one question on the LSNS, which is beyond the range of the response options provided (0-5). This was identified as a data entry error and corrected. Similar occurrences were discovered on the variables *jobstatus* and *medications*, and these were also resolved. In each circumstance, values were either corrected, or left blank if the correct value could not be determined. In addition to these identified errors, a number of statistical outliers (i.e., values beyond 3 standard deviations from the mean) were identified. These values were vetted to ensure that they were not the result of error. For example, one long distance caregiver responded that she/he lived 48 hours away from the care recipient, which is more than 3 *SDs* from the mean travel time of 6.3 hours. However, it was determined that this was an appropriate response given that the same respondent reported living 2000 miles from the patient. In only one case was a statistical outlier removed from the dataset. On the variable *hoursofcare*, which measures the number of hours of care provided during the previous week, a value of “999” was eliminated and treated as missing.

Inferential Limitations

When using inferential analyses, generalizations and inferences are only relevant to the extent to which a sample is similar to its parent population. An important assumption of inferential statistics is the use of random sampling (or random assignment) to ensure

representativeness by minimizing sampling bias (Healey, 2002; Rubin & Babbie, 2005). Due to the numerous logistical barriers (e.g., garnering the approval of a large number of health care organizations to conduct the research), limited scope, and finite funds, a random sample of informal caregivers of advanced cancer patients across the country was not feasible for this research. Alternatively, this study employed a non-random sampling approach. Because of the inclusion of non-probability sampling techniques, the representativeness of the sample is suspect. Systematic biases in the way in which potential study participants were identified and recruited may have distorted key characteristics of the sample (Healey; Rubin & Babbie). In this case, the sample's representativeness cannot be guaranteed. Therefore, the findings of this study, including reported *p*-values and statistical significance, should be read and interpreted with respect to these methodological limitations.

Attrition/Mortality

One of the challenges of conducting longitudinal and repeated measures research is that participation rates tend to decrease over time (Rubin & Babbie, 2005). In this study, the attrition/mortality rate was relatively high, with an overall rate of 66%. Thus, two-thirds of those who participated in the initial administration of the pre-death survey were not included in the analysis of post-death surveys. Further exploration of participant attrition revealed that more than half of the attrition rate was due to the fact that participants did not qualify for the second round of data collection. Qualifying for the post-death survey was contingent upon the expected death of the individual receiving hospice care, and a substantial number of patients were still alive at the conclusion of this study. As result, 38% of participants in the initial pre-death survey did not qualify for, and were never administered, the post-death survey. Non-response to the bereavement questionnaire accounted for 12% of the attrition rate. The remaining contribution to

the attrition rate (16%) was the result of individuals who responded, but their surveys could not be included in the analysis (e.g., if the post-death survey was returned blank).

Multivariate Assumptions

Multivariate analyses are predicated on a number of important assumptions, in addition to the previously discussed assumptions required for inferential statistics (see page 92). In studies using continuous measures (which, in this study, are the dependent variable and control variables) the frequency of scores should maintain univariate normality, linearity, homoscedasticity, while avoiding multi-collinearity (Mertler & Vannatta, 2005). All of the key continuous dependent variables and covariates involved in this study were evaluated for these qualities.

Normality

Normality is present when scores from a measure are symmetrically distributed and resemble a normal curve (also referred to as a “bell curve” or “Gaussian distribution”) and the mean and median and mode should be equivalent (Healey, 2002). Additionally, the distribution should be free from extreme skewness (i.e., extreme lop-sidedness) or kurtosis (i.e., being too spiked or too flat). The normality of a distribution can be evaluated in a number of ways. A normal probability plot, also called a normal Q-Q plot, is one way to determine whether a variable distribution is acceptably normal (Mertler & Vannatta, 2005). The normal Q-Q plot provides a visual assessment of the distribution of scores on a given variable by comparing expected values with observed values. Expected values are plotted along x-axis and observed values are plotted on the y-axis. If scores are normally distributed, the plot will resemble a straight line (Mertler & Vannatta). Evaluations of Q-Q plots suggested that the majority of

variables were normally distributed; however, two of the DASS subscales, anxiety and depression, produced unusual (non-straight line) Q-Q plots, requiring additional exploration.

The Kolmogorov-Smirnov statistic also helps to evaluate the assumption of univariate normality by comparing the distribution of sample scores against a (theoretical or ideal) normal distribution (Mertler & Vannatta, 2005). This goodness-of-fit test uses Z-scores (Kolmogorov-Smirnov's z [KSz]), to test the null hypothesis that a variable's scores produce a Gaussian distribution. In this case, statistical significance (i.e., when probability values fall below an alpha of .05) indicates scores are substantially different from a perfect normal distribution and that the variable in question does not meet the assumption of normality.

Using a one-sample Kolmogorov-Smirnov test of the key study variables resulted in non-significance for the WHO-5, Herth Hope Index, LSNS-6 and the DASS-21. Evaluations of the multidimensional scales (the LSNS-6 and DASS-21) elicited significant results for two of the DASS subscales, the DASS depression ($KSz = 1.797, p = .003$) and anxiety subscales ($KSz = 2.068, p < .001$). These findings suggest that the scores produced by these measures are not normally distributed and require further data transformation to accommodate the multivariate assumption of normality. Both the DASS depression subscale and anxiety subscale are positively skewed (with skewness statistics of 1.82 and 2.26 respectively). For measures of skewness, a zero indicates that there is no skew and the measure's scores maintain perfect symmetry. Values greater than zero indicate a positive skew while values less than zero indicate negative skew. Thus, for the anxiety and depression subscales the distribution of values is influenced by extremely high scores. When scores are skewed in a positive direction, simple arithmetic transformations can help realign the distributions toward normality. Moderately skewed scores

may only require a square root transformation, while strongly skewed scores may necessitate a logarithmic calculation.

Scores for the DASS depression subscale were transformed using a simple square root transformation, which produced an acceptable, non-significant KS_z of 1.281. A similar transformation of the DASS anxiety subscale was attempted, but simple data transformations (i.e., square root, logarithmic, and inverse) did not sufficiently normalize the distribution of scores (Mertler & Vannatta, 2005). Subsequently, a Cox-Box transformation was considered, but since the DASS anxiety subscale is not a key variable in this analysis, further transformation was not attempted. As result, analyses involving the anxiety subscale were not preformed.

Linearity

The assumption of linearity requires that when two interval/ratio level variables are correlated, they approach a straight line relationship (Mertler & Vanetta, 2005). Analytic techniques based on the general linear model, such as ANOVAs and MANOVAs, require that the model's continuous variables are free from non-linear relationships when combined with one another. Linearity can be evaluated through the use of residual plots. Since residual plots are also used to identify the presence or absence of heteroscedasticity, results from the residual plot tests are reported in the following section.

Homoscedasticity/Heteroscedasticity

Avoiding heteroscedasticity (i.e., ensuring the homogeneity of variance/covariance) is an important assumption of multivariate statistics (Grimm & Yarnold, 1995; Mertler & Vannatta, 2005). In other words, the distribution of scores on measures of the dependent variables (for the purposes of this study: the DASS-21 and LSNS-6) and covariates that are continuous (i.e., the QOD-Hospice) should be equally dispersed when regressed on one another. Z-plots were used to

evaluate the presence of heteroscedasticity between the DASS-21, LSNS-6, and QOD-Hospice. Although somewhat subjective, this visual assessment allows for an estimate of the presence or absence of heteroscedasticity. If variable combinations are free from heteroscedasticity, the scatterplot distribution will take the shape of a football or oval. However, if heteroscedasticity is present, the plot will form a conical or triangular shape. Results suggest no heteroscedasticity (i.e., good homogeneity of variance) between the DASS-21 and LSNS-6; and low to moderate heteroscedasticity between the QOD-Hospice and DASS-21, as well as between QOD-Hospice and LSNS-6. This visual interpretation was corroborated by colleagues (Drs. Pat Dattalo and Matthias Naleppa; see Figures 3, 4, and 5).

Figure 3

Residual Plot: LSNS-6 (predictor) by QOD-Hospice (dependent)

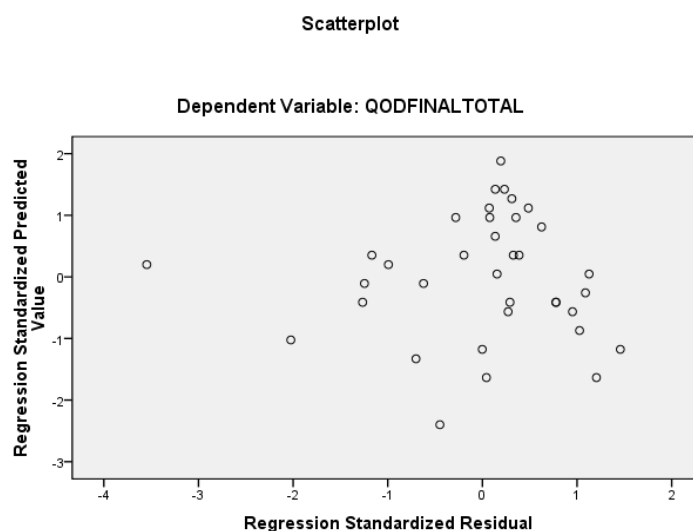


Figure 4

Residual Plot: DASS-21 (predictor) by LSNS-6 (dependent)

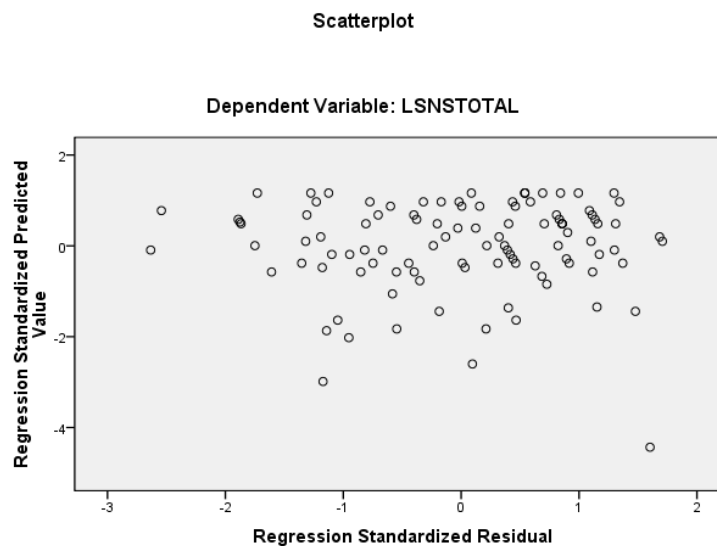
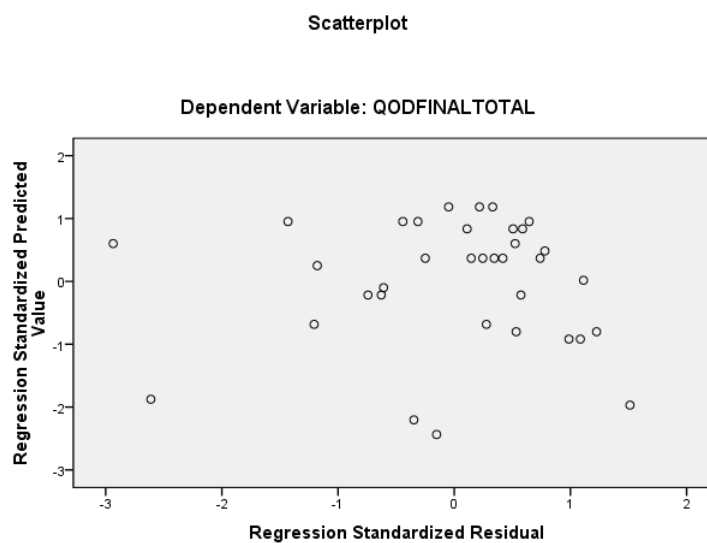


Figure 5

Residual Plot: DASS-21 (predictor) by QOD-Hospice (dependent)



Multi-Collinearity

While linearity is an important assumption in multivariate analyses, conversely the presence of excessive multi-collinearity among variables is undesirable (Grimm & Yarnold,

1995). Strong inter-correlations between variables within a multivariate model create unnecessary redundancies, which can contribute to spurious results. A correlation matrix was used to examine bivariate relations among the primary variables within this study, the DASS-21 (both pre and post), LSNS-6 (pre and post), and the QOD-Hospice (see Table 7). As expected, the strongest correlations were found among repeated measures. Scores from the pre-death and post-death versions of the LSNS-6 produced a strong positive relationship ($r = .78, p < .001$), while the repeated iterations of the DASS-21 elicited a moderate positive relationship ($r = .56, p < .001$). The control variable used to account for perceptions about quality of dying, the QOD-Hospice, was correlated, with weak to moderate strength, to both the DASS-21 and the LSNS-6. QOD-Hospice was negatively correlated to the DASS-21 (pre-death: $r = -.45, p = .006$; and post-death: $r = -.30, p = .07$). As psychological distress increased, respondents had less favorable perceptions about the decedent's quality of dying. The QOD-Hospice was positively correlated with the LSNS-6 (pre-death: $r = .46, p = .005$; and post-death: $r = .39, p = .025$), indicating that as levels of social support increased, so too did positive perceptions about quality of dying. Thus, as a covariate within the multivariate model, moderate correlations between the QOD-Hospice and dependent variables are expected; however, this may contribute some shared variance within the overall model.

Instrumentation

The properties of all psychometric instruments (see Table 8 and Table 9) were explored, including reported means (M), measures of dispersion (range and SD), and internal reliability (Cronbach's α). Each measure elicited an acceptable internal reliability coefficient, ranging from an alpha of .76 on the pre-death version of the DASS anxiety subscale to an alpha of .94 on the

post-death iteration of the DASS-21. These results suggest moderate to excellent levels of internal consistency among instruments.

Table 7

Correlation Matrix among Key Study Variables

Variable	1	2	3	4	5
1. DASS-21 (Pre-Death)	---	.56**	-.24*	-.11	-.45**
2. DASS-21 (Post-Death)		---	-.13	-.22	-.30
3. LSNS-6 (Pre-Death)			---	.78**	.46**
4. LSNS-6 (Post-Death)				---	.38*
5. QOD-Hospice					---

Note. * $p < .05$; ** $p < .01$

For the large part, mean instrument scores were unremarkable, with the majority reported at normal or moderate levels. There was one exception, however. On the pre-death administration of the WHO-5, a tool used for evaluating a respondent's level of well-being, the mean participant score was 12.97. According to Olsen and colleagues (cited in Bech, 2004) a WHO-5 score of 13 or below indicates the need for further assessment of depression. Scores on this measure range from 0-25, with higher scores reflecting greater well-being. Although the WHO-5 is not a clinical tool for diagnosing depression, previous studies have found it to be negatively correlated with depression and an excellent predictor of Major Depressive Disorder (Henkel et al., 2003). A relatively strong negative relationship between the WHO-5 and the DASS depression subscale was also evident in this study ($r = -.64, p < .001$). However, the mean

participant score for the DASS depression subscale (pre-death) was 8.1, well below the cut-point of 28+, which is considered "extremely severe" (Lovibond & Lovibond, 1995).

Table 8

Instrumentation: Pre-Death (N = 106)

Measures	Properties			
	<u>Cronbach's α</u>	<u>Range</u>	<u>M</u>	<u>SD</u>
WHO-5	0.92	0-25	12.97	6.26
LSNS-6	0.88	1-30	18.49	6.87
Family subscale	0.82	0-15	9.72	3.72
Friends subscale	0.89	0-15	8.68	3.95
DASS-21	0.93	0-116	23.4	20.75
Depression subscale*	0.89	0-42	8.1	8.91
Stress subscale	0.87	0-36	10.75	8.85
Anxiety subscale*	0.76	0-38	5.05	6.15
Herth Hope Index	0.84	6-39	28.62	5.57

Note: * Non-normal distribution; untransformed

Caregiver Proximity

Univariate analyses were used to examine the socio-demographic characteristics of each caregiver group. This is followed by an analysis of group equivalency.

Long Distance Caregivers

Of the 106 respondents included in the final analysis, 25 caregivers met the criteria to be considered a long distance caregiver. On average, long distance caregivers in this sample lived 559 miles ($SD = 836$) and 6.3 hours ($SD = 9.7$) away from the care recipient. However, these statistics were positively skewed, and, as result, may not reflect characteristics of the typical long

distance caregiver. The median number of miles away was 200 and 3.5 hours of travel. The mean age of long distance caregivers was 58 years old ($SD = 14.8$). Their median income fell between \$35,000 to < \$50,000; and the median education level was “some college.” Forty percent (40%) of respondents in this group indicated they were providing care to a parent, and 20% said that the care recipient was “some other relative” (i.e., not a parent, child, sibling, or spouse/partner).

Although all of the respondents in this study were identified as caregivers by the care recipient (or a proxy decision-maker), 29% of long distance caregiver did not consider themselves to be caregivers. Interestingly, on the pre-death survey long distance caregivers reported providing an average of 40.5 hours of patient care during the previous week.

