LIVING IN THE MEMORY OF LOSS:

EXPLORING THE IMPACT OF AGGRESSIVE, PALLIATIVE, AND HOSPICE CARE

AND SURVIVING LOVED ONES

By

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Submitted to the graduate degree program in Social Welfare and the
Graduate Faculty of the University of Kansas
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy.

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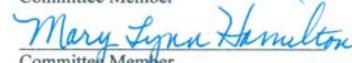
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Date Defended _August 14, 2009_

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that this is the approved version of the following dissertation:

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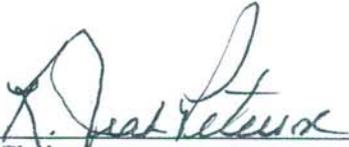
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CARE AND SURVIVING LOVED ONES

Theresa A. Gordon

University of Kansas

"For what is it to die,
But to stand in the sun and melt into the wind?
And when the Earth has claimed our limbs,
Then we shall truly dance."
--Kahlil Gibran

Acknowledgements

This has been a long journey. At times, I wondered why I had started the journey; at other times, I wondered if I was up to the task. I could not have successfully completed this work with the support of others. I am indebted to the encouragement, humor, and wisdom of my colleagues, mentors, and loved ones.

I would first like to thank the participants in my study. Many years ago I learned that people are extremely generous even in the light of their own pain. My participants allowed me to share in their grief. Their courage, insight, and grace blessed me. Many wrote that if their experience could help others in the future, they were honored to participate. I am the one who was honored.

Others have aided me along the way both with personal and professional support. While I can't single out all of them, I do want to thank Dr. K. Jean Peterson, my committee chair, and Dr. Holly Nelson-Becker, my methodologist. To Dr. Peterson, thank you for believing in me. Thank you for using your ability to see connections and conceptualizations to guide me as I strove to understand what I wanted to ask, how I wanted to ask it, and how I came to understand the results of my study. To Dr. Nelson-Becker, thank you for grounding me. Your patience and guidance kept me with my "eye on the prize" and your insights into grief, loss, and spirituality helped me understand the grieving process more completely. I would like to also express my thanks to my other committee members, Dr. Rosemary Kennedy Chapin, Dr. Ann Weick, and Dr. Mary Lynn Hamilton. Thank you all for your time, your feedback, and your support.

I would also like to thank my children and friends for their support. To my son, Daniel and his wife, Michelle; my daughter, Keunok Maniquis and her husband, Mike; my daughter Amy and her husband, Brendan; and my daughter, Rebecca, thank you for walking this doctoral journey with me. To my good friends, Linda Hammen, Uta Walter, Jocelyn Martin, and Joanne Gordon, thank you for listening to my self-doubts, for being there as I blew off steam, and for helping me keep my goals in sight.

I frequently tell people that I've won the lottery yet I've never bought a ticket. I'm rich in friends, family, and remarkable mentors. I'm rich in the love of learning. I'm not done yet…I'm just beginning.

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Abstract

This study is predominantly a quantitative investigation into the model of care received by deceased loved ones and its impact on the grief reactions of their caregiver. Grief is conceptualized to include both positive reactions, as finding comfort in memories, and negative reactions, as becoming depressed. Guiding theoretical paradigms are studied with associations between positivism and aggressive care; social constructivism and palliative care; and transpersonal theory and hospice care reviewed. A Continuum of End-of-Life Care Services is proposed that integrates all the models of care.

The Inventory of Complicated Grief-Revised assessed the incidence of complicated grief among the surviving caregivers. A newly created scale, the Positive Grief Scale, assessed the incidence of positive grief. Additional data were analyzed regarding the delivery of best practices in end-of-life care and their helpfulness. Analyses included the impact of length of engagement with model of care and demographic risks factors for complicated grief. Four qualitative questions were included in the questionnaire.

The sample included 180 caregivers whose loved ones received services from a local cancer support agency. A mailed questionnaire was used to collect the data. Independent sample t-tests, ANOVA, chi square tests, correlations, and frequencies were employed. Factor analyses were performed on the positive grief scale to obtain initial validity data.

Results failed to confirm any significant difference among the three models of care and grief reactions. Demographic factors and length of stay in hospice also were not significantly predictive of either positive or negative grief. Best practices, including emotional and spiritual support; information on dying and bereavement; community resource referrals; and availability of the health care provider were significantly more likely to be present in hospice and rated more helpful by the participants. Multidisciplinary teams work was also substantiated. Qualitative data appeared to confirm the simultaneous presence of positive and negative grief. The Continuum of Health Care Services was revisited in terms of the results.

Implications for social work practice, policy advocacy, and further research are examined. This research adds to the body of knowledge about what practices supports surviving caregivers to live well after the death of a loved one.

CHAPTER 1: Overview of Current End-of-life Care

"...have patience with everything unresolved in your heart
and try to love the questions themselves...
Perhaps then, someday far in the future,
you will gradually, without even noticing it, live your way into the answer.
--R.M. Rilke

Death and Dying in the Twenty-first Century

The quest for good end-of-life care is a selfish one. We all will die. With the advent of remarkable medical health care advances, better nutrition, better living conditions, and less dangerous work environments, lifetimes have been extended The population at risk for imminent death has changed. Today the population at need for good end-of-life care is predominantly old (over 65) and chronically ill (Bern-Klug, Gossert & Forbes, 2001).

Life Extended

Globally, people are living longer and the increase in life expectancy for the average American is dramatic. For example, the average American born in 1997 could expect to reach 77 years of age (Centers for Disease Control, 2009)—about thirty years more than the person born in 1900. Survival to "old" old age (85 and above) has also increased. The Centers for Disease Control (CDC) reports that based on current mortality rates, a 65-year-old person in 2005 could expect to live to be nearly 84 years old and an 85-year-old in 2005 to live to be over 90 (National Center on Health Statistics, 2008).

In addition, with the demographic consequences of the post-World War II baby boom, persons over the age of 65 will comprise a larger portion of the population than at any other time in the history of the world (Federal Interagency Forum, 2000). The first wave of baby boomers will reach 65 as early as 2011 and will continue their impact until 2031. This impact coupled with the increase in

chronic disease management will substantially increase the numbers of people

needing care through their dying process and the need for quality end-of-life care.

Moreover, the causes for death have also changed from acute conditions,

such as accident, pneumonia, or disease, to chronic ones. The CDC (2004) has

identified the four top causes of death in 2002 as heart disease, cancer, stroke, and

lung diseases. These four diseases account for 63.8% of all deaths. Consequently,

older persons with chronic diseases predominantly comprise the dying population of

today.

Dying Extended

Chronic disease management has also affected the time of death. Death

trajectories were at one time simple and linear. When examining only disease

trajectories (excluding catastrophic injury), dying occurred fairly rapidly within one

or two weeks and decline to death was straightforward and irreversible (Field &

Cassels, 1997). With the advent of improved medical procedure, technologies, and

drug interventions, the current dying trajectory is "less predictable and much less

readily recognized" (Bern-Klug et al, 2001, p.41).

The chronic nature of illness and "living in the light of death" (Bartholome,

1999, p.1) has propelled us to find new, better, and more long-standing ways to cope

psychologically, spiritually, and socially. Awareness of mind and body connections

and the impact of psychosocial interventions in proving quality of life have risen to

the forefront both in scientific and secular literature. Dr. William Bartholome, who

lived over five years with a grave prognosis, attributed his longevity and quality of

life to "allowing oneself to be radically open to what is going on in the world" (p.26)…and to realize the importance of relationships, spirituality, and embracing life fully (1999). The effects of these intrapersonal and extrapersonal factors has propelled search for meaningfulness over time.

In summary, death and dying in this country has changed dramatically in the latter half of the twentieth century. More of us are reaching old age (65+) and we are living longer. We are dying differently. Our deaths are more prolonged in time. Finding meaning in the dying experience is not a goal to reach but a process over time. The results of this new dying experience are varied and extensive, and they have shaped current policies, practices, and research concerned with death and dying.