Table 9

Instrumentation: Post-Death (N = 36)

Measures	Properties			
	<u>Cronbach's α</u>	<u>Range</u>	<u>M</u>	<u>SD</u>
WHO-5	.92	0-25	13.6	5.7
LSNS-6	.84	2-28	16.7	5.9
Family subscale	.77	2-15	9.1	2.9
Friends subscale	.85	0-15	7.7	3.7
DASS-21	.94	0-72	21.3	19.3
Depression subscale*	.91	0-36	7.4	8.9
Stress subscale	.87	0-30	10.2	8.2
Anxiety subscale*	.82	0-18	3.7	4.5
Herth Hope Index	.84	11-36	27.5	6.2
TRIG-2	.88	13-60	41	10
QOD-Hospice	.85	55-100	88.7	10.9

Note: * Non-normal distribution; untransformed

Proximate Caregivers

Twenty seven participants were identified as proximate caregivers, all of whom reported living within an hour of their respective care recipient. This group was primarily female (70%), with a mean age of 51 years ($SD = 12$); and a large majority were Caucasian (79.2%). These caregivers were fairly educated, with a median educational level of “some college” and a reported annual household income between \$35,000 to < \$50,000. On average, proximate caregivers lived 7.2 miles ($SD = 13.8$) away from the person for whom they provided care. Half (50%) of proximate caregivers were providing care to a parent, while a fifth (20%) were caring for a sibling. When respondents in this group were asked how many hours of care/support they provided for the patient over the previous week, they reported giving an average of 25.6 hours ($SD = 21.7$) of care.

Co-residing Caregivers

Approximately half (51%, $n = 54$) of participants were co-residing caregivers. This group was, for the large part, White (79%) and female (66%), with a mean age of 59 years ($SD = 13.8$). Co-residing caregivers reported a median education-level of acquiring a high school diploma or GED, and an income-level between \$20, 000 to less than \$25,000. On the pre-death survey, this group of participants indicated that during the previous week they had provided an average of 80 hours ($SD = 64$) of care to their loved one. More than half of co-residing caregivers were providing care to a partner or spouse (55%), and approximately a fifth (19%) were caring for a parent.

Table 10

Demographic Characteristics by Caregiver Groups

Variable	Caregiver Groups		
	Co-residing Caregivers (<i>n</i> = 54)	Proximate Caregivers (<i>n</i> = 27)	Long Distance Caregivers (<i>n</i> = 25)
Gender			
Male	34% (<i>n</i> = 18)	29% (<i>n</i> = 7)	32% (<i>n</i> = 8)
Female	66% (<i>n</i> = 35)	70% (<i>n</i> = 17)	68% (<i>n</i> = 17)
Mean Age	59yrs.	51yrs.	58yrs.
Race/Ethnicity			
AA/Black	9.4% (<i>n</i> = 5)	8.3% (<i>n</i> = 2)	12% (<i>n</i> = 3)
Latino/Hisp. Am	-	-	-
Asian Am/Pac-Isl.	-	-	-
Native-Am./Alsk Nat.	5.7% (<i>n</i> = 3)	8.3% (<i>n</i> = 2)	4% (<i>n</i> = 1)
Euro-Am./White	79.2% (<i>n</i> = 42)	79.2% (<i>n</i> = 19)	84% (<i>n</i> = 21)
Bi-racial/Multi-racial	3.8% (<i>n</i> = 2)	-	-
Other	1.9% (<i>n</i> = 1)	4.2% (<i>n</i> = 1)	-
Relationship to Patient			
<i>The patient is my...</i>			
Spouse/Partner	54.7% (<i>n</i> = 29)	-	4% (<i>n</i> = 1)
Child	1.9% (<i>n</i> = 1)	12.5% (<i>n</i> = 3)	8% (<i>n</i> = 2)
Parent	18.9% (<i>n</i> = 10)	50% (<i>n</i> = 12)	40% (<i>n</i> = 10)
Sibling	11.3% (<i>n</i> = 6)	20.8% (<i>n</i> = 5)	12% (<i>n</i> = 3)
Other Relative	5.7% (<i>n</i> = 3)	8.3% (<i>n</i> = 2)	20% (<i>n</i> = 5)
Friend	1.9% (<i>n</i> = 1)	-	4% (<i>n</i> = 1)
Other	5.7% (<i>n</i> = 3)	8.3% (<i>n</i> = 2)	12% (<i>n</i> = 3)

Evaluating Group Equivalency

In order to evaluate equivalency between caregiver groups, differences between co-residing, proximate, and long distance respondents were explored. Readily evident was that the three groups differed in size. More co-residing caregivers participated (Pre-death *n* = 54; Post-

death $n = 16$) than proximate (Pre-death $n = 27$; Post-death $n = 12$) or long distance (Pre-death $n = 25$; Post-death $n = 8$). The imbalance in group sizes can affect both power and precision during the main analysis. Although equal groups are not a necessary assumption for the MANCOVA procedure, post-hoc analyses may be affected (Garson, 2008).

Caregiver groups did not differ in terms of age, gender, race/ethnicity, or employment status. However, differences between groups were found on the demographic variables of income, education, and relationship to the patient. Co-residing caregivers were found to have lower income levels (median \$20K-\$25K) than proximate or long distance caregivers (median \$35K-\$50K [$\chi^2 = 9.616$, $df = 2$, $p = .008$]). Co-residing caregivers also reported having a slightly lower educational level (median “some college”) than the other caregiver groups (median “college degree” [$\chi^2 = 9.903$, $df = 2$, $p = .007$]). Regarding the relationship to the patient, more co-residing caregivers were providing care to a spouse/partner than were proximate and co-residing caregivers. In this sample, long distance caregivers and their proximate counterparts were more often providing care to a parent. Since the relationship status between caregiver and care recipient is known to influence bereavement outcomes (Bernard & Guarnaccia, 2003; Center for the Advancement of Health, 2003) these group disparities were investigated further.

Bivariate Analyses

Geographic Proximity and Bereavement Adjustment

A series of bivariate analyses were performed to examine the relationship between geographic proximity and bereavement adjustment. These tests addressed the first research hypothesis (H_1) which states that post-death adjustment will differ among caregiver groups. In order to explore group differences on measures of bereavement adjustment, one way ANOVAs were conducted to examine post-death adjustment scores (i.e., using the WHO-5, HHI, and

DASS-21) between the three caregiver groups (co-residing, proximate, and long distance). Results of the ANOVAs found no significant group differences on measures of hope (HHI) or psychological distress (DASS-21). A significant difference was discovered between caregiver groups ($F = 3.447$, $df = 2$, $p = .044$) on the measure of well-being (the WHO-5). However, this finding was somewhat obfuscated during the follow-up analysis (a post hoc Bonferroni's correction), which did not identify any significant group-by-group differences. In other words, results are difficult to interpret because differences were identified during the family-wise analysis, but not during the case-wise analysis.

As reported in the summary of findings (see pages 118-119), the difference in well-being appears most evident between co-residing caregivers and proximate caregivers (M difference of 5.1, $p = .065$; see Table 11). Well-being scores between long distance caregivers and co-residing caregivers (M difference of 4.3, $p = .21$) may also have contributed to the significant results of the ANOVA. Even though the ANOVA results support the research hypothesis (H_1), the ramifications of this finding remain unclear. This change in significance levels between the ANOVA and post hoc test is most likely the result of the small sample size and (related to this) an indicator of poor statistical power. This finding certainly warrants further investigation, but these results were deemed too error-prone to warrant inclusion in the implications.

Table 11

Post-Death Well-Being Scores by Caregiver Group

Measure	Caregiver Group		
	Co-residing ($n = 15$)	Proximate ($n = 11$)	Long-Distance ($n = 8$)
WHO-5 (Post-Death)	10.9($SD = 5.5$)	16($SD = 5$)	15.3($SD = 5.7$)

Relationship Status

Previous bereavement studies suggest a decedent's relationship (i.e., whether sibling, parent, or partner) to the bereaved may influence bereavement outcomes (Bernard & Guarnaccia, 2003; Li, 2005). Some evidence also suggests that the death of a partner or spouse may be a more difficult adjustment process for survivors than coping with the loss of parent or sibling (Bernard & Guarnaccia, 2003). To explore this in more depth, the variable relationship status was recoded into a dichotomous variable, with one category defined as partners/spouses and the other category as non-partners/spouses. On bereavement measures (including the DASS-21, TRIG2, WHO-5, LSNS-6, and Herth Hope Index) a series of independent samples *t*-test revealed no differences between partner/spouse caregivers and non-partner/spouse caregivers. Differences were identified, however, on pre-death levels of the DASS-21 ($t = 2.424$, $df = 36.598$, $p = 0.02$). Prior to the patient's death the mean DASS-21 score for partners/spouses was 33 ($SD = 27.2$) while the mean score for other caregivers was 20 ($SD = 16.3$), indicating that those caring for an intimate partner had higher levels of psychological distress. These group differences were also detectable on the DASS subscales of depression ($t = 2.336$, $df = 36.28$, $p = 0.025$) and stress ($t = 2.186$, $df = 46.152$, $p = 0.034$) subscales. Mean depression score of 11.6 ($SD = 11.3$) non-partner and non-spouse caregivers had a mean depression score of 6.3 ($SD = 6.7$). The mean score for stress was 13.9 ($SD = 9.7$) for partners/spouses and 9.4 ($SD = 8.3$) for non-spouse/non-partners.

Differences in Caregiver Responsibilities

An analysis was performed to investigate differences in the level of care involvement (i.e., share of care, hours providing care, and specific ADL and IADL care tasks) between caregiver groups. A caregiver's level of involvement in the care of the care recipient may be an important and potentially confounding factor to consider. Although not a main study hypothesis,

a *distance-decay* effect (Joseph & Hallman, 1998) was expected. In other words, the further away a caregiver lives from the care recipient, the less involved in the care they are likely to be. A one-way ANOVA and subsequent Bonferroni's correction identified significant differences between caregiver groups. On the pre-death survey, co-residing caregivers reported providing more hours of care and support over the past week to the care recipient ($M = 81$ hours, $SD = 65$) than proximate ($M = 26$ hours, $SD = 21$) or long distance caregivers ($M = 41$ hours, $SD = 41$) ($F = 11.398$, $df = 2$, $p < .001$). Co-residing caregivers also provided more Instrumental Activities of Daily Living (IADLs; $M = 4.4$, $SD = 1.9$) than long distance caregivers ($M = 3.1$, $SD = 1.9$) ($F = 13.856$, $df = 2$, $p = .032$). However, group differences between co-residing, proximate, and long distance caregivers were not observed on the variable Activities of Daily Living (ADLs). It was suspected that providing assistance with ADLs was more due to patient functionality because a high functioning care recipient does not require as much assistance with ADLs as a low functioning care recipient. A simple linear correlation between the PPSv2 (a measure of functionality at the time of admission) and number of ADLs provided by the respondent supported this assumption ($r = -.31$, $p = 0.002$; see Table 12). This weak to moderate, negative correlation suggests that as a patient's functionality increases, the number of hands-on care needs is reduced – as one might expect.

The bereavement questionnaire asked respondents to retrospectively evaluate their caregiving involvement. The question asked "Overall, what share of the patient's care were you responsible for?" with possible response options of: "Nearly 100%," "A large majority," "About half," "A small share," or "Almost none." Results of a Kruskal-Wallis test found significant differences between caregiver groups ($\chi^2 = 19.703$, $df = 2$, $p < .001$). Co-residing caregivers reported taking on the largest portion of the care (Mean Rank = 11.6; Note - lower ranks indicate

a greater share of the care) followed by proximate caregivers (Mean Rank = 20) and long distance caregivers (Mean Rank = 30.9).

Table 12

Correlation Matrix: QOD-Hospice, Bereavement Measures & Patient Characteristics

Variable	1	2	3	4	5	6	7	8	9
1. QOD-Hospice	---	-.55**	-.30	.29	.05	.05	.46**	-.29	-.23
2. TRIG2		---	.63**	-.08	-.09	.24	-.16	-.05	.05
3. DASS-21 (Post-Death)			---	-.03	-.23	-.03	-.13	.05	.09
4. PPSv2				---	-.21*	.20*	.08	-.31**	-.15
5. N of Caregivers					---	-.19*	.10	.01	-.21*
6. Pain-Level						---	.19	-.01	.07
7. LSNS-6 (Post-Death)							---	-.12	-.05
8. N of ADLs								---	.51**
9. N of IADLs									---

Note. * $p < .05$; ** $p < .01$

Level of care involvement was also linked to symptoms of depression. A Spearman's rho analysis between a respondent's reported share of care and DASS depression scores during bereavement identified a positive association ($\rho = .34, p = .041$). Caregivers who assumed a greater share of the care responsibilities reported higher levels of depressive symptoms during bereavement. Similarly a positive correlation was found between on hours of care reported on the pre-death survey and DASS depression scores post-death ($r = .39, p = .020$).

Caregiver Proximity and Depressive Symptoms

A one-way ANOVA was used to investigate differences in levels of depressive symptoms between caregiver groups. This evaluated the research hypothesis which proposed that co-residing caregivers would have higher levels of depressive symptoms than other caregiver groups ($H_{3 \text{ Sub } 2}$). In this analysis depressive symptoms were measured using the DASS depression subscale. Results revealed the presence of group differences ($F = 4.393$, $df = 2$, $p = .015$) in pre-death levels of depressive symptoms. A post hoc Bonferroni's contrast identified differing DASS depression scores between long distance and co-residing caregivers. More specifically, co-residing caregivers reported higher levels of depressive symptoms ($M = 10.3$, $SD = 10.4$) than long distance caregivers ($M = 4.8$, $SD = 4.3$). (Note: these findings were significant regardless of whether using the transformed version of the DASS depression subscale or the original, unaltered scores.) The heterogeneity between caregiver groups should be considered with respect to these findings. Reported means are unadjusted for potentially intervening variables such as relationship status and/or level of involvement in care.

Changes in Repeated Measures across Combined Groups

To examine the research hypothesis which posited differences between pre-death and post-death levels of social support (H_2), a paired samples t -test was performed on repeated measures of the LSNS-6 using combined caregivers groups (i.e., co-residing, proximate, and long distance were consolidated into one group). Similar to results of the MANCOVA (see page 116), t -test results were non-significant when exploring pre-death and post-death differences in social support. Even apart from the main analysis (the multivariate model with adjustments for covariates) social support did not significantly change over time.

In order to evaluate the research hypothesis that levels of pre-death adjustment differ from levels of post-death adjustment (H_3), a series of paired samples t -test were used to detect changes in the remaining dependent variables. Repeated measures scale-level variables that measured psychological adjustment (the DASS-21, WHO-5 and HHI) were evaluated across combined caregiver groups. Significant changes were not observed on measures of the DASS-21 or WHO-5. The only significant difference over time was on paired measures of the Herth Hope Index ($t = 2.112$, $df = 37$, $p = .042$) ($SE = .75511$). When evaluating caregiver groups together, mean HHI scores dropped from 29.1 ($SD = 4.3$) during caregiving to 27.5 ($SD = 6.23$) three months into bereavement. Thus, for combined caregiver groups, levels of hope and optimism were significantly lower after the death.

Table 13

Correlation Matrix: Pre-Death Measures and Caregiver Variables (Pre-Death $N = 106$)

Variable	1	2	3	4	5	6	7	8	9
1. DASS-21 (Pre-Death)	---	-.24*	-.62**	-.53**	.14	.17	.01	-.04	-.17
2. LSNS-6 (Pre-Death)		---	.36**	.40**	-.12	-.05	.07	-.03	-.14
3. WHO-5 (Pre-Death)			---	.47**	-.34**	-.20*	-.23*	.03	-.04
4. HHI (Pre-Death)				---	-.03	-.05	.17	-.09	-.05
5. N of ADLs					---	.51**	.33**	-.11	.04
6. N of IADLs						---	.31**	-.17	.00
7. Hours of Care							---	-.20	-.12
8. Miles Away								---	.56**
9. Hours Travel									---

Note. * $p < .05$; ** $p < .01$

Self-Rated Health Status

Respondent health status was measured using a self-report rating on a 0 to 10 continuum, “0” indicating “extremely poor” and “10” indicating “excellent.” Group differences were analyzed using a Kruskal-Wallis test, which is a chi-square variant appropriate for ordinal-level data. Results found that self-rated health differed between caregiver groups ($\chi^2 = 6.454$, $df = 2$, $p = .038$). Co-residing caregivers reported lower self-rated health status (Mean Rank = 49.2) than proximate (Mean Rank = 63.84) and long distance caregivers (Mean Rank = 65.52).

Caregiver Self-Identification

Even though each participant had been identified as a caregiver by the referring patient (or the person making decisions on the patient’s behalf), not all respondents considered themselves to be a caregiver. Caregiver proximity was associated with caregiver self-identification ($\chi^2 = 9.577$, $df = 2$, $p = 0.008$). Only 6% of co-residing caregivers and 8% of proximate caregivers did not identify themselves as a caregiver, compared to 29% of long distance caregivers.

Anger and Guilt

Between group differences were explored on ordinal measures of guilt and anger. These analyses were used to test study research hypotheses $H_{3 \text{ Sub } 3}$ and $H_{3 \text{ Sub } 4}$. Hypothesis $3_{\text{Sub } 3}$ proposed that long distance caregivers would report higher levels of guilt than other caregiver groups. Likewise, Hypothesis $3_{\text{Sub } 4}$ advanced that long distance caregivers would report higher levels of anger. Results of a Kruskal-Wallis test found no group differences in reported anger or guilt between co-residing, proximate, and long distance caregivers. Consequently, corresponding null hypotheses were not rejected.

Satisfaction with Hospice

On pre-death and post-death surveys, three questions asked respondents about their satisfaction with hospice services. These questions used Likert-type response sets to gather data on satisfaction regarding hospice services including: (1) the information received, (2) availability of staff, and (3) the care provided. A non-parametric Kruskal-Wallis test was used to examine differences in levels of satisfaction among caregiver groups. Levels of satisfaction during bereavement did not differ between caregiver groups. However, prior to the patient's death, group differences were identified. Co-residing caregivers (Mean Rank = 58.8) and proximate caregivers (Mean Rank = 53.9) reported higher satisfaction with hospice availability than long distance caregivers (Mean Rank = 37.1) ($\chi^2 = 11.055$, $df = 2$, $p = .004$). Differing levels of satisfaction with hospice care were also discovered ($\chi^2 = 6.362$, $df = 2$, $p = .042$). Again, co-residing and proximate caregivers (Mean Rank = 56.4 and 53.4 respectively) reported greater levels of satisfaction than long distance caregivers (Mean Rank = 40.92). An original study hypothesis ($H_{4 \text{ Sub } 1}$) proposed that long distance caregivers would be less satisfied with the information received from hospice. This hypothesis was not supported. Although, the test statistic was near significant ($\chi^2 = 5.792$, $df = 2$, $p = .055$), with co-residing (Mean Rank = 56.3) and proximate caregivers (Mean Rank = 55.3) indicating greater levels of satisfaction with the information provided by hospice than long distance caregivers (Mean Rank = 41).

The DASS-21 as a Measure of Bereavement Adjustment

In this study, the DASS-21 was used to evaluate bereavement adjustment. As a composite measure of depression, anxiety, and stress, the DASS-21 was selected as a general measure of psychological distress, appropriate for detecting changes over time. However, the DASS-21 has not been validated as a measure of bereavement adjustment. To explore the appropriateness of

using the DASS-21 to evaluate bereavement adjustment, a correlation analysis between scores on the DASS-21 and a validated measure of grief, the TRIG2, was performed. DASS-21 scores on the post-death survey were strongly, positively correlated ($r = .63, p < .001$; see Table 14) with scores on the TRIG2. As expected, as a respondent's level of emotional grief increased, so did their psychological distress.

Table 14

Correlation Matrix: QOD-Hospice, Bereavement Measures, & Length of Stay

Variable	1	2	3	4	5	6	7	8	9
1. QOD-Hospice	---	.27	-.30	-.55**	.38*	.29	.05	.53**	.05
2. WHO-5 (Post-Death)		---	-.71**	-.54**	.25	.17	.43*	.16	.00
3. DASS-21 (Post-Death)			---	.63**	-.22	-.03	-.23	-.21	-.03
4. TRIG2				---	-.19	-.08	-.09	-.30	.24
5. LSNS-6 (Post-Death)					---	.21	-.04	-.22	.09
6. PPSv2						---	-.21*	.18	.20*
7. N of Caregivers							---	.12	-.19*
8. Length of Stay								---	-.07
9. Pain-Level									---

Note. * $p < .05$; ** $p < .01$

Additional support for utilizing the DASS-21 as a post-death assessment of adjustment was explored. When compared to self-rated guilt during bereavement (an ordinal-level measure, with higher values indicating greater guilt) the DASS-21 was found to have a moderate, positive association ($\gamma = .36, p = .031$); and a similar association was found between the DASS-21 and self-rated anger ($\gamma = .46, p = .001$).

Control Variables: QOD-Hospice and Gender

The original analysis plan identified two possible intervening variables, which may need to be partialized and controlled for in the MANCOVA. These potentially confounding variables are (1) gender and (2) perceived quality of dying and death. Previous research suggests that these two variables impact levels of grief and bereavement adjustment (Carr, 2003; Stroebe, Stroebe & Schut, 2001). To explore this association within these data, an independent samples *t*-test was performed to examine gender differences on measures of psychological distress during bereavement (using the DASS-21) and grief (using the TRIG2). Significant differences were identified. On the post-death version of the DASS-21, mean scores were higher for women ($M = 24.8$, $SD = 8$) than for men ($M = 12$, $SD = 21$) ($t = -2.666$, $df = 34$, $p = 0.018$).

In bereavement research, another potentially intervening variable to consider is a person's perceptions about the quality of their loved one's dying and death (Carr, 2003). For example, if a bereaved individual believes that their loved one's final days were marred by intractable pain and suffering, or if treatment preferences were not honored, then these factors may influence bereavement adjustment and grieving (Carr, 2003). The QOD-Hospice was used to evaluate a respondent's perception about the decedent's quality of dying. A correlation matrix exploring relationships between the QOD-Hospice, LSNS, DASS-21, and TRIG2 supported this assertion (see Table 12). In this sample, the QOD-Hospice was positively correlated with LSNS scores, on both the pre-death and post-death surveys ($r = .46$, $p = .005$ and $r = .38$, $p = .025$ respectively). Although these associations are only moderately strong, as social support increased, so did levels of the perceived quality of death. Also, the QOD-Hospice was negatively correlated with the TRIG2 ($r = -.55$, $p = .001$), meaning that as respondents' opinions about quality of dying improved, levels of emotional grief declined.

Main Analysis

A multivariate analysis of covariance (MANCOVA) for repeated measures was used to evaluate changes in social support and psychological adjustment over time and across the three groups of caregivers (co-residing, proximate, and long distance) while controlling for gender and perceived quality of dying. This type of analysis is sometimes referred to as a doubly multivariate repeated measures MANCOVA. As a covariate, gender was coded as a dummy variable with female respondents coded as “1” and males coded as “0,” indicating “other than female.” Due to unequal cell sizes, the analysis was run using the SPSS[®] sum of squares model IV.

Within-Group Results

The MANCOVA explored within-groups changes in social support and psychological adjustment over time. Results of the analysis identified no significant within-group differences. Therefore, when adjusting for gender and quality of dying, no differences were found between pre-death and post-death measures of the DASS-21 and LSNS-6. Additionally, the interaction effects of the control variables, QOD-Hospice and gender, were not observed within-groups (i.e., across time). As result, corresponding research hypotheses (H_2 , H_3 , and $H_{3 \text{ Sub } 1}$) were not supported by this model. Diminished power, due to small sample sizes in the bereavement portion of the study may have contributed to these findings.

Between-Group Results

No between-group differences were identified on measures of the dependent variables when adjusting for gender and QOD-Hospice. Across the three caregiver groups, DASS-21 and LSNS-6 scores did not differ. These findings fail to support the study hypotheses predicting

group differences on psychological adjustment (H_1) and social support (H_4); accordingly, null hypotheses were not rejected. However, the QOD-Hospice was found to have a significant between-groups interaction effect on the DASS-21 ($F = 6.278, df = 1, p = .018$) and a near significant between-groups effect on the LSNS-6 ($F = 3.386, df = 1, p = .076$). The effects of the QOD-Hospice in this model only explains a small portion of variance in the dependent variables (partial $\mu^2 = .183$ on the DASS-21 and partial $\mu^2 = .108$ on the LSNS-6) (see Table 15). A multivariate table produced a significant Wilks' Λ of .782 (F exact = 3.765, $df = 2, p = .036$) for QOD-Hospice. This suggests that the QOD-Hospice contributes to variance in the dependent variables within the model, but that this contribution accounts for a small portion of total explained variance. Additionally, given the model complexity, lack of differences on measures of the dependent variables, and methodological limitations, statements about the relative impact of quality of dying on between-group variance of the dependent variables should be made with caution. Table 16 displays mean DASS-21 scores with and without adjustments for QOD-Hospice.

Table 15

Explanation of Selected MANCOVA Statistics

Statistic	Definition
Eta squared (μ^2)	An estimate of the proportion of explained variance, ranging from 0 to 1, with higher levels indicating more explained variance.
Wilks' Lambda (Wilkes' Λ)	A multivariate statistic used to assess the amount of unexplained variance in the dependent variables, ranges from 0 to 1, higher levels indicate more unexplained variance.

(Grimm & Yarnold, 1995)

Table 16

Mean DASS-21 Scores With and Without Adjustments for QOD-Hospice

Caregiver Group	DASS-21 Pre-Death		DASS-21 Post-Death	
	Adjusted <i>M</i>	Unadjusted <i>M</i>	Adjusted <i>M</i>	Unadjusted <i>M</i>
Co-residing	24.88 ^a	25.12 ^a	27.19 ^a	27.37 ^a
Proximate	21.99 ^a	16.92 ^a	17.65 ^a	17.05 ^a
Long Distance	13.92 ^a	17.80 ^a	17.71 ^a	20.31 ^a

Table 17

Group Differences on Pre-Death Measures (Unadjusted Means)

Measure	Group		
	Co-residing Caregivers (<i>n</i> = 54)	Proximate Caregivers (<i>n</i> = 27)	Long Distance Caregivers (<i>n</i> = 25)
LSNS-6	18.5	20.1	14.6
Family	9.8	10.7	7.8
Friends	8.8	9.4	7
Herth Hope Index	29.3	30.9	28.7
WHO-5	11.9	15.9	13.3
DASS-21*	23.4	19	20.6
Depression**	6.9	7.6	4.2
Anxiety***	4.2	4.4	4.3
Stress	12.3	7	12

Between Group Differences: * Co-residing vs. LDC DASS-21 ($p = .032$) and
Co-residing vs. Proximate ($p = .07$)

**Co-residing vs. LDC DASS-Depr ($p = .025$)

***Significant but the distribution is non-normal

Table 18

Summary Results of Research Hypotheses

Research Hypothesis	Variable Significance	Result
H ₁ - Post-death adjustment will differ among caregiver groups.	WHO-5* Co-residing/Proximate	Reject Null
H ₂ - Levels of pre-death social support will differ from levels of post-death social support.	None	Accept Null
H ₃ - Levels of pre-death adjustment will differ from levels of post-death adjustment.	HHI	Reject Null
H _{3 Sub 1} - Co-residing caregivers will show greater improvement on adjustment measures overtime.	None	Accept Null
H _{3 Sub 2} - Co-residing caregivers will have more depressive symptoms.	DASS-depression Co-residing/Long distance	Reject Null
H _{3 Sub 3} - Long distance caregivers will report higher levels of guilt.	None	Accept Null
H _{3 Sub 4} - Long distance caregivers will report higher levels of anger.	None	Accept Null
H ₄ - Levels of perceived support will differ between caregiver groups.	None	Accept Null
H _{4 Sub 1} - Long distance caregivers will report higher levels of dissatisfaction with the amount of information	None**	Accept Null

*One way ANOVA was significant, post hoc analysis was non-significant

**Kruskal-Wallis test near significant ($p = .055$)

Summary of Quantitative Results

Main Analysis

Results of the main analysis did not support the proposed multivariate model. No significant differences were identified within-groups or between-groups on measures of psychological adjustment (using the DASS-21) and social support. A significant between-groups interaction effect was found on the control variable evaluating quality of death. This effect was only significant on measurements of psychological adjustment. Although it accounted for a small portion of the explained variance, this suggests that quality of death may have a slight interaction effect on psychological adjustment across the caregiver groups identified in this study (i.e., co-residing, proximate, and long-distance). Given the sample size, high rate of attrition, overall complexity of the model, and lack of significant results on measures of the dependent variables, these findings require further investigation.

Hypothesis Testing

Out of the four main study hypotheses and five sub hypotheses (nine in all), only three research hypotheses were supported. See Table 18 for a summary of the result of hypothesis testing. The first hypothesis (H_1) proposed that caregiver groups would differ on levels of post-death adjustment. During bereavement, levels of well-being (WHO-5) bereavement differed between co-residing and proximate caregivers. The third hypothesis (H_3) posited differences between pre-death and post-death levels of adjustment. When caregiver groups were consolidated, levels of hope (HHI) dropped significantly over time. Lastly, the sub-hypothesis which advanced that co-residing caregivers would have more depressive symptoms than other caregiver groups ($H_{3 \text{ Sub } 2}$) was supported. Co-residing caregivers reported higher levels of depressive symptoms (DASS depression subscale) than long distance caregivers. Test results

from the remaining hypotheses were non-significant and, consequently, the null hypotheses were not rejected.

Qualitative Analysis

Although this study is primarily quantitative in nature, both the pre-death and post death surveys provided a blank space in which participants could make written remarks. The open-ended response section posed the following: “Please use the space below to make any additional comments about how you could have been better prepared/supported during the care of your loved one.” On the pre-death survey, 56 subjects responded to this statement. Twenty four individuals provided comments on the post-death survey. These responses were coded and analyzed to identify patterns and thematic content. The general tenets of the constant-comparison method (Glaser & Strauss, 1967; Strauss & Corbin, 1998) were used to analyze these data.

About half ($n = 56$, 52.8%) of those who completed and returned the pre-death survey responded to the qualitative component of the survey. A similar proportion of individuals ($n = 26$, 49%) included remarks on the open-ended question of the bereavement survey. These responses were evaluated to provide additional depth and context to the quantitative findings. The qualitative analysis attempted to identify overarching categories, themes, and sub-themes.

Although the qualitative prompt directed respondents to comment on how they were “prepared” or “supported,” the content of the responses varied greatly. Caregivers used the open-ended format as an opportunity to share about their experiences in general. And, hence, the participants’ narratives covered diverse range of topics. Eight pre-death themes and four post-death themes were identified. Theme which emerged during the analysis of pre-death data were: (1) Preparedness/Preparation, (2) Expressions of Gratitude, (3) Anger/Criticism of Care, (4) the Role of Friends, (5) Needs, (6) Sacrifices, (7) Information and Education, (8) Faith and

Spirituality, and (9) a Sense of Obligation/Giving Back. An analysis of responses to the bereavement survey derived the following themes: (1) Information and Education, (2) Religion and Spirituality, (3) Gratitude, and (4) Loss. Additionally, some of the long distance caregivers described their struggles to negotiate distance.

Preparedness/Preparation

Caregivers remarked about how prepared they were to confront the realities of caring for someone with cancer. A number of passages described being caught off guard by the illness which made preparation a difficult, if not impossible, task. Related to this, responses often referred to the unexpectedness or suddenness of the diagnosis.

- (76yo F long distance) Cancer seems to be part of our family history. I can't see anyway anyone could be prepared to face cancer at any age - even with several relatives having cancer.
- (42yo F co-residing) Prepared. There was no way for that. It hit us like wild fire.
- (28yo F co-residing) I don't think you could ever really be prepared.

Expressions of Gratitude

One common theme was the expression of gratitude. Many respondents used the open-ended forum to share their thanks and appreciation for the efforts of others contributing to the care of their loved one. These accolades were often directed toward hospice staff, family members, or friends.

- (68yo M proximate) Thanks so much to Hospice for the work they do.
- (59yo F long distance) Just met the folks from Hospice last week. They were very professional and supportive of my brother and his wife and his family who are out of town. They responded very quickly to my brother's needs and evaluated his level of pain quickly, and provided the medicines he needed for relief. Our family thanks them for all that they are providing my brother and his wife and us during this stressful time.
- (42yo F co-residing) Thank God for Covenant Hospice. I would be lost without them.

- (52yo F long distance) Your organization has been a godsend on each side of my family. Giving us the preferred choice of having our loved one go with our and your loving care! It is we who thank you!
- (48yo F proximate) This is my first personal experience with hospice. There is no one that I have encountered that has not been kind, caring, and unconcerned. I can not offer any suggestions for improvement. The surroundings at the center, the employees and the services are beyond my expectations. There are no words to describe my gratitude for such a place and group of people to be in my mother's life at this time. My mother is very happy and feels at home there. When I leave from the visit I never worry about her. I know she is receiving the best of care.

Anger/Criticism of Care

Some responses seemed to be expressions of anger, highlighting disappointing aspects of the care and services that were provided to the care recipient. Some of the perceived inadequacies had to do with staff disposition (rudeness, in particular), lack of support, disagreements regarding treatment decisions, and the lack of coordination of home visits made by hospice staff. These criticisms were sometimes directed toward doctors, hospitals and treatment centers, hospice, and other members of the care network (including friends and family). These may provide some feedback regarding ways to improve the care and services provided to cancer patients and their families.

- (Demographic information not provided) There were many times when your nurses would provide very rude remarks and answers to questions we asked. These questions were asked based solely on not knowing the answer.
- (45yo F long distance) I wish my mom's physician had known more about when to contact hospice.
- (60yo M co-residing) The devil raised his ugly head in the form of stage four liver cancer. How could three so-called professionals be so BLIND? [referring to two oncologists and the respondent's daughter, a registered nurse; original emphasis retained]
- (28yo F co-residing) The doctors need to let you know there is help available.

Role of Friends

Friends were identified as an important source of support during caregiving. Some respondents described the close, friendly relationship they had with the patient as a key motivating force behind their commitment to provide care. Others explained that friends were a vital component in the joint effort it takes to meet the needs of a person with advanced cancer.

- (41yo M co-residing) With the Lord's help, true caring friends, and strong self-will, you can make it through.
- (73yo F co-residing) [We] have to rely on friends and neighbors for a lot of assistance.
- (59yo F co-residing) As for support, family, and friends are especially wonderful.

Needs

Caregivers shared an assortment of needs. These needs covered a wide variety of services and resources, including needing: help with chores and maintenance in the home, a list of private-hire caregivers in the community, to "vent," and more flexibility at work. One respondent expressed that she found it especially difficult to ask for help.

- (Demographic information not provided) What a caregiver really needs is more help in the home. Like cleaning, because you don't have time to do it. This is so hard to keep up with.
- (42yo F co-residing) I could have used more help with daily sitters. I would have liked a list (other than the phonebook) of companions. My parent does not need intensive medical care; however, a list of acceptable companions would have been helpful.