<div align="center">Impact of Death and Dying Experience on Caregivers</div>

This new dying experience has also impacted caregiving in the United States and informal caregivers, those family members, significant others, and friends who are providing many services to ill persons and with minimal formal assistance. For example, estimates are that 52 million persons serve as caregivers each day (Fife Assessment Centre for Communication through Technology (FACCT) & Robert Wood Johnson Foundation, 2001). Studies conducted by the American Association of Retired Persons (AARP) describe the typical caregiver as female over the age of 40 with a full-time job, and who provides 18 hours or more a week to caregiving for an older person, usually a family member (Pandya & Coleman, 2000). In 1997, the National Family Caregiver survey found that 23% of all US households had provided

care to a person 50 years or older over the previous twelve months (National

Alliance for Caregiving & AARP, 1997). Current reports from the National Family

Caregivers (2007) confirm that this trend continues. Currently 26.6% of all US

households have provided caregiving and over 50% of all persons over the age of 75

need some type of caregiving assistance. Due to the aging of America and the fact

that people are living longer with severe chronic illness, caregiving is, has, or will be

an issue for virtually every American family.

For the purposes of this study, what is particularly of interest are the effects

of caregiving experiences on surviving loved ones. These burdens and uplifts

experienced by caregivers, especially as they care for the dying can influence their

physical, mental, spiritual, and social well-being, are important to understand. The

impact of these burdens and uplifts begin at the start of the caregiving process,

continue throughout the time of caregiving, and influence the bereavement process

either negatively or positively. A recent national survey of caregivers summarized

the general impact this way:

1. 55% expressed feelings of isolation

2. 50% felt the "burden of caregiving" was too much to handle at
   times

3. 45% reported they could not count on a high level of social
   support

4. 43% felt they were not involved in the care decisions for their
   loved one

5. 39% needed respite care in the last year but only one-half received it

6. 32% of the spousal/partner caregivers reported physical problems

7. 22% had been told by a health care professional that they were depressed (FACCT & Robert Wood Johnson Foundation, 2001).

In the face of this predominantly negative assessment, caregiving has also up lifts. Caregivers report that they have positive rewards for caregiving that positively shapes the caregiving experience. The most common rewards mentioned by caregivers include feeling wanted and needed, experiencing positive self-regard, learning new skills, finding more meaning in life, and fulfilling vows and promises (Switzer, Wishniewshik, Geele, Burns, Winder, Thompson, & Schultz, 2000; Kinney & Stephens, 1989).

<div align="center">The Experience of Grief in the Twenty-first Century</div>

Coupled with the stress and uplifts of caregiving is the experience of grief at the loss of a loved one. Grief is normal and a natural reaction to loss (Rando, 1984). It is a profound sadness that can include feelings of abandonment, fears for the future, spiritual angst, and more (Worden, 2003). The grieving process can manifest itself negatively in psychological ways such as depression, denial, anxiety, and anger; in physical ways such as insomnia, exhaustion, eating disorders and anhedonia; in social ways as isolation and withdrawal; and in spiritual ways such as anger towards God and loss of purpose (Worden, 2003).

This process can also have positive aspects. An alternative definition of grief from a strength perspective is that it involves reconstructing the world and its meaning in light of the challenge of death (Neimeyer, 2000). Psychologically, people can experience relief and joy that the person is no longer suffering; increased self esteem for fulfilling their role with the dying person; greater self efficacy around things that they have learned through the process; and much more. Physically, grieving people can begin or resume physical activities, attend to their own health concerns, and resolve to live healthier. Socially, they can appreciate more the old and new friendships, reach out to others, and find mutual support and value relationship in a deeper way. Spiritually, they can experience a greater connection with the mystery of life, appreciate life more, have stronger bonds to spiritual or religious traditions, and be transformed through their grief (Klass, Silverman, & Nickman, 1996; Rando, 1984; Tedeschi & Calhoun, 1995). Therefore, just as the caregiving experience has both stresses and uplifts, so too does the grieving process. The goal of good end-of-life services is to minimize a loved one's burdens and maximize a loved one's uplifts.

Some form of grief expression occurs at every loss. Many people experience sadness and a time of readjustment to the loss of the loved one, but most are able to adjust, adapt, and find resolution with the loss and go on to live their lives. It is estimated that 80-90% of bereaved individuals are able to maneuver through their grief and come to this resolution (Prigerson, 2004; Rando, 1993; Crenshaw, 1991; Kubler-Ross, 1968). Time from death to this resolution can vary from less than a

year to many years. However, regardless of the time frame, bereaved individuals report that they are able to go on with their lives, incorporating the death but not becoming physical ill, clinically depressed, or socially isolated (Kasl & Prigerson, 2001; Prigerson, 2004, Crenshaw, 1991). For some individuals, this bereavement does not end but instead they appear to become stuck in their grief and this negatively impacts their physical and mental health. This type of grief is referred to as "complicated grief," and it is associated with long-term impairments for those who experience it (Jacobs, Hanson, Kasl, Ostfeld, Berkman, Kosten & Kim1990; Prigerson, Frank, Kasl, Reynolds, Anderson, et al, 1995; Rando, 1993; Silverman, Jacobs, Kasl, Shear, Maciejewshi, et al, 2000; Rando, 1993; Zhang, El-Jawahre & Prigerson, 2006)

Current research has reported that approximately 11% of all bereaved individuals whose loved ones have died from natural causes appear to manifest complicated grief (Latham & Prigerson, 2004; Barry et al, 2001).With approximately 2.5 million deaths per year (CDC, 2004/5), the potential for complicated grief reactions for hundreds of thousands of surviving loved ones is apparent. Research has looked at general bereavement, post-hospice bereavement, and post-palliative care bereavement and explored their effect on surviving caregivers and their well-being. For bereavement research, certain risk factors for complicated grief appear to be identified. They are female gender (Martin & Doka, 1999; Rudd, Viney, & Preston, 1999); lack of support for caregiving (Parkes, 1975); depression during caregiving (Schultz, Mendelsohn, Haley, Mahoney, Allen & Zhang, 2003); caregiver

strain during caregiving (Bass, Bowman, & Nelker, 1991); the severity of the dying

person's symptoms (Grande, Farquhar, Barclay, & Todd, 2004); and the age of

caregiver (older more risky); the relationship to deceased (closer more risky); the

duration of the caregiving experience (longer more risky); the physical health of

caregiver (severity of health problems more risky); and multiple losses (Zhang et al.

2006; Rando, 1984).

Outcomes for complicated grief reactions are both physical and emotional

impairments. Complicated grief has been associated with physical illnesses as

cancer, hypertension, heart problems, and suicidal ideation and completion (Chen,

Bierhals, Prigerson, Reynolds, Shear et al, 1999; Latham & Prigerson, 2004). In

addition, increased alcohol consumption, clinical depression, and increased use of

anti-depressants have also been documented as correlated with complicated grief

symptoms (Ott, 2003; Silverman et al, 2000; Prigerson et al, 1995; Rando, 1993).

With regard to specific health indicators, people with complicated grief appear to

have a greater likelihood to develop high blood pressure, increase their smoking

habits, change their eating habits, have sleep disturbances, engage in poor self care,

and even die (Prigerson et al, 1997; Kaprio, Koskenvui, & Rita, 1987).

Social implications for complicated grief include a "sense of disconnect with

people," and a "sense of alienation," which results in avoidance of social encounters

with friends and family (Prigerson, Wanderweker, & Maciejewski, 2007, p. 8).

Persons with complicated grief report that "life lacks meaning and purpose" and they

"find it extremely difficult" to form new relationships with others or to engage in any social activities (Prigerson et al, 2007, p. 8).

However, the grieving experience is not just one dimensional. Certain factors have also been shown to be supports for grieving well. Expressions by the bereaved of positive appraisals such as evidences of self-growth, awareness of personal strengths, and quality of the relationship appear to be associated with less grief (Bonanno, Moskowitx, Papa, & Folkman, 2005). Those persons who have "protective factors" such as an "acceptance of death, a belief in a just world and instrumental support" appear to grieve well (Bonanno et al., 2005, p.830). Spirituality and its connections to positive grief have been found (Michael, Crowther, Schmid, & Allen, 2003; Walsh, King, Jones, Tookman, & Blizard, 2002). Finally, support prior to the loss significantly reduces bereavement stress even more than support during bereavement (Bass et al., 1991).