Difficulties Asking for Help

- (60yo F proximate) I need to be more willing to accept help from others. My parents were wonderful parents when I was young. I feel so much guilt that I can't have the same energy and patience to take care of them now. Asking for help makes me feel weak.

Sacrifices

Several caregivers remarked about the personal sacrifices they made to ensure that the patient was adequately cared for. They also identified some of the specific burdens which they

experienced. Some respondents reported that providing care was taxing on their job, finances, personal health, and other relationships. Finances, in particular, were a prevalent concern. A number of respondents shared experiences of feeling financially vulnerable. This economic instability was brought on by a number of factors. Some caregivers cited the costs associated with treatment, care, and lost-wages as sources of their financial concerns.

- (62yo F proximate) I had to miss a lot of work.
- (72yo F co-residing) I do wish we had been saving more and had a good insurance policy in place. I will be in serious financial problems if my husband passes away before I do.
- (39yo F proximate) More financial stability to take more time off of work.
- (44yo F co-residing) It tends to cause a little of financial crippling. It has also taken time from my marriage.
- (59yo F co-residing) Certainly earn more money for the future and healthcare needs.

Information and Education

Being well-educated and adequately informed was an important and recurring theme for caregivers. Some individuals felt they were given the right amount of information they needed. Others described a sense of not knowing enough, or that significant information might have been withheld from them. A subtheme associated with this topic was the importance of good communication within the care-network, between and among both the informal caregivers and professional care providers.

- (52yo F long distance) I felt uneducated, though only briefly and only because of the rush of dealing with the road of life along with the rapid deterioration of our loved one (3 months from diagnosis, about 2 weeks of hospice). Education was promptly and courteously given by hospice employees and was greatly valued.
- (42yo F proximate) Unfortunately, my dad has been deemed mentally incompetent. This has resulted in a communication breakdown. It is often difficult to obtain information from Hospice regarding my dad's status because the times I visit and the times that the

Hospice staff is present often do not overlap. I often feel that a lack of communication exists in my dad's case.

Faith and Spirituality

A number of narratives cited spiritual and religious beliefs as a source of personal support.

Knowledge of a higher power, a sense of purpose, and prayer were described as important and helpful aspects during the care of a loved one.

- (41yo M co-residing) Faith in the Lord, inner strength, inner peace helps a lot in these times. I don't feel I could go back on this and do anything different. You ask for the Lord's will. Whatever his decision is you have to accept it.
- (84yo F long distance) God certainly walks with us in every situation we face.
- (68yo M proximate) We can never be ready for the events that come very unexpected, but as a person of deep personal faith in God, with love for our love ones we must do what needs to be done.
- (76yo F long distance) A good outlook is very important and prayers of any one that will is also important.

Sense of Obligation/Giving Back

A number of respondents mentioned they assumed the caregiving role out of a sense of personal responsibility or obligation. In some cases, caregivers were "returning the favor" by giving care to a patient who had provided care to others. Respondents also described the benefits they received as a result of fulfilling these obligations. Care-related rewards (uplifts, as they are sometimes called) included cherishing the patient's wisdom and teachings, enhanced personal strength, feeling supported by others, and enjoying the patient's sense of humor.

- (68yo M proximate) The patient involved was always a caregiver for her mother, father, and her sister, who was my mother. My brother and I are returning the love that she gave to others hopefully to her. She had no children of her own, she always considered my brother and I as her own children. We intended to stand by her through whatever happens.

- (54yo F long distance) He went with me to another surgical procedure and fed me, gave me my medicine with the help of another friend, I am on ten medicines including 2 insulin's. He took care of me then so I am returning the favor.
- (42yo F co-residing) Because in cases like ours, I can't work and I am the only one caring for my husband 24/7. And to me that is what I should do, it was in our vows.
- (41yo M co-residing) You never know when a loved one will become deathly ill. Some try to handle it by placing them in a professional care home. Some buckle down under the stress and give in to their share of responsibility. We can only do for them as they have done for us.

Qualitative Findings from Bereavement Surveys

Information and Education

Similar to what was discovered in the responses prior to death, those in bereavement also commented on the importance of education and information. Participants wanted to know more about the dying process and to get a better idea of when the death would occur.

- (80yo M co-residing) I could have been better informed on what to expect as the process of dying progressed.

Religion and Spirituality

Reliance on spiritual beliefs, personal faith, and the availability of a religious community were noted as helpful by bereaved respondents. Several participants shared that their faith cultivated a sense of purpose, helping to make meaning out of the death. Others described their beliefs as an instrumental source of strength or contributed to a sense of continuation (i.e., to eventually be reunited with their loved one in heaven).

- (60yo M co-residing) Looking back in retrospect, I fully understand that God was in control of everything concerning the end of my wife's life here on earth.
- (demographic information not provided) I have a strong faith that God allows things to happen for a purpose.
- (proximate; other demographic information not provided) The moment my sister passed away. I felt God's presence. He lifted a burden off of me immediately and I felt he was telling me "good job." I'll take care of her now. The peace that overcame me was

overwhelming. I was prepared for a long drawn out hard death, but God took her quickly, painless, and with dignity.

- (63yo F co-residing) I know he [the decedent] is at God's house and is waiting for me. I will join him as we will be with God forever. This is what keeps me going.

Gratitude

As revealed in the pre-death surveys, respondents to the post-death survey were also complementary about the care and support which they received from hospice. It was apparent that many of the caregivers had developed close bonds with some of the hospice staff members.

- (48yo F proximate) I would not have changed a thing about my mother's care or place of care. They were wonderful to her!
- (58yo F co-residing) As for the support my entire family and I got, it couldn't have been better or any stronger. The nurses and entire staff treated my sister like a queen. She was pampered and made to feel very extra special. Of course this helped our family tremendously. I never saw a group of nurses and support personnel give 100% of their time and love to patients. Our family was just as important to them as was my sister. They hugged our necks when we came to visit and always had time to answer any questions we had.
- (proximate; other demographic information not provided) Before going with Covenant we met with another Hospice company. There was no comparison and our choice was easily made. Your staff [...] are truly special, gifted people. I'll always cherish knowing them. They were a great support to my sister and anyone around.

Grief and Loss

Bereaved participants expressed profound feelings of grief and loss. They commented on experiences of longing and a deep sense of absence. Ruminations about the decedent were also prevalent.

- (72yo F co-residing) My husband fought his cancer for 11 years. We loved each other very much and just did not want our time together on earth to end. Now that he is gone, I miss him very much!
- (77yo F co-residing) The actual death was so peaceful, but the void in my life is horrendous.

- (58yo F co-residing) Another thing, my sister would call out to me and says [identifying content removed] please help me. That was one of the things that bothered me greatly and still haunts me today.
- (58yo F proximate) I didn't prepare, I thought she would do better and I didn't know it was so bad. And it hurt to lose two sisters two years apart that are younger than you are. I'm doing fine, but it hurt to know that my little sister had gone and left me here.
- (demographic information not provided) I was just getting over the loss of my husband when [the decedent] was diagnosed with terminal cancer. It was like re-living my husband's death as I watch her go from a beautiful, vibrant person to a pale, thin, dying person. Now she is gone and I am left alone in Florida.
- (63yo F co-residing) I think of my husband always with love and sometimes tears, but that's ok. It helps to wash away the pain and I look for the laughter and love had in our 40 years together.

Long Distance Caregivers:

Long distance caregivers revealed distance as an apparent barrier. They shared about their experiences of having to rely on local caregivers. Expressions of worry (regarding how the decedent was cared for) and frustrations about "not knowing" were noted.

- (52yo F long distance) My biggest concern was being 8 hours away and not knowing should I go home to visit or wait until I get the phone call. I went home for 4 days every two weeks but still worried about not being there in my dad's house when I had to return to my home.
- (49yo F long distance) The most difficult thing for me was distance. I was on one side of the U.S. and my father on the other. I was able to be with him and help with his care. I felt we both gleamed [*sic*] closure at the end.

Summary of Qualitative Findings

Results from the analysis of open-ended responses revealed a wide range of topics and highlighted the uniqueness and complexity involved in caring for someone with cancer. Content from participant responses prior to death were organized under the following themes: (1) Preparedness/Preparation, (2) Expressions of Gratitude, (3) Anger/Criticism of Care, (4) the Role of Friends, (5) Needs, (6) Sacrifices, (7) Information and Education, (8) Faith and Spirituality,

and (9) a Sense of Obligation/Giving Back. Responses during bereavement elicited similar domains, including: (1) Information and Education, (2) Religion and Spirituality, (3) Gratitude, and (4) Loss. Comments from long distance caregivers detailed the challenges of trying to ensure that the recipient's care needs were being met from far away.

CHAPTER FIVE

Discussion

In this chapter the findings and implications of study results are discussed. It begins with an overview of the study, followed by a review of the limitations. Findings are then presented along with implications for the social work profession, hospice, and palliative care. Directions for future research are also recommended.

Overview of Study

The purpose of this study was to explore how caregiving impacts bereavement; and, in particular, how a caregiver's proximity to their care recipient affects social support and psychological adjustment. Participants were informal (unpaid) caregivers of individuals who had been diagnosed with advanced cancer and were receiving hospice services. Using a prospective design, questionnaires were administered to participants within one week of admission into hospice service and, again, three months after the death of the patient. Leading scholars in the field of bereavement have recognized a lack of prospective studies, which can be used to identify which pre-death variables predict post-death outcomes (Bass, Bowman & Noelker, 1991; Schulz et al., 2001; Schulz et al., 1999; Singer & Bowman, 2002; Stroebe, Stroebe & Schut, 2003). This study was designed to help fill this research gap.

Coping with the death of a loved one is a complex process. While some aspects of loss may be universal (Center for the Advancement of Health, 2003), there is a considerable amount of variation in how people react to a loss. This study does not purport to speak for the grief experience of all individuals, nor does it capture the unique constellation of emotions which manifest during bereavement. Rather, the intent of this study was to help contribute to our understanding of the interplay between caregiving, bereavement, and geographic proximity.

Limitations

Every study includes its share of methodological limitations and analytic short-comings, all of which should be acknowledged and considered. In addition to the inferential limitations described in Chapter 4 (see page 92), this research included the following weaknesses addressed below: concerns about instrument validity, sample size and attrition, study duration, lack of comparison groups, and an inability to control for nested groups.

Instrumentation

In this research, the main (dependent) variables in the study were measured using previously validated instruments, with well-known psychometric properties. However, a number of study variables were operationalized using unvalidated measures. Assessments of a respondent's anger, guilt, self-care, self-rated health status, and satisfaction with hospice were evaluated using a single question and a corresponding ordinal-level response option. These abbreviated measures were adopted for a number of reasons, e.g., to minimize respondent burden and/or known, validated measures were not appropriate for the sample population, or for use with repeated measures. Using a single question to assess complex constructs such as "guilt," "anger," or "health" has limitations. These variables, and the results involving them, should be considered with respect to their questionable reliability and validity.

The QOD-Hospice is an instrument designed to measure quality of dying in hospice settings and was developed for the purposes of this study. The measure was modified from the QOD-LTC (Quality of Dying-Long Term Care), an instrument intended for use when the decedent has died while in the care of a long-term care facility (Munn et al., 2007). Since the majority of hospice patients die at home, the original version of the QOD-LTC was inappropriate for use with this population. The QOD-LTC has withstood limited psychometric testing,

resulting in acceptable assessments of its internal consistency and scalability (Munn et al.). However, aside from basic evaluations of internal consistency and face validity, the psychometric properties of the QOD-Hospice are essentially unknown. Until the instrument undergoes further testing, results pertaining to this measure should be read with caution.

Sample Size and Attrition

This research was also limited by the low numbers of those qualifying for, and participating in, the surveys. The diminished numbers of participants were especially disconcerting in the bereavement portion of the study. This reduction in sample size was due, in part, to a relatively high rate of attrition of 66%. For example, only a small number of long distance caregivers ($n = 8$) completed a post-death questionnaire. The low number of participants at this level likely altered group equivalency and likely compromised the statistical power; thus, increasing the likelihood of error (Garson, 2008; Grimm & Yarnold, 1995; Mertler & Vannatta, 2005). In other words, an insufficient number of participants reduced the effect-size and overall statistical power needed to detect mean differences within- and between-groups (Garson).

Limited Study Duration

Although the inclusion of repeated measures is a strength of this research design, data collection only occurred at two intervals, one week after beginning hospice services and 3 months after the patient's death. Because cancer tends to progress over time, patients often need greater levels of care as death becomes more imminent. Consequently, the needs and emotional state of their caregivers may change in response to the patient's needs as death approaches (Carpentier & Ducharme, 2003). This study does not speak to the changing trajectories of caregivers over the course of the illness.

Bereavement, too, is not a steady state. Feelings of loss and other affective responses tend to fluctuate over time. In general, individuals trend toward improvement over time (Aneshensel, Botticello & Yamamoto-Mitani, 2004), although there is tremendous variation in how individuals adjust to the death of a loved one, and several distinct trajectories have been proposed (e.g., Aneshensel, Botticello & Yamamoto-Mitani). Although the consistent administration of bereavement questionnaires at three months after the death may provide a “snapshot” of post-loss adjustment for the participants in the short term, it does not capture the dynamic changes which may occur over the long term. Several studies suggest that the trajectories of grief are non-linear (Schulz et al., 1999). Similarly, the dual-process model of bereavement suggests that the grief experience vacillates as people adjust to the loss (Stroebe, Hansson, Stroebe & Schut, 2001). And, thus this research is limited in that it cannot detect instances of delayed grief, relapse, affective fluctuations, or graduated improvements over an extended bereavement period.

Lack of Non-Bereaved and Non-Caregiver Comparison Groups

The inclusion of non-bereaved and non-caregiver comparison groups would have strengthened the internal validity of this study’s prospective design (Schulz et al., 1999; Stroebe, Stroebe & Schut, 2003). These comparison groups would have helped further isolate the effects of providing care and experiencing the loss of a loved one. For example, respondents in this study were found to have decreased levels of hope (as measured by the Herth Hope Index) over time. An analysis of repeated measures showed higher levels of hope were reported prior to the death and lower levels of hope were reported after the death. Based on these results, concluding that bereavement contributed to the change in hope is unwarranted (although, certainly possible). However, without adequate comparison groups the influence of confounding variables in this

case cannot be ruled out. Perhaps the decreased levels of hope are more attributable to changing concerns about economic recession (or other global issues that might negatively impact one's outlook on the future) rather than a direct effect of bereavement.

Lack of Control for Nested Variables

Nested groups are groups of cases that have similar characteristics because they are embedded in larger groups. Take, for example, children who are taught by the same 4th grade teacher. The students probably have some similarities simply because they belong to the same class. In this illustration, the students are a group that is nested within the larger group, class. For the purposes of the study at hand, caregivers who come from the same family (or care network) can be considered a nested group. Not only do caregivers from the same family/caregiving network often share similar genetics, upbringing, culture, and socio-economic background, but also they all provided care to the same terminally-ill individual. These similarities, sometimes referred to as "kin-effects," should be accommodated during statistical analysis. However, this type of nested group could not be partialized using the MANCOVA procedure. And the sample size was too small to perform a multilevel regression analysis, which can adjust for nested variables (see the additional research notes in Appendix M). Because of this lack of control, the study data reported here may exhibit a reduction in the overall variance of scores, resulting from similarities of those who are members of the same family/care network. This alteration in variance may affect results; and, therefore should be viewed as a potential source of error and a general study limitation.

Discussion of Findings

Main Analysis: No Support for the Multivariate Model

The multivariate model, which explored changes in social support and psychological adjustment over time and across caregiver groups, was not supported by this study. Changes in the dependent variables (DASS-21 and LSNS-6) were not observed on repeated measures. Nor were differences identified between the three groups of caregivers: co-residing, proximate and long distance. Quality of dying (QOD-Hospice), however, was found to have a between-groups interaction effect on psychological adjustment (as measured by the DASS-21). Further analysis of the QOD-Hospice revealed a negative correlation with levels of emotional grief (TRIG2), and positive correlations with length of stay in hospice, and pre-loss and post-loss levels of social support (LSNS-6).

Caregiver Self-Identification

Previous studies have recognized that informal caregivers do not always label themselves as such (Feinberg, Wolkwitz & Goldstein, 2006; Harding & Higginson, 2001). Manthorpe (2001) expressed similar concerns for those who live far away from the person needing care. She argued that those who provide care and support from a distance are less likely to consider themselves caregivers. Results from this study found that fewer of the long distance caregivers (71%) considered themselves caregivers when compared to their proximate (92%) and co-residing (94%) counterparts. This was despite the fact that all participants were identified by the care recipient (or proxy) as a caregiver. This finding may suggest, as Manthorpe did, that those living further away have a more difficult time recognizing themselves as “caregivers” *per se*.

Length of Stay and Quality of Dying

In this study, quality of dying was significantly correlated with patient length of stay. The longer a patient was under the care of hospice, the better the reported quality of dying. This finding may be indicative of a number of associated factors. This may be due, in part, to the quality of care provided by hospice and a testament to their expertise. Alternately, the relationship may be more connected to characteristics of the illness rather than an indicator of the overall quality of care (Carr, 2003). An extended illness prior to death gives caregivers a chance to learn about the patient's care preferences, mobilize resources, initiate advanced planning (care, funeral, estate, etc.), and emotionally prepare themselves for loss (i.e., anticipatory grief). Thus, a more anticipated death may give patients and caregivers more time to attend to the tasks involved in achieving a "good death." As Carr (2003) puts it "anticipated deaths (such as deaths due to cancer) provide the dying person the time to accept their condition and to discuss their death with others, yet these deaths often bring pain and burdensome caregiving demands" (p. 225). This may also lend additional evidence to support those who have called for earlier referrals to hospice (Miceli & Mylod, 2003; Rabow, Hauser & Adams, 2004; Teno et al., 2007), a concern which was also noted in the qualitative findings.