In summary, the experience of death and dying has had both positive and negative impacts on caregivers and other loved ones. These impacts have been both positive (uplift the surviving love one) and negative (decrease in both physical and mental health). The goals of persons who care for the dying and their survivors are to increase the positive impacts of caregiving and bereavement and to decrease these threats to well-being. Health care professionals have an important job to support a good dying experience for the ill person but also for those that survive.

The Experience of Health Care

Persons with a life-limiting illness intersect with different health care professionals in multiple settings and at different times in their disease management. A common experience for an ill individual when they receive a serious diagnosis is to opt for medical treatment options (aggressive treatment). If these options are unsuccessful in combating the disease, measures to minimize the discomfort of the illness may supersede treatments. Also, side effects of the treatments (chemotherapy, radiation, surgeries, nebulizers, and so on) themselves may negatively affect physical health. Again, in addressing these negative side effects, comfort measures may be appropriate (palliative care). Finally, as individuals decide to withdraw from aggressive treatments for their disease and to choose comfort care exclusively, they can experience holistic care for themselves and their caregivers through the dying and bereavement process in hospice care. Even though many people may experience all three models of care (aggressive, palliative, and hospice care), others may choose none of these models or just one or two before their deaths.

Except for those who do not interact at all with the health care system, persons will meet many doctors, nurses, social workers, home health aides, chaplains, and other health care professionals through their dying process. The helpfulness of these health care professionals is an integral part of best practices in end-of-life care. End-of-life empirical research has recognized a core set of best practices from the consumer's perspective with reference to health care professionals. These best practices include communication between ill persons, loved

ones and professionals; respect for self-determination; use of a team approach; attention to spiritual issues; and support for caregivers and surviving loved ones.

These best practices have developed over the last twenty years and have drawn on both quantitative and qualitative studies to identify and confirm the importance of these services both to the dying individual and to their surviving loved ones. The most rigorous and comprehensive study that identified core best practices was the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) (1995). This study collected data on over 9000 participants for a six-month span in over 500 hospitals in the United States from 1989 through 1994. Additional data was collected from 1600 physicians, 500 nurses, and other health care professionals concurrently with the patient participants (SUPPORT, 1995). Over 100 scholarly articles were published from the collected data by its principal investigators (Philips, Hamel, Covinsky & Lynn, 2000). This study was firmly positioned within a medical setting and a medical care approach. All best practices were addressed in the multiple studies that were outgrowths of SUPPORT. Key SUPPORT investigators include Steinhauser, Lo, Daaleman & VandeCreek, and Teno, whose studies are cited in the review of the individual best practices that follows.

Communication as Best Practice

Currently consumers have identified the need for initial and on-going communication with health care professionals as a best practice. Consumers state they need direct, frequent, and timely conversations regarding prognosis, course of

illness and dying process, with health care professionals that listen to them and their family's concerns. Qualitative studies (Azoulay, 2005; Chochinov, 2002; Kayser-Jones, 2002; Kutner, Steiner, Corbett, Jahnigen & Barton, 1999; Nelson-Becker, 2006; Pierce, 1999; Steinhauser, Clipp, McNeilly, Chritakis, McIntyre & Tulsky, 2000a; Vig, Davenport & Pearlman, 2002) and quantitative studies (Chochinov, Hack, Hassard, Krirstjanson, McClement & Harlos, 2002; Cicirelli, 1998; Macdonald, 2003; Mor, 1989; Shrens, Uancey & Kollef, 2003; Schwartz, Wheeler, Hammes, Basque, Edmunds, Reed, Ma, Li, Tabloski & Yanko, 2002; Wenger, Kanouse, Collins, Lie, Shuster, Gifford, Bozzette, & Shapiro, 2001) support the need for communication and continued discussions as both a preventative intervention (decreased stress, anxiety, fear, etc) and as an intervention technique to assist in processing the meaning of life, unfinished business, and reaffirming relationships.

This best practice can be present in all the models of care a dying individual might experience. For those health care professionals in aggressive care settings, communication is valued. Good communication is vital to a person's understanding of what the physician has prescribed and in order for patients to be compliant. Health care professionals in comfort care settings see good communication as crucial to supportive interrelationships, to understand their experience of discomfort and thus decrease psychological suffering, and to promote understanding the context of pain. Within the hospice model, communication is important to understand the person's wishes and thus honor choices for care and to promote self-determination. In

addition, in this model good communication is crucial to support people in their meaning making process.

Personal Autonomy as Best Practice

Closely related to the preference for communication with health care providers is the preference for instruments and methods that foster and support a person's self-determination. Specifically mentioned by persons and their families are on-going opportunities for them to reaffirm control of their care as well as advanced directives and informed consent practice.

Qualitative studies (Danis, Outherland, Garrett, Smith, Heilema, Pickare, Egner & Patrick, 1991; Kutner, Steiner, Corbett, Jahnigen & Barton, 1999; Pierce, 1999; Steinhauser et al, 2000b; Visser, 2003) and quantitative studies (Lo, 1995; Schneider, 1995; Steinhauser et al., 2000a) cite the importance of patient-driven care or a consumer-model care approach.

Once again, any model of practice could support this best practice. For an aggressive model, patient-driven care can be preventive (avoiding unwanted types of care and encouraging compliance). For both palliative care and hospice care models, this care approach can be a type of intervention (encouraging a sense of control and clarifying wishes). Moreover, patient self-determination in advanced care planning is also mandated by the Patient Self-Determination Act of 1990 that is applicable to settings of all three models of care (*Patient Self Determination Act*, 1990).

Multidisciplinary Teams (Holistic Care) as Best Practice

Many studies have affirmed the consumer preference for holistic care delivered by a multidisciplinary team (Pierce, 1999; Sulmasy & McIlvane, 2002; Steinhauser, et al., 2000b). With this approach, a wider range of services, additional treatment interventions, and differing professional perspectives are possible. Typically the team consists of doctors, nurses, and social workers as core components and chaplains, with other disciplines as optional. Aggressive models consistently include the doctor and nurse component, with social workers and chaplains often available if the physician orders their involvement. Thus in this paradigm, physicians are in charge of the team, and they can be threatened by an equalitarian, multi-voiced commitment to care (Steinhauser, et al., 2000b; SUPPORT, 1995). This limitation can also apply to palliative care teams (Higgerson, Finlay & Goodwin, 2001). Physician dominance can also occur here. However, most palliative care teams do have as core professionals the doctor, nurse, and social worker (Higgerson, Finlay & Goodwin, 2001). With a hospice model the full use of the multidisciplinary team (doctor, nurse, social worker, chaplain, therapists, home health aides, and volunteers) is most assured since the hospice philosophy honors all team members as integral to good end-of-life care (MacDonald, 1991; Moore & McCollough, 2000).

Meaning-making and Spirituality as Best Practice

Studies validate that good end-of-life care includes support for a search for meaning. Spirituality and meaning making are connected to positive scores on

quality of life indicators, negative scores on depression scales, and consumer

satisfaction reports (Kayser-Jones, 2002; Nakashima & Canda, 2003, Mulder, 2000;

Reese, 2001; Sulmasy & McIlvane, 2002). Aggressive models historically have not

addressed this component due to their concentrations on observable systems and the

disease process. Many physicians continue to believe that addressing spiritual

matters are not a part of their services (Daaleman & VandeCreek, 2000). Both

palliative care and hospice care philosophically embrace spiritual comfort care as a

key practice (Cohen & Koenig, 2002; Kelleher, 2000; Pierce, 1999; Steinhauser et

al., 2000a).

Diversity Competency as Best Practices

Studies support that good end-of-life care is culturally competent, thus

preventing additional suffering for the person and family through misunderstandings

and insensitivity. Cultural competency allows trusting relationships to develop that

will reduce anxiety (Reese, Melton & Ciaravino, 2003; Wenger et al., 2001).

Aggressive models do encourage cultural competency and acknowledge that

respecting diversity aids in implementing treatment plans (Kagawa-Singer &

Blackhall, 2001). However, an aggressive model continues to elucidate that basically

there is one way to die (Nuland, 1995) and is less likely to realize that there are

multiple "ways of dying" (Doorenbos & Myers, 2004), which palliative care and

hospice models do affirm.