Quality of Dying and Emotional Grief

In this sample, quality of dying was negatively correlated with emotional grief. As a respondent's perceptions about the quality of dying improved, levels of emotional grief declined. Caregivers who believed their loved one had a "good death" were less adversely affected by the loss. This may suggest the quality of a death has a direct impact on the severity of a survivor's grief. Although, equally plausible is the notion that one's level of grief could influence their recollections about the quality of the dying and death. This finding may have important

implications for end-of-life care and bereavement support, although further investigation is certainly warranted.

Hope Declined in Bereavement

Hope is an important aspect of coping with life-threatening illness and eventual loss (Cutcliffe, 1998; Parker-Oliver, 2002). When all caregiver groups in this study were combined, respondents' levels of hope declined after the death. Although scores were significantly different, the overall levels of hope only dropped slightly from an average score of 29 ($SD = 4.3$) pre-death to 27.5 ($SD = 6.2$) post-death. Hope was measured using the Herth Hope Index (HHI), which is a general measure of hope and optimism (Herth, 1992). Since hope can be expressed in a number of ways, and with different meanings associated with it, it is difficult to speculate about this finding. This reduction in hope may suggest that respondents held on to hope that the patient would not die, which could explain why levels of hope were lower post-loss. If this is the case, then how caregivers define hope may be an important factor to consider when caring for patients and families in hospice and palliative care settings (Parker-Oliver). Additionally, these changes in hope may reflect part of a "normal" grief process, by which bereaved respondents are less optimistic about their current situation and future.

Social Support and Quality of Dying

Social support prior to the loss and during bereavement was correlated with quality of dying. Greater levels of social support were linked to improved assessments of the decedent's quality of dying. Social support and feeling connected have been identified in previous studies as a key components of a good death (Singer & Bowman, 2002; Steinhauser et al., 2002; Stewart, Teno, Patrick, & Lynn, 1999). Maintaining social ties, freedom from isolation, and the presence of close friends and family are significant domains of quality dying and death (Stewart et al.).

Items on the QOD-Hospice instrument provided assessments of affective social support, including whether the patient “received affectionate touch,” and had someone with whom they “could share his/her deepest thoughts” (see Appendix D, questions 70-90). This, of course, has important implications for those who are involved in a patient’s care network, perhaps lending evidence to encourage these participants to stay engaged and to continue to maintain social connections (of course, taking into account the expressed needs and preferences of the patient). It may also be beneficial to help ‘others’ know how to be supportive, especially friends, neighbors, and those at a distance.

Gender Differences in Bereavement

Results from this study found gender differences on measures of psychological distress during bereavement. Women reported higher levels of distress compared to men. These differences were not observed prior to the death, lending evidence to suggest a bereavement-specific effect. This is a curious, although not wholly unusual, result. Previous studies have found, that when general gender differences are taken into account (i.e., in the general population women tend to have higher rates of depressive symptoms than men), men are more negatively affected (Stroebe, Stroebe, & Schut, 2001). The relationship between gender and bereavement-related distress, however, is admittedly complex (Stroebe, Stroebe, & Schut). Perhaps the gender differences identified in this study are a result of using an expanded definition of caregiver. This study relied on the patients and proxy informants to identify members of a patient’s care network. Since gender plays a key role in how care responsibilities are delegated among friends, neighbors and family members (Neuharth & Stern, 2000) these findings may reflect the impact of gender inequalities when the larger system of caregivers is taken into consideration. These findings may also suggest the influence of socially constructed (and internalized) expectations

that women place upon themselves when providing care (Parker, Church & Toseland, 2006). However, since non-probability sampling techniques were used, gender-based differences may be influenced by sampling bias. Regardless, these relationships warrant further investigation.

Caregivers and Gender

Previous studies have suggested that gender disparities tend to equalize as geographic distance increases (Baldock, 2000). However, a chi-square analysis of gender and geographic proximity (co-residing, proximate, and long distance) proved non-significant. In this sample, regardless of geographic proximity, roughly two-thirds of respondents were female. This finding, however, may not be reflective of the general caregiver population. Larger studies, such as those conducted by MetLife (2004) and Koerin and Harrigan (2002), used representative sampling techniques and found that, in terms of gender, long distance caregivers had nearly equal proportions of men and women. Future research on caregiving should further explore the relationship between geographic proximity and gender.

Differing Levels of Depression between Co-residing and Long Distance Caregivers

Results found that co-residing caregivers had significantly higher levels of depressive symptoms (DASS depression subscale score $M = 10.3$, $SD = 10.4$) than long distance caregivers ($M = 4.8$, $SD 4.3$) on pre-death measures. This finding might suggest that those who provide in-home care to a person with advanced cancer are more at-risk for depressive symptoms. However, these results may be confounded by group differences other than geographic proximity. This particular analysis could not control for two possibly intervening variables: relationship status and level of care involvement. Since co-residing caregivers were more likely to be a spouse or partner, this may account for differences in symptoms of depression. Additionally, co-residing

caregivers were found to have higher levels of involvement in terms of number of hours, number of IADLs, and a greater share of care.

Financial Concerns

One theme that emerged in the qualitative analysis was a concern about personal finances. A number of participants remarked that their financial stability had been compromised. The exact cause of these economic losses was unclear; however, out-of-pocket expenses for treatment and care and unpaid leave from work were mentioned by respondents. Previous research has also noted that a diagnosis of terminal illness often includes a large financial “price tag,” which only further exacerbates the stressfulness of the situation (Emanuel, Fairclough, Slutsman, & Emanuel, 2000). For example, the seminal study on care at the end of life by SUPPORT investigators (1995) found that caring for a dying person can jeopardize a family’s financial solvency. Even though study participants were well-insured, nearly a third reported losing “most or all of the family savings” (SUPPORT, 1995, p. 1632). Financial crises may be made worse when families are faced with decisions regarding funeral arrangements, burial, and cremation. At present, the average cost of a funeral exceeds \$8,500 (National Funeral Directors Association, 2004). Worry about monetary resources may negatively impact coping during bereavement. For instance, financial stressors have been shown to impede post-loss adjustment, particularly in women (Baarsen & van Groenou, 2001).

Education and Information

Qualitative findings suggest that respondents wanted to be adequately informed and educated. They expressed wanting detailed information about the patient’s condition, care needs, and prognosis. They also indicated a desire to be educated about: (1) what is required of them (i.e., specific care-related tasks), (2) the extent to which care would be required, (3) what

resources are available in the community, and further details related to the diagnosis and prognosis.

Implications for Social Work

Clearly, social work has a strong presence in end-of-life and palliative care. A nationwide survey by Coluzzi et al. (cited in Taylor-Brown & Sormanti, 2004) found that “75% of supportive counseling services for cancer patients at National Cancer Institute-designated cancer centers was provided by social workers” (p 3). Social workers are often recognized as core interdisciplinary team members in hospice, oncology, and palliative care settings. In addition, the vast majority of mental health services in the United States are provided by social workers; and the profession is also a significant provider of bereavement support services (Walsh-Burke, 2000). However, social work in healthcare faces many challenges, including constricted work roles, financial restrictions, and time demands (Davidson & Foster, 1995; Greene, 2000). Given the perceived overlap with nursing, pastoral care, and other professionals in some multidisciplinary settings, social workers need to more clearly articulate and demonstrate their professional roles and contributions to the teams and patients (Davidson & Foster, 1995). Despite these challenges, findings from this study may provide some direction for future social work practice in health care.

Recognizing the Efforts of Long Distance Caregivers

Given the finding that caregivers who live an hour away or more from the care recipient were less likely to self-identify as a caregiver, social workers can help articulate this role. Social workers may benefit long distance caregivers by acknowledging their efforts, and by helping to clarify and legitimize their role. Providing access to publications such as *So Far Away: Twenty Questions for Long-Distance Caregivers* (National Institute on Aging, 2007) or the *Handbook*

for Long-Distance Caregivers (Rosenblatt & Van Steenberg, 2003) may help distant caregivers further define their role, while also letting them know that they are a part of an important and fast growing group of informal care providers.

Those who live out-of-town, but still want to provide care and support to a sick or disabled loved one, may be able to stay engaged through specialized roles (Roff et al, 2007) such as managing finances, offering social/emotional support by phone, and providing respite to local caregivers. In response, social workers can help involve distant caregivers through ongoing contact and proactive care planning (as recommended by Collins et al., 2003; Harrigan & Koerin, 2007; Koerin & Harrigan, 2002; Roff et al, 2007). Social workers should also strive to include long distance caregivers in family meetings. This may be facilitated through use of conference calls or video phone (Demiris, Parker-Oliver, Courtney & Day, 2007; Mickus & Luz, 2002; Roff et al, 2007; Travis et al, 2002). Fostering open communication between service providers and caregivers who live afar may also help improve satisfaction with the care and perceptions of availability (and, thereby addressing another finding of this study). When inclusive family conferences are possible, social workers can discuss care-related responsibilities, current and potential needs, and available resources (Roff et al., 2007). Educating caregivers about what local services and resources are available is another potential avenue for social work intervention. Whether it is meals-on-wheels, legal services, house-keeping services, home health care, or the hiring of a geriatric care manager, social workers should strive to connect out-of-town caregivers with the appropriate service providers.

Social workers may also help to shine the spotlight on the needs of distant caregivers by educating their fellow health care team members (e.g., nurses, aides, physicians, chaplains) and other professionals about this group. As Parker and his colleagues suggest (2002) social workers

can also explore the hidden ‘anguish’ of long distance caregivers. Addressing persistent feelings of inadequacy, irritation, guilt, and frustration, might be an opportunity for social workers to use their clinical expertise to provide counseling and emotional support to those who are geographically separated from their loved ones (Harrigan & Koerin, 2007).

Addressing the Needs of Caregivers

Findings from the qualitative portion of this study suggest that caregivers have a variety of needs. Participants identified a number of specific services and resources with which social workers may be able help. As evidenced by some respondents, caregivers may require assistance with locating someone to help with chores and maintenance around the home. Social workers might be able to meet this need by identifying other members within the patient’s care network who could assist with such tasks, such as a friend, neighbor, or hospice volunteer. Some caregivers may need a list of geriatric care managers or private-hire caregivers within the care recipient’s community. Still others may need help coordinating time off from work or assistance accessing benefits (e.g., leave from work) from the Family Medical Leave Act. Social workers can educate individuals about what employment-related benefits may be available, and facilitate the application process. Social workers should also bear in mind that caregivers may not want to be perceived as a burden and, thus, may be reluctant to request help.

Quality of Dying and Death

Several key findings in this study involved quality of dying. It was negatively correlated with levels of emotional grief; and positively correlated with social support. In addition, perceptions about a decedent’s quality of dying were found to have an interaction effect between caregiver groups on measures of psychological distress. Social workers in hospice, palliative care, oncology, and other end-of-life care settings can play an active role in facilitating a “good

death” for their terminally ill clients. Quality of dying may be improved by (1) helping to complete advance directives, (2) assisting with funeral planning, (3) preserving the patient’s dignity and worth, (4) building trust and rapport with family members, (5) creating an open atmosphere to communicate about issues of death and dying, (6) working toward acceptance of death, (7) educating the patient and family about the illness and what to expect, and (8) relaying information about a patient’s care needs to the appropriate team members. Additionally, since findings from this study seem to support previous research that there is a positive relationship between social support quality of dying, social workers may encourage social engagement and the maintenance of close relationships - if desired by the patient.

Sacrifices - Financial Concerns

In response to the financial concerns identified in the qualitative analysis, social workers can help families by evaluating sources of real or in-kind support within the family/caregiving network. This may also include help applying for assistance and locating resources. Additionally, social workers can pursue macro-level changes and advocate for additional support for informal caregivers from government entities, perhaps via tax credits, expanding the Family Medical Leave Act (FMLA) benefits, and/or expanding Medicaid reimbursement for caregivers. Moreover, mental health services should include more funding and support for dying persons and their families (Bern-Klug, 2004). Rabow, Hauser and Adams (2004) remarked that, as it stands government assistance for family caregiving is lacking. In only a few states does Medicaid provide reimbursement to family caregivers. Plus, the FMLA only allows family members to take unpaid leave. These authors call for new legislation to “improve and integrate caregiver policy” (Rabow, Hauser, & Adams, p. 489).

Educating Families

Evidence from the qualitative portion of the study suggests that caregivers could be better educated about their role, available resources, and their care recipient's diagnosis and prognosis. Providing accurate and reliable information in end-of-life settings fosters empowerment and self-determination (Bern-Klug, 2004; Lee, 1996). Some evidence suggests that social workers may feel ill-equipped to provide education about end-of-life topics (Christ & Sormanti; Csikai & Bass; Kovacs & Bronstein, 1999). However, Cagle & Kovacs (in press) describe education as a complex but critical intervention for social workers who encounter families that are dealing with a life-threatening illness.

Reframing Hope

In this study, participants' level of hope was lower after the death. This may have ramifications for care at the end of life and bereavement support. However, hope is a very complex social construct, one which can take on a variety of meanings. At the end of life, some caregivers and patients may understand hope to mean hope for: a cure, survival, dignity, spiritual growth, enhanced relationships, and comfort (Parker-Oliver, 2002; Sullivan, 2003). Remaining optimistic during times of adversity can be a very powerful and beneficial coping strategy (Parker-Oliver). With a life-threatening diagnosis such as cancer, if respondents view hope as "hope for a cure" or "hope for survival," then the patient's death could be a devastating blow to those expectations. A scenario like this might create some cognitive dissonance or demand a re-evaluation of one's outlook on the world. In short the death would directly challenge one's sense of hopefulness.

In end-of-life settings, social workers can proactively work to reframe hope as opportunities for personal and spiritual growth, dignity, and comfort in the patient's remaining

days (Bern-Klug, 2004; Parker-Oliver, 2002). This may involve helping family members come to terms with a more reasonable and reachable goal, one of hoping for a death with quality, comfort and perhaps some resolution and important family time. According to Parker-Oliver, the redefinition of hope involves a transition from focusing on disease outcomes to concerns about quality. If the death has already occurred, hope and hopefulness may remain important aspects of coping with loss. According to Cutcliffe (1998) hope is clearly connected to positive bereavement outcomes; and, thus, is a prime target for therapeutic counseling and intervention. Although the best way to foster hope with bereaved persons requires further research.

Implications for Hospice and Palliative Care

The National Hospice and Palliative Care Organization (2004) has called for research to explore: (1) the experiences informal caregivers of dying persons, (2) how pre-death interventions affect outcomes during bereavement, and (3) the influence of hospice care on bereavement outcomes (p. 491). Findings from this research may help address some of these priority areas for hospice research. Results suggest a number of implications for hospice and palliative care providers, including improving the timeliness of referrals, further attention to quality of dying, and efforts to reach out to long distance caregivers. Furthermore, in hospice and other palliative care settings, comprehensive bereavement support should begin as soon as a patient is referred to the organization (Aranda & Milne, 2000). Evidence from this study (particularly regarding length of stay) suggests that timing is important; and that pre-death interventions to enhance a patient's quality of dying may have significant ramifications for how survivors experience bereavement.

Timely Referrals to Hospice

In 2006 the average length of stay in hospice was 61.25 days and the median length of stay was 20.81 days (Hospice Foundation of America, 2007). Findings from this study suggest that earlier referrals to hospice may contribute to an enhanced quality of dying, which may in turn facilitate beneficial bereavement outcomes. A positive correlation was found between quality of dying and number of days under hospice care (i.e., the length of stay) while a negative correlation was discovered between quality of dying and level of emotional grief. Hospice experts have acknowledged that it is difficult to provide good care when actively dying patients are referred to hospice agencies at the last minute (Teno et al., 2007). Shorter lengths of stay have been associated with fewer services (Schockett, Teno, Miller, & Stuart, 2005) and decreased satisfaction as reported by family members (Rickerson et al., 2005). Others have found links between perceptions about the timing of a referral to hospice (whether it is viewed as “too late” or not) and family satisfaction (Miceli & Mylod, 2003; Teno et al., 2007) as well as quality of death (Carr, 2003). According to Miceli and Mylod (2003):

When a referral is not made until the patient is actively dying, then the hospice team is thrown into the more acute aspects of care without the benefit of having already developed a relationship with the patient and family. Similarly, family members may have a more difficult time assisting in the care of their loved one if their first experience doing so occurs during the more active phase of dying (p. 370).

Findings also suggest implications for informal caregivers. Caregivers, both near and far, have contributions to make and needs for information to help them fulfill their roles. This, along with needing time to engage in the anticipatory planning and grief work, may not be manageable when the referral comes so close to the end of life. With late referrals, hospice team members

may have to prioritize their time and provide brief, targeted interventions. In these instances team members may not have the opportunity to establish rapport or to develop a comprehensive care plan to address the physical, emotional, social, and perhaps spiritual needs of the patient and caregivers. Further, short hospice admissions and deaths that are perceived as sudden by survivors may warrant specialized interventions during bereavement (Carr, 2003).