Attention to the Needs of Caregivers and Loved Ones as Best Practices

Best practices also reiterate the importance of including of others who are significant to the dying person as family and friends in care plans. Supporting these loved ones, educating them in caregiving and dying processes, and providing anticipatory grief as well as bereavement supports have been reported to help the dying person's process and have a positive impact on all. Moreover, studies have documented specific interventions that correlate with surviving loved one's ability to grieve well (Kasper, Steinbach, & Andrews, 1990; Teno, Clarridge, Casey, Welch, Wetie, Shield, & Mor, 2004).

Several of these studies point out that awareness of the expectation of death facilitate better coping by spouses (Potocky, 1993); that crisis intervention services that decrease additional stressors correlate with less prolonged grief (Potocky, 1993; Rubin & Schechter, 1996); that concrete services decrease caregiver burden and correlate with healthier caregivers and less negative physical manifestations of grief (Teno et al, 2004); that attention to particular psychosocial needs of caregivers decreases negative grief reactions and less complicated grief (Ahrens, Yancey, & Kollef, 2003; Bernard & Guamaccia, 2003; Dawson, 1991); that encouragement of social support results in better grief resolution (Thorton, 1997); that support for expressions of spirituality and finding meaning results in positive life restructuring and less depression (Harrison & Harrington, 2001; Smith, 1999) and that bereavement follow-up services decrease complicated grief (Forte, Barrett, & Campbell, 1996; Franco, 1996; Kramer, 1992).

Furthermore, surviving loved ones who witness and themselves experience good communication with their health care providers, respect for their wishes, attention to all facets of the person including spirituality, opportunities to interact with providers from differing theoretical and practice, cultural competent practices, and special attention to their particular needs as supporter of the dying person are more likely to be positively impacted and able to grieve healthily. These interventions are viewed as preventives for complicated or disenfranchised grief (Barry et al, 2001; Vanderweker & Prigerson, 2004). The connections between the type of services that are received at life's end and the impact on grieving survivors have been empirically validated (Zhang, El-Jawahri, & Prigerson, 2006; Vanderweker, & Prigerson, 2004; Prigerson et al, 1995).

Support for caregiving and surviving loved ones is not an expected practice in aggressive care models. No payment stream is afforded for these types of services, and although some individual physicians may do some follow up or collateral contacts, it is not the norm. Palliative care also may attend more to family concerns while the person is alive and under care. But they too have no payment stream or expectation to do supportive follow-up (Von Guten, 1999). Only the hospice care model mandates attention to caregivers and loved ones during the dying process and follow-up bereavement support for one year after the death. This bereavement follow-up although ordered is not funded.

Research Findings Associated with Model of Care

With regard to actual services, hospice involvement has been found to be beneficial to the bereavement process. Hospice involvement yielded significantly lower scores on measurement of depression and anxiety and use of tranquilizers in bereavement (Ransfor & Smith, 1991). Participation in hospice is associated with less severe grief reactions (Steele, 1990).

Additional studies have confirmed the benefits of hospice to surviving caregivers in promoting healthy grieving (Dawson, 1991; Kramer, 1992; O'Brien et al, 2000). Studies of hospice have also shown that hospice's impact on bereavement appear to fluctuate in relation to length of stay. People who had three days or less of hospice services were significantly more likely to be depressed than those with longer enrollments (Bradley, Prigerson, Carlson, Johnson-Horsley, & Kasi, 2006).

Palliative care services (non-hospice-based) also have a positive effect on surviving loved ones and their bereavement. People whose loved ones died in hospital palliative care unit had fewer depressive symptoms, less anger, and less complicated grief than those in other areas of the hospital (Cameron & Parkes, 1983).

However, there are some mixed results. Some studies have shown that the majority of bereaved persons experience only transitory grief (Bonanno, 2004; Wortman & Silver, 2001). Caregivers have also reported both improved family relationships and positive self regard more often than negative feelings of loss and

regret (Koop & Strang, 2003). Also, hospice services have been found not to have a significant impact on bereavement (Grande et al., 2004).

In addition, research has indicated that advanced preparations for loss (awareness of death and discussions about the impending death) and having good social support can lessen the risk for developing a complicated grief reaction (Barry et al, 2001; Vanderweker, & Prigerson, 2004). In any model of care, preparations for loss can exist. However, palliative care and hospice services make advanced planning an integral part of the treatment plan (Morrison & Morris, 1995; Moore & McCollough, 2000). In summary, best practices as validated through research are possible in all areas of end-of-life care. However, hospice models support these practices both philosophically and in mandated practices; palliative care models support some but not all the practices; and the aggressive models have fewer encouragements to support them

<div align="center">Social Work's Involvement in End-of-life Care</div>

Social workers are key health care professionals that serve people who are dying and the loved ones who care for them and who cope with losing them to death. Currently there are 595,000 social workers working in the US (Bureau of Labor Statistics, 2008). Of those 124.000 are directly employed within health care settings (Bureau of Labor Statistics, 2008). Within settings that care for the most severely ill, dialysis, and hospice, social work is mandated as part of the health care team. In addition, oncology units and most hospitals employ social workers to serve their clients. Social workers are key employees in nursing facilities, senior centers,

rehabilitation centers, and other practice sites. This profession provides services to ill

people and their loved ones in multiple venues and in times of loss.

Social Work Values, Theory, and Practice and Good End-of-life Care

As stated previously, social work professionals are key members of care

teams providing services to dying persons and their families and friends. Whether in

hospitals, nursing facilities, hospices, assisted living homes, or other venues, social

workers have provided psychosocial support, advocacy, and counseling services.

Social workers are also advocates, researchers, and policy makers in end-of-life care.

Social work values and values supporting good end-of-life care are important to

explore to examine to see if any conceptual barriers exist.

Social Work's Unique Value Stance

Social work's mission is well defined. It is

to enable all people to develop their full potential, enrich their lives, and

prevent dysfunction. Professional social work is focused on problem

solving and change. As such, social workers are change agents in society

and in the lives of the individuals, families and communities they serve

(International Federation of Social Workers, 2000, p.1).

Definitions of good end-of-life care are emerging. A central concept to a good death

is one that allows a person to die on his or her own terms relatively pain free with

dignity (Institute of Medicine, 1997; Steinhauser, K., Clipp, E., McNeilly, M.,

Christakis, N., McIntyre & Tulsky, 2000b) found that patients and their families

listed six components of a good death: comfort care, patient empowerment,

preparation for death, completion of patient identified tasks, contributions to others, and affirmation of the person.

Within the scope of this mission statement and these definitions, the congruent vision of both good end-of life care and social work values are evident. First, social work envisions lifelong development and enrichment, thus facilitating individuals to live and die on their own terms and to affirm their lives. Second, the social work profession is dedicated to a holistic approach that is also preferred by the family and patient as a focus of good end-of-life care. Third, social work acknowledges the role of change in life and the strengths of individuals as they cope with change. Good end-of-life care values this last opportunity to grow in order to complete unfinished business; to foster strong interpersonal relationships; to seek and obtain forgiveness, and to explore the meaning of life.

Finally, social work is dedicated to the growth and development of society as a foundation for individual support. End-of-life care, like no other area of practice, impacts all individuals within the society. The cliché "nothing is certain except death" is a reminder that death will touch everyone, regardless of gender, ethnicity, socio-economic status, or privilege. Social workers are in unique positions because this field of practice facilitates coping, growth, and well-being for the person and provides work as change agents to prevent individual and societal dysfunction.

Social Work's Unique Theoretical Perspective

Another key variable to be explored is the role of social work in end-of-life care services. Social work is integral to the health care professional team within all

the models of care (medical, palliative, and hospice). Social work theory, practice, and research are also a good fit with current best practices and this study will report family satisfaction with social work services across all the models.

Social work as a multi-theoretical discipline also brings to end-of-life care a plethora of human behavior theories to assist people who are dying and their families and friends. Theories that are particularly applicable to social work practice in end-of-life care include life span theories, ecological perspectives, and the strengths perspective. Life span theories capture the essence of potential growth, development, and change throughout the life course (Robbins, Chatterjee, & Canda, 1998). These theories support the possibility of growth and development up to the time of death. They reinforce the role of meaning making at every phase of life and the importance of meaning making for greater growth. They normalize crisis as inherent to change (Rutter & Rutter, 1992). From a social work perspective, life span theories connect well with our vision and values. With these theories, death is not pathological nor is the possibility for growth or change even at times of illness and decline discounted. They support social work intervention at all times of life as viable for promoting growth and reaffirm that people make sense out of their life events

Ecological perspectives also inform social work practice in this area. Person in environment (PIE), an ecological concept, connects the awareness that people do not exist separate from the environment in which they live. Persons can interact with, be altered by, and can conform to the constraints and opportunities of their physical and social environment (Cohen, 1987; Haynes, 1998). These perspectives emphasize

understanding the entire context of the individual's situation. They reinforce the importance of relationships to others and the systems that impact them, as well as the person's free will to conform or not (Germain, 1978). Social work values are also supported by ecological perspectives. Our awareness of the importance of human relationships and the context of the larger society coincides with an ecological perspective. With these theories, death and dying is not an individual experience but a relational one. Therefore, these theoretical perspectives support the need for attention by health care professionals to all those persons that affect the ill person as well as the institutional systems that are also involved.

Finally, the strengths perspective addresses the strengths of people as they experience loss and capitalize on their innate resiliency. It promotes personal self determination and recognizes that all people have power to direct their lives and their deaths (to some extent). Problems are reframed in light of goals and possibilities for change. Suspension of disbelief, a key tenet of the perspective, allows for acceptance of end-of-life experiences. Moreover, since there is no expert but the person in the situation, validation of the person's unique experience is possible (Saleebey, 2001). Also, this perspective reaffirms that people have most of the skills and tools that they need within themselves, and thus personal fulfillment is within reach (Weick, Rapp, Sullivan, & Kisthardt, 1989). Connections to social work values include the affirmation of the dignity and worth of all persons and the belief that all people can contribute to bettering themselves and their society. With this perspective, the person and his or her potential is honored and built upon. All experiences are validated and

seen as potentially meaningful. The power of the person to live well up until death is acknowledged.   These theoretical perspectives form an overarching framework for social workers on how to think about the opportunities and constraints of working with ill persons and their families and loved ones. From this grounding emerge social work's best practices.

Social Work's Unique Practice Perspective

Social work has been an integral practitioner in end-of-life care from the onset of this specialized type of care. Both Kubler-Ross and Saunders, the founding mothers of the modern-day hospice movement, validate the need for the special skill set of social work as integral to the multi-disciplinary team process (Kubler-Ross, 1968; Moore & McCullough, 2000). They acknowledge that social workers understand family and health care systems, resource acquisition, and the potential for growth for the person and their loved ones. From the inception of the multi-disciplinary team for dying person, social workers have been considered a core component (MacDonald, 1991). That position was codified by the Medicare Hospice Benefit. Social workers and nurses are the key delivery personnel of every hospice and palliative care team (HCFA, 1979; Jacobsen & Breithart, 2003).

The skill set that social workers bring to end-of-life care include acknowledging the importance of relationships and individual dignity and worth as well as a commitment to serve, advocate, and promote healthy growth and change. The social work commitment to cultural competency in practice affirms the unique needs of individuals and the complicated interchange between the individual and the

dominant society. Social work practice wisdom and theoretical knowledge-base informs about the interventions that can promote good end of life care. Finally, this profession has acknowledged the importance of competency in end-of-life practice and been in the forefront of other helping professions in compiling standards of practice relating to end-of-life care (National Association of Social Workers, 2002).

As a response to a national summit to discuss social work standards, a formal document was compiled and published in 2004 by the National Association of Social Workers (NASW) (2002). These standards of practice elucidate best practices for social workers in providing good end-of-life care. Foremost, NASW stresses that competency in end-of-life care is not just applicable to a specific field of practice but applicable to all social work practitioners:

> All social workers, regardless of practice setting, will inevitably work with
> clients facing acute or long-term situations involving life-limiting illness,
> dying, death, grief and bereavement. Using their expertise in working with
> (varying) populations …social workers…must be prepared to assess needs
> and intervene appropriately (NASW, 2004, p.7).

Also within these standards are statements that identify the state of the art in end-of-life care as patient self-determination (key guiding principle); as hospice and palliative care services (current best models for care); and as culturally competent end-of-life care, bereavement follow-up, and caregiver support (NASW, 2004).

These standards also endorse both palliative and hospice care as the "model for quality, compassionate care for people facing life-limiting illnesses or injuries"

(NASW, 2004, p. 11). It enjoins social workers to begin to look at the continuum of illness from first visit to the health care professional, through diagnosis and the variety of treatments possible, to end of life. Social workers, as members of the multidisciplinary hospice, palliative care, and medical care teams, are in a unique position to not only impact clients but also professionals from other disciplines. This opportunity allows social work to expose other professions to its vision and broaden their understandings for care, ethical foundations, and commitment to the person in environment, empowerment, and a strengths-based focus. As professionals, social workers are in a position to share this broad theoretical approach to other professionals and to influence the growth and development of good end-of-life care as a means of fulfilling the social work practice mandates to care for individuals and their families in times of stress and need.

Contributions of Social Work to End-of-life Care

Social work research, with its use of both qualitative and quantitative methodologies, engages in inquiry as to best practices, program evaluations, and theoretical development in end of life care. Some social work research explores the ramifications of legislation (Galambos, 1998; Roff, 2001) and specific policy mandates as advanced directives (Galambos, 1998; Hobart, 2001; Moore & Sherman, 1999); particular practice venues as prisons (Griffen, Rohrer & Arete, 1994), hospices (Csikai, 2004; Becker, 2004) and nursing homes (Osman & Becker, 2003); specific populations (Leichtentritt & Rettig, 2001; Todd, 2002); scale validation (Buckley & Abell, 2004); and social worker education on end-of-life

issues (Becker, 2004; Hobart, 2001; Taylor-Brown & Sormanti, 2004; Werner,

Carmel & Ziedenberg, 2004).

Moreover, social work research has paid particular attention to listening to all

the voices impacted by this life-altering experience in order to support survivors and

dying individuals so that social work professionals can make informed

recommendations to society of the efficacy and effectiveness of interventions and

programs. Specific studies have recorded the preferences for older adults and their

families and friends regarding what was either beneficial or an impediment to good

care in dying (Bullock, McGraw, Blank,& Bradley, 2005; Kane & Hawkins, 2005;

Luptak, 2006; Mjelde-Misset & Chan, 2007; Nelson-Becker, 2006; Munn &

Zimmerman, 2006; Wetie, Shield, Teno, Miller & Welch, 2005) and in bereavement

(Baker, 2005; Botsford, 2000).

On the practice front, social work's contribution to fostering knowledge in

this area has not been as extensive. The importance of the multidisciplinary team (of

which social workers are key members) present in end-of-life care has been well

documented (Pierce, 1999; Sulmasy & McIlvane, 2002; Steinhauser, et al., 2000b).

However, one study has reported inconclusive findings in demonstrating the positive

benefits of social workers to the hospice team (Parker-Oliver, Bronstein &

Kurzejeski, 2005). In other areas of end-of-life research, social workers have been

the focus of studies that assess their knowledge of advanced directives and their

assistance in completing them with patients (Lacey, 2005). In addition, studies have

focused on social work as a positive influence in end-of-life care (Csikai, 2004;

Hobart, 2001; Reese & Raymer, 2004). For example, Reese and Raymer (2004) show that higher client satisfaction and fewer nights of inpatient care occur when there is more frequent social work intervention on hospice teams.

In summary, social work as a profession has a key role in end-of-life practice, theory, policy-making and research. Social workers are in a unique position to raise a professional voice to improve end-of-life care in the United States and internationally. Furthermore, the goals of good end-of-life care are congruent and are well supported by social work's core values and standards

Overview and Research Questions

The importance of this research is to add to the body of knowledge regarding which approach supports surviving family members to cope with their loss (especially in reducing the incidence of complicated grief) and to foster living well after the death of a loved one. The impact of unresolved grief and fears for the future is evident both in costs to the person and society. This impact can manifest for the person in physical illness, depression and other mental health illnesses, substance abuse, and suicide (Dersh, Polatin & Gatchel, 2002; Monsen & Havik, 2001, Neimeyer, 2005; Rando, 1993). Costs to society can be general societal well-being, economic and cultural productivity, and health care expenditures (Feldman, 1992; NHPCO, 2003; Rando, 1993). Depression alone was estimated to cost the United States workplace up to $35 billion dollars annually, and much of this depression can be linked to bereavement (Feldman, 1992). These costs are avoidable if society clearly understands what types of interventions best aid people in successfully

coping with loss.