Attention to Quality of Dying

At its heart, the goal of hospice is to enhance the quality of dying and death of terminally ill persons. The National Hospice and Palliative Care Organization (2006) describes hospice as “the model for quality, compassionate care for people facing a life-limiting illness or injury” (NHPCO, 2006). With their knowledge and expertise on providing support and comfort care to persons dealing with end of life, hospice is in a prime position to help facilitate a positive (or high-quality) dying experience. Team members may further enhance a patient’s quality of dying by facilitating conversations about end-of-life preferences, advance planning, and any need to resolve “unfinished” business. Given the prevalence of late hospice referrals and short lengths of stay, these issues are probably best addressed sooner rather than later.

Involving Long Distance Caregivers

Long distance caregivers in this study reported lower levels of satisfaction with hospice care and availability than their local counterparts. Individuals who provide care from a distance may not be able to readily meet face-to-face with hospice team members and other health care providers. In these cases, a phone conference could help bridge the communication gap, allowing the out-of-town caregiver a chance to participate in team meetings or decision-making forums (Travis et al, 2002). Satisfaction levels may also be improved by giving those who live further away a more active role in proactive care planning and crisis prevention (e.g., Parker et al.,

2002). Additionally, the incorporation of new technology such as videophones or web-based forums may prove useful in facilitating communication with, and accessibility to, hospice team members (Demiris, Parker-Oliver, Courtney & Day, 2007).

Contribution to Theory

This research relied on a myriad of theories, models, and perspectives to help funnel down the complexities involved in caregiving and coping with loss. Although this research did not attempt to test a particular theory or model, the main analysis was constructed with the stress and coping model in mind (e.g., Lazarus & Folkman, 1984). Schultz and his colleagues (1997) advanced an integrative model for understanding the transition from caregiving to bereavement. In particular, the prospective nature of this design could have provided evidence toward either the “relief hypothesis” or the “depletion hypothesis.” However, because the main analysis proved non-significant for any main effects, this does not lend support to either of the rival hypotheses. Nevertheless, findings may have highlighted the importance quality of dying as an important factor to consider in future conceptualizations regarding the transition from caregiver to bereavement. As Schulz and his colleagues (1997) note comprehensive theories of bereavement must include considerations for how the “dynamics of caregiving of prior to death” impact outcomes during bereavement (p. 269). Given the findings of this study, the quality of a care recipient’s final days may be an important aspect to consider when attempting to explain or predict bereavement trajectories.

Future Research

Further research is needed for a more nuanced investigation of how the caregiving experience impacts bereavement. Particularly needed is the ability to identify those who are at risk for complicated bereavement adjustment (Kelly et al., 1999). Since most individuals tend to

be resilient and can cope with a loss without expert help (Center for the Advancement of Health, 2003; Jordan & Niemeyer, 2003), it is important to be able to determine those who need help and to systematically examine what types of post-death support are most beneficial.

Even though most bereaved persons tend to recuperate after a loss, a number of negative outcomes are associated with bereavement, including persistent depression, ill health, and increased mortality risk (Bondar & Kiecolt-Glaser, 1994; Kelly et al., 1999; Kurtz et al., 1997; Rodinson-Whelan et al., 2001; Schulz & Beach, 1999; Wyatt et al., 1997). The pathways that contribute to these risks, and interventions that effectively address them, are limited. Future research should attempt to resolve these unknowns. The goal should be to predict these risk factors and to provide proactive, preventative interventions to mitigate their effects. Few studies have considered how the physical, social, and psychological impacts of providing care to a loved-one subsequently affects how survivors cope during bereavement (Schultz et al., 1997).

Further Validation of the QOD-Hospice

Previous scholars and experts on care at the end of life have recognized a need for instruments that can assess a patient's quality of dying and death (Fowler, Coppola, & Teno, 1999; Steinhauser, 2000). Monitoring the quality of dying in hospice can facilitate quality improvement, adjustments to standard practices, and targeted interventions. Since a large number of dying patients are unable to complete questionnaires themselves, proxy-report measures are a necessary alternative (Fowler, Coppola, & Teno). Future research on the reliability and validity of the QOD-Hospice could contribute to a more accurate evaluation of the factors which influence quality at the end of life. This could involve exploring correspondence among members of the same care network (inter-rater reliability) or assessing the instrument's sensitivity and stability over time (test-retest reliability) (i.e., do perceptions about quality of

dying change later into bereavement?), and factor analysis. Additionally, since expectations about care at life's end are strongly influenced by a person's cultural background (Bonanno & Kaltman, 1999; Field & Cassel, 1997; Stroebe, Hansson, Stroebe & Schut, 2001), the QOD-Hospice should be validated among a variety of culturally and ethnically diverse populations.

Relationship Quality

While this study did consider how relationship status (e.g., whether the care recipient was a partner, sibling or parent) influenced bereavement outcomes, it did not, however, explore the *quality* of the patient-caregiver relationship. Future research should take into account the nature of a caregiver's relationship with the care recipient and others involved within the care-network. The unique dynamics of the relationship, whether emotionally close, enmeshed, strained, indifferent or estranged (for example), likely impacts how survivors adjust after the death (Given et al., 1988)

Caregiving Networks

Using a patient-centered approach to identify caregivers, in this study 104 patients identified 253 caregivers. So, on average, patients were being cared for by two to three individuals, rather than by a single "primary" care provider. Additionally, nearly a quarter of the caregivers who participated in this study met the criteria to be considered long distance caregivers. The contributions, needs, and experiences of this "hidden" group deserves more attention. It has been suggested that the number of long distance caregivers in the United States will reach 14 million by 2020 (National Council on Aging, 2006), yet little remains known about this fast-growing population. Previous studies on long distance caregiving have involved largely White, affluent, and highly educated subjects (the exception being the NAC & AARP surveys). Future research should strive to include more diverse populations, in terms of race/ethnicity,

educational background, and socio-economic status. The latter is particularly crucial since the ability to negotiate long distances is tied to financial status.

In short, future research may gain a more accurate understanding of how informal care is provided by adopting a broader and more inclusive view of who is considered a “caregiver.” Furthermore, future research may benefit from in-depth investigations of caregiving networks, their transformations over the duration of an illness, their dynamics and idiosyncrasies.

Defining Long Distance Caregivers

There is a debate in the literature regarding how to define long distance caregivers as a group (see Chapter 1 page 12 for a more developed discussion of this topic). I argue that for groups of long distance caregivers, using mean-based measures of distance (whether quantified by mileage or travel time) in an attempt to describe the “typical” long distance caregiver only tells part of the story. By definition, long distance caregivers are characterized by living far from their care recipient. Thus, regardless of how researchers might operationalize geographic distance, extreme values (i.e., statistical outliers) are expected for long distance caregivers. And, as a measure of central tendency, the mean is strongly influenced by outlying values. Thus, using mean-based statistics to describe this group of individuals is ill-advised.

The Impact of Quality of Death and Dying on Bereavement Outcomes

In general, quality of dying and death encompasses: freedom from pain and suffering, acceptance of one’s impending death, care preferences that are clearly identified and honored, maintenance of intimate social ties, preservation of a person’s dignity and worth, and the comfort of not feeling like a burden on others (Emanuel & Emanuel, 1998; Singer et al., 1999; Steinhauer et al., 2000). However, little attention has been paid to how bereavement outcomes are impacted by perceptions about quality of dying and death. In fact, Carr (2003) wrote “I know

of no study that systematically examines linkages between death quality and psychological distress of recently bereaved older adults” (p. 216). Enhancing care at the end-of-life may not only benefit dying patients, but the surviving caregivers as well (Carr, 2003). Further research can explore this relationship in greater depth. If this apparent link between quality of dying and death and bereavement outcomes is substantiated by further research, a number of additional research questions should be explored. For instance: What aspects of quality of dying are the best predictors of bereavement outcomes? Which post-loss outcomes are most affected? Do changes in quality of dying influence bereavement-related health risks, including mortality risk? And, is the risk of complicated grief reduced by improvements in quality of dying?

Conclusion

The transition from caregiver to bereaved is a complex process, and despite some innovative research in this area, much remains unknown. This study used a prospective design to investigate the experiences of informal caregivers of advanced cancer patients; and in particular, to explore how a caregiver’s geographic proximity impacted their social support and bereavement adjustment. Results of a repeated measures MANCOVA procedure did not support the proposed multivariate model. However, quality of dying (as measured by the QOD-Hospice) was identified as an influential between-groups covariate within the model. Further exploration of the QOD-Hospice revealed a negative correlation with levels of emotional grief, and positive correlations with length of stay in hospice, and pre-loss and post-loss levels of social support. These results suggest that timely referrals to hospice, improvements in care for the dying, and increased attention to quality of dying, may have a beneficial impact for survivors during bereavement. Furthermore, findings from this study suggest, as Carr (2003) did, that the quality of a person’s final days may play an important role in how the surviving caregivers adjust to the

loss. Not only can high quality end-of-life care benefit dying patients, but it may also facilitate bereavement adjustment for those who participated in their care network. However, findings were limited and further investigation of these relationships is warranted.

At the end of the 20th century, several prominent studies concluded that the state of end-of-life care in America was inadequate (Field & Cassel, 1997; SUPPORT Principal Investigators, 1995). These and similar findings led to a nationwide call to enhance the quality of care for dying persons (Last Acts, 2002; Project on Death in America, 2004). To answer these clarion calls, researchers, scholars and practitioners have endorsed a multi-focal campaign targeting various levels of change, ranging from individual attitudes and behaviors to professional education and policy (Byock, Norris, Curtis & Patrick, 2001; Field & Cassel, 1997; Virani & Sofer, 2003). A primary goal of this campaign focuses on supporting informal caregivers prior to a patient's death, as well as into bereavement (Last Acts; Project on Death in America).

Both research and practitioners have begun to recognize that when a serious illness occurs within a family system, a network of care providers is often mobilized to address the needs of the care recipient. Modern care networks often consist of both formal and informal caregivers (Barker, 2002; Emanuel et al., 1999). Many times concerned family members as well as un-related persons (neighbors, friends, community members, etc.), whether living nearby or far away, work together to negotiate care-related responsibilities (Barker; Emanuel et al.). The contributions of those living at a distance, and the dynamics of their involvement, are just beginning to be understood. The body of scholarship on long distance caregivers is still emerging. Researchers should continue to strive to identify the needs of this group and to tailor appropriate interventions to address those needs. But, equally important, is the need to recognize

these “invisible” caregivers, acknowledge their efforts, and hear their stories. As Thompsell and Lovestone (2002) remind us, “we should learn not to forget those living further away” (p. 806).

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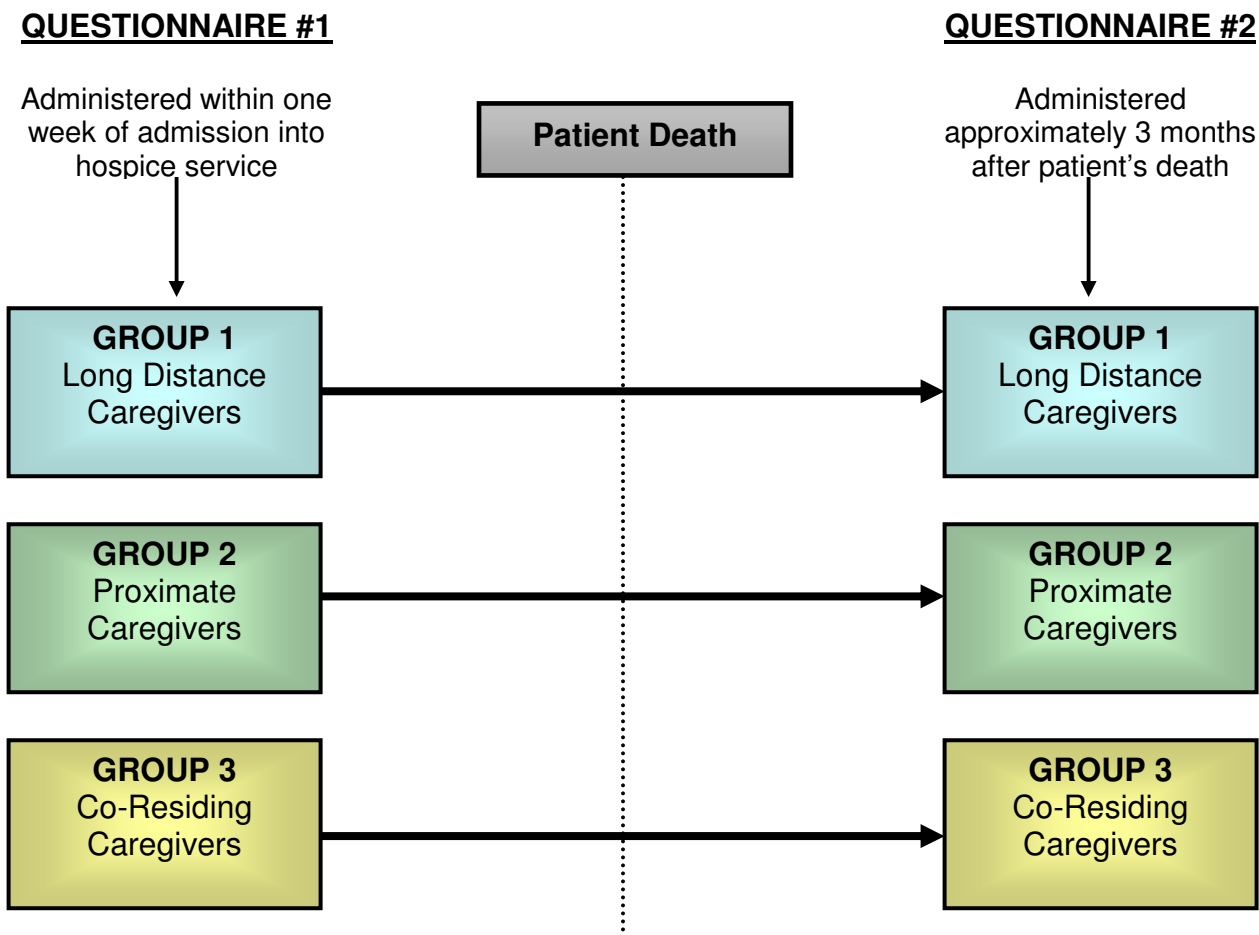
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Appendix A.

STUDY DESIGN



Appendix B.

Palliative Performance Scale (PPSv2)

PPS Level	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
90%	Full	Normal Activity Some Evidence of Disease	Full	Normal	Full
80%	Full	Normal Activity with Effort Some Evidence of Disease	Full	Normal or Reduced	Full
70%	Reduced	Unable Normal Job / Work Some Evidence of Disease	Full	Normal or Reduced	Full
60%	Reduced	Unable Hobby / House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance Necessary	Normal or Reduced	Full or Confusion
40%	Mainly in Bed	Unable to Do Most Activity Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to Do Most Activity Extensive Disease	Total Care	Normal or Reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to Do Most Activity Extensive Disease	Total Care	Minimal to Sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to Do Most Activity Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

(Anderson et al., 1996)

Appendix C.

Caregivers of Cancer Patients

A Research Survey



Part 1 of 2

John G. Cagle, Ph.D. candidate
 c/o Virginia Commonwealth University
 School of Social Work
 P.O. Box 842027
 Richmond, VA 23284-2027



Web-Based Survey Option:

If you would prefer to complete the survey online,
 please log on to:

<http://survey.vcu.edu/cgi-bin/qwebcorporate.dll?idx=WEN98K>

and enter the log in code:

Q1233

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**FLORIDA STATE
 UNIVERSITY**

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A. INSTRUCTIONS: This survey is designed for persons who have a loved one that has been diagnosed with cancer and is currently under hospice care. For the first two questions, please place a check mark next to the most appropriate response.

1. Do you have a loved one who has been diagnosed with some form of cancer (including leukemia or other blood-borne cancer)?

Yes No →

If "NO," you are finished with the survey. Please return it using the envelope provided. Thank you.

↓

IF "YES," PLEASE CONTINUE

2. Is the individual with cancer currently under hospice care?

Yes No →

If "NO," you are finished with the survey. Please return it using the envelope provided. Thank you.

↓

IF "YES," PLEASE CONTINUE

B. INSTRUCTIONS: For the next few questions, please check the appropriate response(s)

3. Do you consider yourself a caregiver for the person with cancer?

Yes

No

4. Over the past 30 days, which of the following Activities of Daily Living (ADLs) have you helped your loved one with? (check all that apply)

- Getting in and out of beds and chairs
- Getting dressed
- Getting to and from the toilet
- Bathing or showering
- Dealing with incontinence or diapers
- Feeding
- Managing medicines, pills, injections

5. Over the past 30 days, which of the following Instrumental Activities of Daily Living (IADLs) have you helped your loved one with? (check all that apply)

- Managing finances
- Grocery shopping
- Housework
- Preparing meals
- Transportation
- Arranging or supervising services

C. INSTRUCTIONS: For the next questions, please write the appropriate number in the space provided.

6. In the past 30 days, about how many hours have you devoted to providing care and/or support for your loved one?

_____hours

7. In total, how far away do you live from the patient? (write "0" if you live with the patient)

_____miles

8. In total, how long does it typically take you to travel to the patient's residence? (write "0" if you live with the patient)

_____hours

WHO-5 Well-Being Questionnaire

D. INSTRUCTIONS: For each of the following five statements, please circle the number which is closest to how you have been feeling over the last two weeks. Notice that higher numbers mean better well-being.