Social workers, who are essential providers of both proactive counseling for anticipatory grief and reactive counseling to help with complicated, unresolved, and disenfranchised grief, need to know and understand the efficacy of the approaches. Consequently, a component of this study will explore family perceptions of the helpfulness of the health care providers. This will also be correlated to the end-of-life care approach that the family experienced.

Research has explored the efficacy of medical, palliative, and hospice care approaches in direct patient care and bereavement support, but no study has explored the lasting effects of these philosophies on the surviving family. This study will explore if these approaches result in differences in the way survivors view their ability to grieve well. Also, the family voices will identify their perceptions of assists from health care providers and others.

Therefore, the questions driving this study are as follows:

1. Is positive grief associated with the model of end-of-life care received by a loved one at the time of his or her death?

2. Is complicated grief associated with the model of end-of-life care received by a loved one at the time of his or her death?

3. Does any particular demographic factor place persons more at risk for complicated grief? (Are any associated with positive grief/)

4. Are services or supports (identified best practices) delivered by health care

professionals more present in a particular model of care or are rated as

more helpful in a particular model of care?

Chapter 1 Summary

Death is a universal constant but how we die and how we support the dying and their loved ones has undergone a change both in substance and in practice over the past fifty years. Death has changed from an acute to predominantly a chronic event. This has impacted informal and formal caregiving resources and served to extend and complicate caregiver's emotional strain and grief responses. Caregivers and surviving loved ones are left to make meaning of their loss and go on. Factors that support healthy grieving can include good communication and listening, emotional and spiritual support, use of a team approach, and cultural competency. Risk factors for complicated grief include gender (female), caregiver strain, and closeness of relationship.

As health care professionals, social workers are integral health care practitioners that have provided direct care, theoretical analysis of the dying and grieving process, and have been key researchers in end-of-life care. As a profession, social work has developed professional standards for good end-of- life care that is consistent with identified best practices in end-of-life care and our professional values.

From this beginning, the next chapter will concentrate on the theoretical paradigms that impact delivery of end-of-life care. Key to the coming analysis is the interface of grief theory and paradigm perspectives and how that supports or impedes health care professionals in delivering best practices that can support grieving loved ones and families.

CHAPTER 2: State of the Art of Death and Dying Theory, Policy, Practice,

and Research in End-of-life Services

"Take death for example. A great deal of our effort goes into avoiding it. We make   extraordinary efforts to delay it and often consider its intrusion a tragic event. Yet we'd find it hard to live without it. Death gives meaning to our lives. It gives importance and value to time. Time would become meaningless if there were too much of it."

--Ray Kurzweil

Theoretical Shifting Paradigms

End-of-life care does not exist in a vacuum. It is grounded in conceptual and societal mores that frame what is knowable, doable, and acceptable in end-of-life care. These shifting paradigms that direct end-of-life care will be examined. Following,   the impact of these paradigms on grief theory and an emerging conceptualization of a basic services continuum for end-of-life care will be explored. Finally, these concepts will be reviewed in light of social work practice knowledge and wisdom.

Traditionally, death and dying have been the purview of the health care community. This community for the last 150 years has followed closely the medical model paradigm, a positivistic approach to the nature of reality. Recent critiques have encouraged a shift to other ontological paradigms, specifically social constructivism and transpersonal theories (Field & Cassels, 1997). The theoretical and practice modalities that have arisen from these different methods of approaching end-of-life care are important to study so that best practices, best policies, and best research implications can be clearly understood. Each paradigm's key elements will be briefly explored with the resulting implications to practice, policy, and research.

Medical Model Paradigm

The medical model is a direct outgrowth of a positivistic paradigm stance and it rests on the following assumptions:

- "Truth" or "reality" are constant, knowable, and quantifiable;

- Knowledge is acquired through deductive and inductive reasoning and empirically stable (generalizable);

- Knowledge, and subsequently research, are value-free and objective; and

- Change is threatening unless controlled by expert interventions;

- Power is held by experts (Balbour, 1995; Helman, 1991; Roberts, 1989).

Codicils to the medical model uphold the physician as the operant director of care; the consumer as the receiver of care; tests to validate the presence or absence of illness are more reliable than consumer assessments; and death as something to be fought, since death is unknowable and an indicator of failure of the treatment plan (Balbour, 1995).

Positivism and the medical model's descriptions of a good death reflect an understanding of death and dying as a fixed reality and it presupposes that there is one universal way to approach death and dying, which is knowable and constant, while inferentially presupposing that helpers can fully understand the dying process. It also sees death, as the antithesis of life, which must be defeated. This adversarial approach leaves little room to seek the meaning of death or to explore growth and development, since it limits this type of reflection on life and death. Deviations from stated norms logically pathologize the unusual dying experience and devalue it (Kubler-Ross, 1968).

With regard to best practices, a medical model paradigm

- values communication as it supports stated goals (these goals may be mutually determined or may not);

- supports self-determination when it follows the physician-directed plan of care (when it is against the plan of care, person may be labeled non-compliant);

- includes holistic care when those aspects of care are quantifiable and expert knowledge is hierarchical and directing the team's care;

- applies to symptom management for those symptoms that are obvious and measurable;

- does not encourage meaning making/spirituality (it is not an appropriate realm of inquiry since meaning is not observable or measurable);

- downplays diversity since dying is a constant and uniform procedures should apply to all;

- supports caregiver needs since this interaction is useful to supporting the treatment plan (caregiver needs in and of themselves are not necessary valued); and

- encourages cost effectiveness and solvency since it is quantifiable (Lautrette, 2007; SUPPORT, 1995; Wenger et al, 2001; Wenrich et al, 2003; Werner et al, 2004).

Finally, with the emphasis on purposeful (as defined in the treatment plan) activity, bystanders (family, friends, society) are seen as tools for assisting in coping, adaptation, and mastery not as prospective guides, or fellow explorers of life. Moreover, the interaction between loved ones and the dying person and the synergy

that can result as one struggles to understand and find meaning is unacknowledged and possibly discounted. With this approach, one does not fully appreciate connections to others and the importance of these connections to psychosocial and spiritual well-being.

Medical Model's Impact on End-of-life Care

However, it is important neither to discount the importance of the medical model to end-of-life care in the United States nor to diminish the positive elements it has contributed to good end-of-life care. The advances in medical knowledge and technology have enabled people to live much longer with a good quality of life. At the turn of the twentieth century the top causes of death were accidents, infections, and influenza or pneumonia—all acute or communicable conditions/diseases. Today the top reasons for death are chronic diseases (National Center on Health Statistics, 2008). The medical model has succeeded very well in eradicating many of these acute reasons for death and also in extending life expectancy for those with chronic disease.

In addition, the medical model is the foundation for most pain and symptom management interventions. These interventions are cornerstones for good palliative care (Abrahm, 2000; Fine, 2003; Finn, 2005; Stein, 2004; Wachter, 2003). Moreover, without the commitment of the medical model to research into new drugs, therapies, and treatment protocols there would not be access to the tools available to provide options for treatments (Roberts, 1989). The medical model has strengths and benefits to good end-of-life care.

The limitations of the medical model become most evident when the focus is away from the curative orientation and is directed more at palliative care. Health care professionals firmly entrenched in the medical model express their difficulty in addressing conversations around end-of-life because there are no set guideposts and they are no longer involved in a quantifiable process (Bustin & Huskamp, 2002; Bradley, 2000; Virnig, Persily, Morgan, & DeVito, 1999). These limitations become very evident when exploring areas around client choice and palliative care.

Medical Model's Impact on Policy, Practice, and Research

Policies that reflect a medical model paradigm position the physicians, in particular, and the medical community, in general, as expert gatekeepers for services (Balfour, 1995). For example, the Patient Self-Determination Act (PSDA) (1990) centers medical communications for future care within the hospital or nursing home setting. Access to these forms for health care preferences are primarily regulated by employees of these institutions and discussions are only mandated when consumers access these institutional services, thus by default couching these conversation in times of medical crises at times when people are less reflective and less able to make informed decisions. In addition, the expectation is that these forms are completed once and are never discussed again. This reflects two things:

- First, that decisions are static and never changeable since the dying process is not a developmental, growth opportunity; and
- Second, that decisions can be made to cover all contingencies. Context doesn't matter since there is only one answer and this is immutable.

This positivistic stance is even evident in the Medicare Hospice Benefit (1983) where physicians are the only entity able to certify terminal illness. Further policy regulations require that consumers must forego aggressive care, and have a six-month prognosis. These gate keeping regulations assume that a death trajectory is knowable and linear and that diagnosed people decline at fixed rates and in predictable ways.

Practice experience, as well as empirical research, has refuted the assumptions contained in these policies. Advanced planning documents can be completed and are preferred by consumers to be completed in non-crisis settings with advice from an array of persons (Steinhauser, Christakis, Clipp, McNeilly, McIntyre & Tulsky, 2000a). Caring Conversations, a national program of the Practical Center for Bioethics (1999), encourages these conversations to occur first and foremost with family and friends and later with health care professionals. They also encourage updates to these documents yearly and/or when health conditions change.

Moreover, a one-size fits all approach to advance care planning has proven to be culturally insensitive and completion rates are dismal for persons of diverse backgrounds (Crawley et al., 2000; Gordon, 1995; Koenig & Gates-Williams, 1995; Murphy & Price, 1998; Reese et al., 1999). Advance care planning forms themselves also reflect this approach. The health care preferences are treated as all-or-nothing entities and precluded the context for decision-making (Teno, Stevens, Spernak, & Lynn, 1998).

End-of-life research also reflects the positivistic paradigm. For example, the seminal study, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) chose as its experimental intervention a physician and nurse team to address advanced planning within the hospital setting. The findings of this study were that this team approach did not yield significant improvement in planning activities (SUPPORT, 1995). Doctor controlled and directed care were additional criticisms of this research, as problems in communication of wishes, wants, and needs were spotlighted.

On the other hand, some in-roads have been made in supporting differing ways of knowing. This has resulted in some evidence that flexibility in treatment plans, patient self-determination, and lessening of fixed regulations are occurring. For example, the six-month prognosis regulation for hospice eligibility, which ten years ago resulted in many hospice patients being discharged because they "weren't dying fast enough", has been modified to continue eligibility post six months if the person continues to decline (NHPCO, 2003). Nevertheless, the positivistic point of view does continue to dominate the health care system.

In general, the medical model is most closely associated with aggressive treatments for diseases. Therefore, for this study, aggressive treatment approaches and the medical model will be used interchangeably

Social Constructionist Paradigm

Another theoretical framework that is making headway in the health care system is social constructionism. This post-modern theoretical approach views the

process of understanding end of life as an "outcome of social relationships, described

and shaped by the language we use, and dependent on the social context" (Gergen,

2000, p.236). Social constructionism focuses on the view of reality as contingent

upon social relationships and it is through social context, especially language, that

reality is conceived and articulated. Meaning is seen as "solidified within a group"

(Gergen, 2000, p. 235) not as an intrapsychic process but a communal one. The

conceptual contributions of this perspective to death and dying theory and research

have centered on the importance of social context, the implications of a contextual

reality, the core functions of narrative and ritual, and greater understanding of

change and growth.

> The social constructivist model assumptions are as follows:
>
> - Truth or reality is not constant but ever-changing within context; people
>   "construct" their own realities and truths;
>
> - Knowledge is obtained through multiple ways of knowing;
>
> - Knowledge, and subsequently research, are never value-free and
>   objective but are always based on values whether stated or not;
>
> - Change is possible and ways to change are understood. If societal mores
>   are constructed in context, they can be deconstructed and reconstructed in
>   more meaningful ways. The emotional threat of change is transformed
>   into a neutral transactional occurrence; and

- Power is placed with those who intimately know what their reality is and the power to change or alter that reality remains locally focused (Gergen, 2000).

By stressing relationship and the force of language and ritual, the importance of communication and interaction with our society and others is substantiated (Searle, 1998). With this perspective, change is tied to choice and from a social constructionist point of view choice is a function of awareness of possibilities and the social supports that foster change.

Within end-of-life policy, a shift to a social constructivist paradigm can be seen in the rise of the movement for palliative care that has occurred over the last forty years. This palliative care approach is completely embodied in hospice philosophy. However, hospice's version of palliative care and the current emergence of palliative care hospital units, care teams etc. are different. These non-hospice views of palliative care are linked to maintaining aggressive (curative treatments), and do not postulate that death is an opportunity for growth and development.

The World Health Organization (WH0) has defined palliative care as an active total care of patients, including control of pain and other symptoms, and psychological, social and spiritual problems (WHO, 1990). Palliative care has borrowed from hospice a holistic position, meaning that the whole person and their loved ones are the focus of care. Five principles of palliative care have been enumerated:

1. Palliative care respects the goals, likes, and choices of the dying person.

2. It attends to the medical, emotional, social, and spiritual needs of the dying person.

3. It supports the need of family and friends.

4. It supports access to all health care providers and all appropriate settings with all treatment choices available.

5. It places the onus of responsibility on the health care provider to assure that the best possible comfort care is assured for every person. (Care of the Dying, 2003).

Palliative Care Model's Impact on End-of-life Care

Palliative care as a treatment modality provides holistic, comfort care in whatever setting the individual chooses. It is a philosophy of care that looks to pain and symptom management as basic rights in health care delivery (Reb, 2003).

Furthermore, even though many define palliative care as compatible only with those conditions not responsive to aggressive (curative) treatment, palliative care principles have been embraced by the medical model proponents as important for good care regardless of prognosis or treatment choice (Reb, 2003). It certainly is well-established within a social constructivist paradigm since it values the voice and language of the person, perceives pain as socially constructed, acknowledges multiple meanings of pain (suffering), and supports the social context (i.e. the loved ones, and recognizes that a clear values stance for comfort care is important in all

care settings). For this dissertation, palliative care and a social constructivist approach will be connected.

Palliative Care Model's Impact on Policy, Practice, and Research

Current evidence of the rise of a palliative care/social constructivist theoretical model in policy making include the Healthcare Research and Quality Act of 1999, the PSDA of 1990, and various state initiatives in Maryland, New York, and Nevada. These acts serve to expand consumer choice, move for better end-of-life care supportive services, and facilitate pain/symptom management. In the 2005-2006 session of the Kansas Legislature, a patient pain bill of rights in Kansas was enacted (*The Pain Patients Quality of Care Act*, 2006). This bill requires that patients be treated with dignity and respect, including having their pain thoroughly assessed and treated without repercussions to physicians regarding opiate use (*The Pain Patients Quality of Care Act*, 2006). Clearly, this bill mirrors a palliative care/social constructivist paradigm.

From a practice point of view, the largest growing aspect of end-of-life care in hospitals is the rise of palliative care teams. These teams have multidisciplinary members that include physicians, nurses, social workers, and chaplains. They are a consultation service to attending physicians specifically to assist with symptom management and comfort care as well as emotional and spiritual support for both the ill individual and their loved ones. These teams can only consult when "invited" by the doctor and in this sense continue to be based in a medical model but they have expanded the view of the medical community to providing holistic, best practices.

Palliative care teams in hospitals have grown extensively and from 2000 through 2003, they increased 63% (Higgerson, Finlay & Goodwin, 2001; Morrison, Maroney-Galen, Kralovec & Meier, 2005). In 2003, 25% of all US hospitals had some form of palliative care team consultation (Morrison et al, 2005). By 2007, the American Hospital Association Annual Survey of Hospitals reported that this figure had grown to 31.7% of all US hospitals (Kuehn, 2007).

Research also reflects an examination of a palliative care focus and a social construction paradigm. For example, the number of articles reporting research in areas of pain and symptom management that were identified in just one database, Expanded Academic ASAP, was 642. Of these, 539 of them were published after 2000. This search was conducted in June of 2008. Specific articles can range from an integrated psychosocial-spiritual model for cancer pain (Otis-Green, Sherman, & Baird, 2002) to meaning spouses attribute to their loved one's pain (Mehta & Ezer, 2003) to the use of clinical hypnosis for pain management (Liossi & Hatira, 2000).