	At No Time	Some of the Time	Less than half the Time	More than half the Time	Most of the Time	All the Time
<i>Over the last two weeks...</i>						
9. I have felt cheerful and in good spirits	0	1	2	3	4	5
10. I have felt calm and relaxed	0	1	2	3	4	5
11. I have felt active and vigorous	0	1	2	3	4	5
12. I woke up feeling fresh and rested	0	1	2	3	4	5
13. My daily life has been filled with things that interest me	0	1	2	3	4	5

E. INSTRUCTIONS: For the next three questions, please place a *check in the space provided or circle the number* that indicates the most appropriate response.

14. Over the past seven days, which of the following self-care activities have you done?

- Exercise
 Ate healthily
 Socialized with friends or family
 Slept adequately
 Took personal time (to do something you like to do)
 Meditated or Prayed
 Other (please specify) _____

15. How would you rate your self-care?

0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10
 Extremely Poor Fair/OK Excellent

16. How would you rate your current health?

0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10
 Extremely Poor Fair/OK Excellent

Lubben Social Network Scale – 6

F. INSTRUCTIONS: Please read each of the following questions and circle the number that best reflects your answer.

FAMILY: Considering the people to whom you are related either by birth or marriage...

17. How many relatives do you see or hear from at least once a month?

0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

18. How many relatives do you feel at ease with that you can talk about private matters?

0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

19. How many relatives do you feel close to such that you could call on them for help?

0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

FRIENDSHIPS: Considering all of your friends including those who live in your neighborhood....

20. How many of your friends do you see or hear from at least once a month?

0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

21. How many friends do you feel at ease with that you can talk about private matters?

0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

22. How many friends do you feel close to such that you could call on them for help?

0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

DASS-21

G. INSTRUCTIONS: Please read each statement and *circle a number 0, 1, 2 or 3* which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

	Did Not Apply to Me At All	Applied to Me Some of the Time	Applied to Me a Good Part of the Time	Applied to Most of the Time
23. I found it hard to wind down	0	1	2	3
24. I was aware of dryness of my mouth	0	1	2	3
25. I couldn't seem to experience any positive feeling at all	0	1	2	3
26. I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
27. I found it difficult to work up the initiative to do things	0	1	2	3
28. I tended to over-react to situations	0	1	2	3
29. I experienced trembling (e.g., in the hands)	0	1	2	3
30. I felt that I was using a lot of nervous energy	0	1	2	3
31. I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
32. I felt that I had nothing to look forward to	0	1	2	3
33. I found myself getting agitated	0	1	2	3
34. I found it difficult to relax	0	1	2	3
35. I felt down-hearted and blue	0	1	2	3
36. I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3

	Did Not Apply to Me At All	Applied to Me Some of the Time	Applied to Me a Good Part of the Time	Applied to Most of the Time
37. I felt I was close to panic	0	1	2	3
38. I was unable to become enthusiastic about anything	0	1	2	3
39. I felt I wasn't worth much as a person	0	1	2	3
40. I felt that I was rather touchy	0	1	2	3
41. I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
42. I felt scared without any good reason	0	1	2	3
43. I felt that life was meaningless	0	1	2	3

H. INSTRUCTIONS: For the next four questions, please *circle the number* that indicates the most appropriate response.

44. How satisfied/dissatisfied are you with the information you have received from the hospice staff members regarding your loved one's care?

1. Very Dissatisfied 2. Dissatisfied 3. Neither Satisfied Nor Dissatisfied 4. Satisfied 5. Very Satisfied

45. How satisfied/dissatisfied are you with the availability of the hospice staff members providing care to your loved one?

1. Very Dissatisfied 2. Dissatisfied 3. Neither Satisfied Nor Dissatisfied 4. Satisfied 5. Very Satisfied

46. Overall, how satisfied/dissatisfied are you with the care being provided by hospice?

1. Very Dissatisfied 2. Dissatisfied 3. Neither Satisfied Nor Dissatisfied 4. Satisfied 5. Very Satisfied

Herth Hope Index

I. INSTRUCTIONS: Listed below are a number of statements. Please read each statement and *circle the number* that describes how much you agree with that statement *right now*.

	Strongly Disagree	Disagree	Agree	Strongly Agree
47. I have a positive out look toward life	0	1	2	3
48. I have short and/or long range goals	0	1	2	3
49. I feel all alone	0	1	2	3
50. I can see possibilities in the midst of difficulties	0	1	2	3
51. I have a faith that gives me comfort	0	1	2	3
52. I feel scared about my future	0	1	2	3
53. I can recall happy/joyful times	0	1	2	3
54. I have deep inner strength	0	1	2	3
55. I am able to give and receive caring/love	0	1	2	3
56. I have a sense of direction	0	1	2	3
57. I believe that each day has potential	0	1	2	3
58. I feel my life has value and worth	0	1	2	3

J. INSTRUCTIONS: We are interested in how you feel about the following statements. Read each statement carefully. Please *circle the number* that best reflects your level of agreement with each statement.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
59. Lately I have been feeling guilty	1	2	3	4	5
60. Lately I have been feeling angry	1	2	3	4	5

The Informal Care Network

K. INSTRUCTIONS: This section gives us a general overview of the family, friends, and acquaintances involved in the patient's care. There are four parts, please respond to each.

61. In column A, insert the initials of each family member, friend, or acquaintance involved in the care of your loved one. Please do not include hired professionals. If there are more than six persons, please list the ones you feel are *most* involved.

62. In column B, indicate your relationship with the person listed in column A. For example, if the person is your sister, write "sister." If the person is a friend, write "friend."

63. In column C, use a scale from 0-10 to describe how involved the person is in providing care. A "0" indicates "not involved at all," a "10" means "as involved as humanly possible."

64. In column D, use a scale from 0-10 to describe how well you get along with the person in column A. Zero means "not at all," a 10 indicates "extremely well."

A B C D

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.

EXAMPLE:

	A	B	C	D
1.	L. S.	Sister	8	7
2.	R. T.	Friend	4	9

L. INSTRUCTIONS: The following questions will be used to help describe the demographic characteristics of our survey sample. Please *place a check mark* next to the most appropriate response or *write in* your answer.

65. What is your birth month and year? (month/year)

____/____

66. What is your gender?

____ Male ____ Female

67. About how often do you get to see/visit your loved one? (check one)

- ____ Every day
 ____ Once a week
 ____ Once or twice a month
 ____ Every few months
 ____ Once a year
 ____ Less than once a year

68. Are you currently taking any medications, prescribed or over-the-counter, to help with any of the following conditions? (check all that apply)

- ____ Trouble sleeping
 ____ Blood pressure
 ____ Depression
 ____ Anxiety/panic attacks
 ____ Stress

69. What is your race/ethnic group?

- ____ African-American/Black
 ____ Latino/Hispanic-American
 ____ Asian-American/Pacific Islander
 ____ Native-American/Alaskan Native
 ____ Euro-American/White
 ____ Bi-racial/Multi-racial
 ____ Other (please specify)_____

M. INSTRUCTIONS: The following questions will be used to help describe the demographic characteristics of our survey sample. Please *place a check mark* next to the most appropriate response or *write in* your answer.

70. What is your relationship to the patient?

The patient is my.....

Spouse/Partner

Child

Parent

Sibling

Some Other Relative

Friend

Other (please specify)_____

71. Which of the following best describes your annual household income from all sources? (select one response.)

Less than \$10,000

\$10,000 to less than \$15,000

\$15,000 to less than \$20,000

\$20,000 to less than \$25,000

\$25,000 to less than \$35,000

\$35,000 to less than \$50,000

\$50,000 to \$75,000

Over \$75,000

72. What is your highest level of education?

Elementary/middle school

Some high school

High school diploma or GED

Some college

College degree

Some graduate school

Graduate school degree

73. What best describes your employment status?

Full time

Part time

Unemployed

Retired

Student

Other (please specify)_____

N. INSTRUCTIONS: For this question, please *use the space provided* to make your comments. Your remarks will be read and taken into account.

74. Please use the space below to make any additional comments about how you could have been better prepared/supported during the care of your loved one. If you need additional space for your comments, please feel free to use the back page.

Thank you for taking the time to complete our survey. Your contribution is greatly appreciated. Please place the completed survey in the envelope provided and return it by mail.

Again, Thank You!

Appendix D.

Caregivers of Cancer Patients

A Research Survey



John G. Cagle, Ph.D. candidate
 c/o Virginia Commonwealth University
 School of Social Work
 P.O. Box 842027
 Richmond, VA 23284-2027



Web-Based Survey Option:

If you would prefer to complete the survey online,
 please log on to:

<https://survey.vcu.edu/cgi-bin/qwebcorporate.dll?idx=HYSBZE>
 and enter the log in code:

Q2041

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 HOSPICE
 A Special Kind of Care

Hello. This is the final questionnaire in a study help us better understand caregiver support and bereavement adjustment. Please answer all questions. If you wish to comment about a particular question, you are welcome to use the margins.

WHO-5 Well-Being Questionnaire

A. INSTRUCTIONS: Please indicate for each of the following five statements, which is closest to how you have been feeling *over the last two weeks*. Notice that higher numbers mean better well-being. Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, circle the number 3 in the upper right corner.

	At No Time	Some of the Time	Less than half the Time	More than half the Time	Most of the Time	All the Time
<i>Over the last two weeks...</i>						
1. I have felt cheerful and in good spirits	0	1	2	3	4	5
2. I have felt calm and relaxed	0	1	2	3	4	5
3. I have felt active and vigorous	0	1	2	3	4	5
4. I woke up feeling fresh and rested	0	1	2	3	4	5
5. My daily life has been filled with things that interest me	0	1	2	3	4	5

B. INSTRUCTIONS: For the two next questions, please *check the appropriate response(s)*

6. Overall, what share of the patient's care were you responsible for?
- Nearly 100%
- A large majority
- About half
- A small share
- Almost none
7. Are you currently taking any medications, prescribed or over-the-counter, to help with any of the following conditions? (check all that apply)
- Trouble sleeping/insomnia
- Blood pressure
- Depression
- Anxiety/panic attacks
- Stress

Texas Revised Inventory of Grief (Part 2) – Present Emotional Feelings

C. INSTRUCTIONS: Please *circle the number* which indicates how you presently feel about your loved one's death.

	Completely False	Mostly False	Both True and False	Mostly True	Completely True
8. I still cry when I think of the person who died.	1	2	3	4	5
9. I still get upset when I think about the person who died.	1	2	3	4	5
10. I cannot accept this person's death.	1	2	3	4	5
11. Sometimes I very much miss the person who died.	1	2	3	4	5
12. Even now it's painful to recall memories of the person who died.	1	2	3	4	5
13. I am preoccupied with thoughts (often think) about the person who died.	1	2	3	4	5
14. I hide my tears when I think about the person who died.	1	2	3	4	5
15. No one will ever take the place in my life of the person who died.	1	2	3	4	5
16. I can't avoid thinking about the person who died	1	2	3	4	5
17. I feel it's unfair that this person died.	1	2	3	4	5
18. Things and people around me still remind me of the person who died.	1	2	3	4	5
19. I am unable to accept the death of the person who died.	1	2	3	4	5
20. At times I still feel the need to cry for the person who died.	1	2	3	4	5

Lubben Social Network Scale – 6

D. INSTRUCTIONS: Please read each of the following questions and *circle the number that best reflects your answer.*

FAMILY: Considering the people to whom you are related either by birth or marriage...

21. How many relatives do you see or hear from at least once a month?

0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

22. How many relatives do you feel at ease with that you can talk about private matters?

0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

23. How many relatives do you feel close to such that you could call on them for help?

0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

FRIENDSHIPS: Considering all of your friends including those who live in your neighborhood....

24. How many of your friends do you see or hear from at least once a month?

0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

25. How many friends do you feel at ease with that you can talk about private matters?

0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

26. How many friends do you feel close to such that you could call on them for help?

0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

DASS-21

E. INSTRUCTIONS: Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

	Did Not Apply to Me At All	Applied to Me Some of the Time	Applied to Me a Good Part of the Time	Applied to Most of the Time
27. I found it hard to wind down	0	1	2	3
28. I was aware of dryness of my mouth	0	1	2	3
29. I couldn't seem to experience any positive feeling at all	0	1	2	3
30. I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
31. I found it difficult to work up the initiative to do things	0	1	2	3
32. I tended to over-react to situations	0	1	2	3
33. I experienced trembling (e.g., in the hands)	0	1	2	3
34. I felt that I was using a lot of nervous energy	0	1	2	3
35. I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
36. I felt that I had nothing to look forward to	0	1	2	3
37. I found myself getting agitated	0	1	2	3
38. I found it difficult to relax	0	1	2	3
39. I felt down-hearted and blue	0	1	2	3
40. I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3

	Did Not Apply to Me At All	Applied to Me Some of the Time	Applied to Me a Good Part of the Time	Applied to Most of the Time
41. I felt I was close to panic	0	1	2	3
42. I was unable to become enthusiastic about anything	0	1	2	3
43. I felt I wasn't worth much as a person	0	1	2	3
44. I felt that I was rather touchy	0	1	2	3
45. I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
46. I felt scared without any good reason	0	1	2	3
47. I felt that life was meaningless	0	1	2	3

F. INSTRUCTIONS: For the next four questions, please *circle the number* that indicates the most appropriate response.

48. How satisfied/dissatisfied are you with the information you have received from the hospice staff members during your loved one's care?

1. Very Dissatisfied 2. Dissatisfied 3. Neither Satisfied Nor Dissatisfied 4. Satisfied 5. Very Satisfied

49. How satisfied/dissatisfied are you with the availability of the hospice staff members during the care of your loved one?

1. Very Dissatisfied 2. Dissatisfied 3. Neither Satisfied Nor Dissatisfied 4. Satisfied 5. Very Satisfied

50. Overall, how satisfied/dissatisfied are you with the care that hospice provided?

1. Very Dissatisfied 2. Dissatisfied 3. Neither Satisfied Nor Dissatisfied 4. Satisfied 5. Very Satisfied

Herth Hope Index

G. INSTRUCTIONS: Listed below are a number of statements. Please read each statement and circle the number that describes how much you agree with that statement *right now*.

	Strongly Disagree	Disagree	Agree	Strongly Agree
51. I have a positive out look toward life	0	1	2	3
52. I have short and/or long range goals	0	1	2	3
53. I feel all alone	0	1	2	3
54. I can see possibilities in the midst of difficulties	0	1	2	3
55. I have a faith that gives me comfort	0	1	2	3
56. I feel scared about my future	0	1	2	3
57. I can recall happy/joyful times	0	1	2	3
58. I have deep inner strength	0	1	2	3
59. I am able to give and receive caring/love	0	1	2	3
60. I have a sense of direction	0	1	2	3
61. I believe that each day has potential	0	1	2	3
62. I feel my life has value and worth	0	1	2	3

H. INSTRUCTIONS: For the next questions, please write the appropriate number(s) in the space provided.

63. In the 90 days before your loved one's death, about how many days were you able to spend with him/her?

_____day(s)

64. What is your birth month and year? (month/year)

_____/_____

I. INSTRUCTIONS: For the next three questions, please *check the appropriate response(s)*

65. Please indicate which of the following you experienced as a result of providing care to your loved one. (check *all* that apply)

- A sense of purpose
 A closer relationship with the patient
 Satisfaction knowing the patient was well cared for
 Personal growth
 A sense of accomplishment
 Increased knowledge
 Increased sense of control
 Feeling like I was 'giving back'

66. In what way(s) did you provide care/support to your loved one? (check *all* that apply).

- Financial support
 Relieved other caregivers
 Direct, hands-on care
 Participated in making health-related decisions
 Emotional support/encouragement
 Informed and educated my loved one about his/her condition
 Other _____

67. Which of the following services and/or equipment helped you provide care/support to the your loved one? (check *all* that apply).

- Computer/Internet
 Mobile Phone
 Meals on Wheels
 Personal vehicle (car, truck, etc.)
 Legal services
 Hire geriatric care manager
 Other _____

K. INSTRUCTIONS: We are interested in how you feel about the following statements. Read each statement carefully. Please *circle the number* that best reflects your level of agreement with each statement.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Over the past week...					
68. ...I have been feeling guilty	1	2	3	4	5
69. ...I have been feeling angry	1	2	3	4	5

QOD-Hospice

INSTRUCTIONS: The following statements have been considered important during the dying process. Thinking back over the last month of your loved one's life, please indicate how true each statement is *by circling the appropriate number – or “DK” if you don't know.*

	Not at all	a little bit	a moderate amount	quite a bit	completely	Don't Know
70. There was a nurse or aide with whom my loved one felt comfortable.	1	2	3	4	5	DK
71. My loved one received affectionate touch daily.	1	2	3	4	5	DK
72. He/she appeared to be at peace.	1	2	3	4	5	DK
73. Members of the hospice team knew him/her as a whole person including life and personality.	1	2	3	4	5	DK
74. My loved one had treatment preferences in writing (either his/her own or by a surrogate decision maker).	1	2	3	4	5	DK
75. My loved one indicated he/she was prepared to die.	1	2	3	4	5	DK
76. His/her funeral was planned	1	2	3	4	5	DK
77. My loved one had named a decision maker in the event he/she was no longer able to make decisions.	1	2	3	4	5	DK
78. My loved one maintained his/her sense of humor.	1	2	3	4	5	DK

	Not at all	a little bit	a moderate amount	quite a bit	completely	Don't Know
79. His/her dignity was maintained.	1	2	3	4	5	DK
80. His/her clothes and body were clean.	1	2	3	4	5	DK
81. My loved one's wishes were met regarding the place of death.	1	2	3	4	5	DK
82. My loved one had treatment preferences in writing.	1	2	3	4	5	DK
83. There was someone from hospice whom he/she trusted.	1	2	3	4	5	DK
84. The hospice staff was comfortable talking about death and dying.	1	2	3	4	5	DK
85. My loved one was free from pain.	1	2	3	4	5	DK
86. My loved one experienced shortness of breath.	1	2	3	4	5	DK
87. His/her wishes were met regarding spiritual support.	1	2	3	4	5	DK
88. His/her wishes were met regarding who was present at the time of death.	1	2	3	4	5	DK
89. My loved one knew what to expect about his/her illness.	1	2	3	4	5	DK
90. There was someone with whom he/she could share his/her deepest thoughts.	1	2	3	4	5	DK

L. INSTRUCTIONS: Please *circle the number* that best reflects your level of agreement with each statement.

91. How would you rate your self-care?

0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10
Extremely Poor Fair/OK Excellent

92. How would you rate your current health?

0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10
Extremely Poor Fair/OK Excellent

M. INSTRUCTIONS: For this final question, please *use the space provided* to make your comments. Your remarks will be read and analyzed for common themes.

93. Please use the space below to make any additional comments about how you could have been better prepared/supported during the care of your loved one. If you need additional space for your comments, please feel free to use the back page.

Thank you for taking the time to complete our survey. Your contribution is greatly appreciated. Please place the completed survey in the envelope provided and return it by mail.

Again, Thank You!

Appendix E.

Patient Hospice Chart Data Collection Form

1. Pain rating upon admission (a patient reported rating on a scale from 0-10, with zero indicating no pain). Please circle.

0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10

2. Length of stay (i.e., number of days under hospice care).

_____days

3. Palliative Performance Score (PPSv2) upon admission

_____ (0-100)

4. Patient's gender (please circle)

Male / Female

5. Primary Diagnosis

6. Patient's location at time of admission

___ Patient's residence

___ Hospital

___ Nursing Facility

___ Assisted Living

___ Other, please specify _____

7. Place of death

___ Patient's residence

___ Hospital

___ Nursing Facility

___ Assisted Living

___ Other, please specify _____

Appendix F.

Thank You Card (Pre-Death)

Last week a questionnaire seeking your opinions about providing care and support to a person with cancer was mailed to you. You were identified as a potential participant in our survey by a family member or friend (or perhaps you referred yourself, in which case – thank you).

If you have already completed and returned the questionnaire to us, please accept our sincere thanks. If not, please do so today. We are especially grateful for your help because it is only by asking people like you to share your experience that we can understand the needs and concerns of those who provide care to persons with cancer.

If you did not receive a questionnaire, or if it was misplaced, please call us toll free at 1-800-541-3072 and we will send you another one by mail today.

John G. Cagle
% Virginia Commonwealth University
School of Social Work
P.O. Box 842027
Richmond, VA 23284-2027

Thank you!
JG

Covenant
HOSPICE
a special kind of caring


GERIATRIC SOCIAL WORK INITIATIVE

 Florida State University

 Virginia Commonwealth University


Appendix G.

Pre-Notification Card

We deeply appreciate your participation in the first part of our caregiver study. Next week, we will be mailing out the final part of our two part survey. This final questionnaire is a bereavement survey. The feedback from this survey will be used to help those coping with similar circumstances.

Filling out a survey after the death of a loved-one can be a difficult task. We want to be sensitive to your needs, so please take your time and return the survey whenever possible. Thank you.

Sincerely,



John G. Cagle
%Virginia Commonwealth University
School of Social Work
P.O. Box 842027
Richmond, VA 23284-2027

Covenant
HOSPICE
a special kind of caring

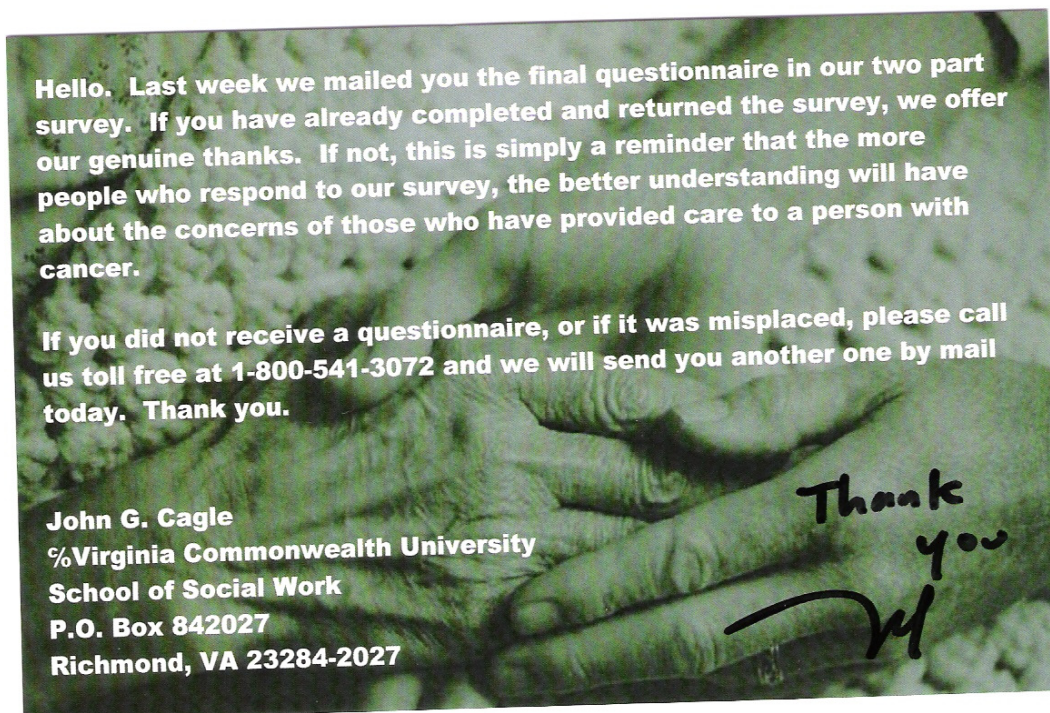

 GERIATRIC SOCIAL WORK INITIATIVE

 Florida State University

 Virginia Commonwealth University

Appendix H

Thank You/Reminder Card



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 GERIATRIC SOCIAL WORK INITIATIVE

 Florida State University

 Virginia Commonwealth University

Consent Form – Patient/Proxy Consent

PURPOSE OF THE STUDY

Thank you for considering our university-based research study on the needs of caregivers of cancer patients.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Please know that your involvement in this research is entirely voluntary. You should not feel pressured to participate, and can withdraw at any time. Whether or not you participate will not affect the care you receive from the social worker or from Covenant Hospice.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

We are requesting that you assist with this research in two ways. First we request your permission to contact you by phone so that you can recommend informal caregivers that you think should participate in this study. Second, we ask that you allow us to record 6 items from your medical chart. These include: (1) pain rating (on a 0-10 scale), (2) number of days under hospice care, (3) Karnofsky score (a 0-100 score indicating functionality), (4) gender, (5) primary diagnosis, and (6) general location (e.g., home, nursing facility, or hospital)

RISKS

Your participation in this study involves minimal risks. However, sometimes mentioning these subjects cause people to become upset. You do not have to talk about any subjects you do not want to talk about, and you may withdraw from the study at any point. If you become upset, the study staff will give you names of counselors to contact so you can get help in dealing with these issues.

BENEFITS

Your involvement in this research may help us understand more about needs of individuals who provide support to persons with cancer. By identifying these needs, health professionals may be able to address those needs with someone in a similar situation.

CONFIDENTIALITY

The information collected during this study will remain private and confidential to the extent allowed by law. Your name will not be connected to the data we collect from the medical chart in any way. The information we collect will be compiled with data from other participants and reported in a group format.

QUESTIONS

If you have any questions, complaints, or concerns about the research, contact:

John G. Cagle, Ph.D. (candidate)
Virginia Commonwealth University
P.O. Box 842027
Richmond, VA 23284-2027
Telephone Number (804) 248-2748
E-mail: caglejg@vcu.edu

If you have any questions about your rights as a participant in this study, you may contact:

Office for Research
Virginia Commonwealth University
800 East Leigh Street, Suite 113
P.O. Box 980568
Richmond, VA 23298
Telephone: 804-827-2157

You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at <http://www.research.vcu.edu/irb/volunteers.htm>.

If you choose to participate, please indicate this by signing below. Again, thank you for your time and potential participation.

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study.

Signature of Patient (or Proxy)

Date

Appendix J.

Social Worker Instructions

NOTE: Use the script below *only* if the patient meets the following criteria:

- (1) the patient has a known cancer diagnosis.
- (2) the patient meets Covenant's admission criteria and has been admitted into hospice care.

Script

To the patient or the decision-making proxy:

“Our hospice is participating in a university-based research study on hospice caregivers. We are interested in learning more about the experiences of informal caregivers, whether they nearby or farther away. Your involvement in this study is entirely voluntary. Whether or not you participate will not affect the care you receive from the social worker or from Covenant Hospice. If you decide to participate, we will need your permission to give your contact information to one of the researchers, who would then contact you by phone and tell you more about the study. Does this sound like something you would be willing to participate in?”

If “Yes” -thank them and present signed consent form.

If “No” -thank them for their time.

Appendix K

VCU IRB Number: HM10530

Consent Cover letter

Dear _____,

My name is John Cagle, a researcher at the Virginia Commonwealth University's School of Social Work. Thank you for taking the time to read this letter. I am writing to request your participation in a university-based research study on the needs of caregivers of cancer patients. You have been identified as a caregiver by a friend or family member (or perhaps you identified yourself, and if so, thank you).

If you choose to participate in our study, you will be asked to complete two questionnaires, one now and another several months from now. Your responses will remain private and confidential to the extent allowed by law. Your answers to specific questions will be compiled with the responses of other participants and reported in a group format. Any comments you make in response to the open-ended questions will be analyzed for common themes. However, your individual remarks will not be made public.

Please do not feel pressured to complete this survey. Your participation is entirely voluntary. However, your responses may help us understand more about needs of individuals who provide support to persons with cancer. By identifying these needs, health professionals may be able to address those needs with someone in a similar situation. We are interested in hearing from a variety of caregivers, including those who live with, or near the person receiving care, as well as those who live out-of-town. If you choose to participate, please complete the attached questionnaire and return it by using the enclosed, stamped envelope. Whether you participate will not affect the care you will receive from Covenant Hospice. It should take you between ?? to ?? minutes to complete. If you require assistance with the survey, that is fine, as long as the questions are interpreted and answered by you.

Please do not put your name on the questionnaire. Questionnaires are coded to protect your identity while allowing us to link responses from the first questionnaire with the second questionnaire. The master list that connects your name with the code will always be kept separate from the answers you provide

Sometimes answering questions about a critically-ill or deceased loved one can be upsetting. If this happens to you, you may stop filling out the questionnaire at any point. Additionally, if you would like to speak with a professional counselor, please contact [INSERT TOLL-FREE HOSPICE NUMBER]

By completing this survey and returning it, you are indicating your informed consent to participate. Again, thank you for your time, attention and potential participation.

Sincerely,

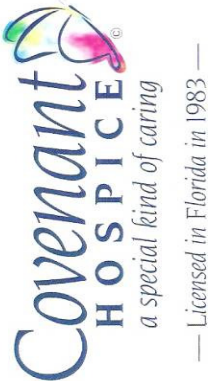
John G. Cagle, Ph.D. (candidate)
Virginia Commonwealth University
P.O. Box 842027
Richmond, VA 23284-2027
Telephone Number (804) 248-2748
E-mail: caglejg@vcu.edu

Pamela J. Kovacs, Ph.D.
Virginia Commonwealth University
1001 W. Franklin Street
P.O. Box 842027
Richmond, VA 23284-2027
Telephone Number (804) 828-2607
E-mail: pjkovacs@vcu.edu


VCU Office of Research Subject Protection
800 E. Leigh Street, Suite 114
P.O. Box 980568
Richmond, VA 23298-0568
Telephone Number (804) 828-0868

Appendix K.

Study Brochure



STUDY BROCHURE



CAREGIVERS OF CANCER PATIENTS

Your Participation Is Important

CONTACT INFORMATION

If you have any questions, complaints, or concerns about the research, please contact:

John G. Cagle, Ph.D. (candidate)
 Florida State University - Panama City
 4750 Collegiate Drive
 Panama City, FL 32405
 Cell: (804) 248-2748
 Office: (850) 522-5520
 E-mail: jcagle@fsu.pc.edu

Pamela J. Kovacs, Ph.D.
 Virginia Commonwealth University
 School of Social Work
 1001 W. Franklin Street
 P.O. Box 842027
 Richmond, VA 23284-2027
 Office: (804)828-2607
 E-mail: pljkovacs@vcu.edu

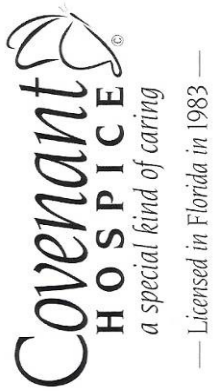
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 800 East Leigh Street, Suite 113
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 Richmond, VA 23298
 Telephone: 804-827-2157
 VCU IRB Number: HMT10530



Florida State University
 Chair of the Human Subjects Committee
 Institutional Review Board
 Tallahassee, FL 32306-2742
 (850) 644-8633

You may also contact these numbers for general questions, concerns or complaints about the research. Please call the numbers if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at: www.research.vcu.edu/irb/volunteers.htm.


This study has been made possible with generous support from:



Virginia Commonwealth University

GERIATRIC SOCIAL WORK INITIATIVE



Florida State University

Greetings...

Covenant Hospice is participating in a university-based research study on caregivers of cancer patients. We are interested in learning more about the needs and experiences of informal caregivers of patients, whether they live nearby or far away. This brochure provides information on what you can expect as a study participant, your rights, and how to contact the research staff if you have a question or concern.



- STUDY INVOLVEMENT -

For Patients:

We are requesting that hospice patients assist with this research in two ways. First we request your permission to contact you by phone so that you can recommend informal caregivers that you think should participate in this study. Second, we ask that you allow us to record 6 items from your medical chart. These include:

- (1) pain rating (on a 0-10 scale)
- (2) number of days under hospice care
- (3) Palliative Performance Score (a score indicating functionality)
- (4) gender
- (5) primary diagnosis
- (6) general location (e.g. home, nursing facility, or hospital)

For Caregivers:

Are you a caregiver?

We are looking for input from a variety of informal caregivers. Many times people who provide care, support, and assistance to hospice patients do not consider themselves to be "caregivers." For the purposes of this study an informal caregiver is any person the patient or family identifies as a provider of physical, mental, emotional, or financial assistance to the patient – regardless of their geographic location. An informal caregiver is usually unpaid (i.e. not an agency employee). Caregivers who choose to participate in our study will be asked to complete two questionnaires, one after admission into hospice and another several months later.

Your Rights: (continued)

~ Your involvement in this research may help us understand more about needs of individuals who provide support to persons with cancer. By identifying these needs, health professionals may be able to address those needs of the patients and families.

~ Please note that the information collected during this study will remain private and confidential to the extent allowed by law. Your name will not be connected to the data you provide in any way. The information we collect will be compiled with data from other participants and reported in a group format.

~ This study has been approved by ethics review boards at both Florida State University and Virginia Commonwealth University



Thank you!

Appendix M

Additional Research Notes

Continuing Data Collection

Since this was a prospective bereavement study, the number of caregivers who qualify for the bereavement survey (i.e., the post-death survey) was contingent upon the death of the care recipient. Since patient mortality varied from family to family, a substantial number of caregivers did not qualify for the bereavement survey prior to the conclusion of the study. *Please note that bereavement surveys will continue to be mailed out and accepted until the IRB approvals expire in October of 2008 - even though this is beyond the scheduled defense date.* This approach has been approved by IRB representatives from VCU and FSU. The researcher felt an obligation to collect the remaining bereavement questionnaires, as participants were informed that they would receive the second survey. Since formal data collection will have ended, *the data from these additional surveys are not included in these dissertation findings.* However, the author intends to include these data in the supplemental analysis and future dissertation-related publications.

Supplemental Analyses

After the conclusion of this dissertation research, the author plans to conduct several supplemental analyses, particularly (1) a multilevel regression and (2) an exploration of the psychometric properties of the QOD-Hospice. The multilevel regression analysis will help control for the inclusion of members of the same family/caregiving-network. It is important to account for the similarities among group members (which is sometimes called “kin-effects”). However, this type of “nested” group cannot be accommodated for in the MANCOVA. Instead a multilevel regression analysis can help tease out the interaction effects of family/network membership.

Appendix N

Vita

John Garland Cagle was born on August 11, 1973, in Oklahoma City, Oklahoma. In 1995, he received a Bachelor of Science Degree in Psychology and English from Mary Washington College in Fredericksburg, Virginia. He later obtained a Master of Social Work Degree from Virginia Commonwealth University in 1998. In 2006, Mr. Cagle was awarded a Hartford Doctoral Fellowship (2006-2008). He was also the recipient of a 2006-2007 College of Palliative Care Mentorship and the 2008 McGrath-Morris Residency & Fellowship. He received his Degree of Doctor of Philosophy in Social Work from Virginia Commonwealth University in 2008. Mr. Cagle has social work practice experience from a number of health care settings, including hospitals, skilled nursing facilities, home health, and hospice. He currently resides in Florida, where he lives with his wife and teaches at Florida State University's Panama City Campus.