A social constructivist paradigm, palliative care, has tried to integrate the elements of client choice and multiple ways of knowing into the medical model. It does allow for culturally sensitive care, flexibility, and consumer choice. However, it also tends to be seen as auxiliary, consultation care. This includes seeing physicians as gatekeepers and services not mandated only suggested. This continues a hierarchical stance in which the services of the palliative care team and their recommendations are secondary to aggressive treatment goals.

In addition, it does not propose that the dying experience is transformational or important. It only concentrates on the need to keep people comfortable, respect their wishes, and support loved ones. For those that see dying as possibly the last growth adventure, social constructionism and palliative care do not offer much support or encouragement. Missing from these perspectives is an appreciation of the place meaning has in our lives and the urge to make meaning that occurs when persons experience significant life events.

Transpersonal Paradigm

The last theoretical paradigm that applies to end-of-life care is transpersonal theory. Transpersonal theory "proposes that by going deep into ourselves to understand the fullness of who we are, we can transcend the ego…and connect profoundly with other people and the universe" (Robbins et al., 1998, p.360). Transpersonal theory sheds light on end-of-life issues in a way neither of the aforementioned paradigms do. A positivistic paradigm sees no benefit in the dying process and sees death primarily as a failure. The social constructivist paradigm sees end-of-life as important to manage thus providing comfort and support to the dying person and his/her loved ones. However, the transpersonal paradigm embraces end-of-life as a continuance of the transformational development of life. As Frankl stated "life is rich with meaning…life is not to be managed and coped but to find meaning, one must first look to growth development…the meaning in life always changes, but…never ceases to be" (1984, p.115). Searching for and understanding the meaning we each make in our lives continues throughout our dying process.

Transpersonal theory's assumptions are as follows:

- Truth or reality exists and is knowable on many different levels. There is ultimate truth but few attain this knowledge;

- Knowledge is obtained through multiple ways of knowing and no one way is preferable to another;

- Knowledge/research are never value-free and should be based on values;

- Change is the nature order of life. Life is developmental, ever changing and striving toward growth, meaning, and understanding. Change is not a neutral event but an exciting positive aspect of life; and

- Power is located within us and we are charged with tapping into that power through self-discovery and self-actualization (Robbins et al, 1998).

For this paradigm, the meaning of life through death, and everything in between, is an opportunity for development and greater understanding. Meaning and growth may continue through death into another existence. Death is the name we give to an event that marks a transformational juncture, but is not necessarily the end of our "journey" (Byock, 2002).

Transpersonal Theory's Impact on Meaning and Death

Maslow (1968), a founder of transpersonal psychology, theorized that there existed a level of the universe, larger than the limited awareness of the person, which provides meaning and significance to the individual. Quest for meaning was then really the quest to transcend to this higher awareness. This transcendence was a drive toward self-actualization. Hastings (1999) concurred and termed the search "a

natural, spontaneous movement toward wholeness...there is an intrinsic tendency for the person to want to learn and to grow in understanding" (p. 203). Meaning making therefore is part of an intrapsychic developmental process that strives toward growth. Initially, our consciousness is very limited. As we mature, consciousness expands encompassing new awareness, refining meanings, and searching for answers. As lower levels of needs are met, such as food, shelter, safety and security, the awareness/desire to attain higher needs emerges. As these become satisfied to some extent, the awareness that there is something more to be understood, experienced and appreciated, continues to propel the person to seek higher and higher levels of self-actualization (Maslow, 1969). Consequently, with this never-ending process, the meaning for existence becomes increasingly clear and refined at each successive stage. Many transpersonal theoreticians believe that death is the ultimate self-actualization (Frankl, 1984; Smith. 2001; Tedeschi, Park, & Calhoun, 1998).

Transpersonal Model's Impact on Policy, Practice, and Research

Just as social constructivist's paradigm was evident in a palliative care framework, transpersonal theory is most evident in hospice philosophy and its service delivery systems. The Medicare Hospice Benefit (MHB) is the primary policy intertwined with a transpersonal paradigm approach. Although with vestiges of a positivistic approach (as mentioned before with the physician as expert gatekeeper and cost containment elements that reflect a one-size-fits-all approach), the MHB traversed into new territory. Inherent is the belief that the current positivistic paradigm was not meeting the needs of terminally ill, dying persons.

Mirroring Elizabeth Kubler-Ross' perspective as elucidated in her landmark work, *On Death and Dying* (1968), the dying process was viewed as a time for potential enrichment and growth, for a celebration of life, for family and friends, and for dignity and meaning. It was not just viewed as an individual, physical process, but the importance of all its elements: physical, emotional, social and spiritual was validated and included in this legislation.

In addition, the hospice work of Dame Cicely Saunders and her treatment protocols and philosophical underpinnings, operationalized at St. Christopher's Hospice in England in the 1960's, became the template for the hospice model (Moore & McCullough, 2000). The legislation states that the "hospice movement as a concept for care…is a viable concept and one which holds out a means of providing more humane care for Americans dying of terminal illness while possibly reducing costs" (American Hospice Association, 1999, p.3).

Policies initially funded hospice pilot programs in 1974 and in 1982, the Medicare Hospice Benefit, as it is known today was passed and the first statutory end-of-life legislation became enacted (HCFA, 1983). This legislation has been modified three times since 1983. Each time clarifications, additional funding, and new provisions have been added. However the original provisions remain essentially the same.

In practice, the transpersonal paradigm looks to transforming end-of-life care. Practice elements support the search for meaning by keeping physical symptoms well controlled (Maslow's concept of meeting basic and safety needs) so that people

can explore their relationships (belonging needs) and be able to grow and transform through their dying process (self-actualization needs). In order to accomplish this, multiple sources of support are needed (a multidisciplinary team) to provided holistic care, where *all* care needs of the individual, whether physical, psychological, spiritual, or social are to be addressed by professionals with multiple ways of understanding. Persons must be able to "direct their care and be the head of the care team because only they know what is meaningful and important to them and paths they need to take. Caregivers and loved ones are also "clients" who are going through their own growth and development process and who can benefit from support as they come to new awareness and understanding. All these transformational elements are evident in hospice's philosophical approach.

Research has also been utilized from both qualitative approaches and quantitative approaches to explore the process of meaning making (Kayser-Jones, 2002; Nakashima & Canda, 2003; Mulder, 2000; Reese, 2001; Sulmasy & McIlvane, 2002) and the transformational growth that is possible even in the face of life-limiting disease (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Tedeschi & Calhoun, 1995; Tedeschi et al., 1998). That growth is possible and that transformation occurs is now being documented more systematically.

In summary, a transpersonal approach to end-of-life care is the dominant paradigm evident in the Medicare Hospice Benefit and in hospice services. This approach has impacted service delivery practices and has had validation in both

qualitative and quantitative methodologies of research. For this study, transpersonal approaches and hospice are connected.

Convergence of Models of Care and Grief Theory

Initial Theoretical Groundings

Models of care and their respective paradigms have also influenced the development of theories of grieving. Firmly entrenched in the medical model are the first coherent grief theories. Espoused in these theories are beliefs in the universality of stages of grieving, with diagnosis and treatment of "pathological" grief reactions, and limits to the "ways of knowing" about grief and loss, in particular the absence of spiritual components.

Freud in his writings was the first to articulate a grief theory. He conceptualized grief as "work" and first distinguished mourning as a normal reaction that could be intense but would eventually be resolved. Melancholia was the term for pathological grief that resulted in isolation, depression, and possible suicide (or at least suicidal ideation) by the bereaved person (Lupi, 1998). Kubler-Ross' theoretical approach to grieving built on Freudian conceptions and postulated a stage-theory of grief that sought to describe feeling and behaviors that occur in a particular sequence as people move through their bereavement process (1968). Although allowing spirituality as a way of coping, Kubler-Ross' theory still rests predominately in a medical model framework and lasting grief reactions are seen as pathological (1968). For example, her stage model is proposed as universal; her stages concentrate on negative reactions to grief, including denial, anger, bargaining, and depression, with

only acceptance having a strengths-based connotation. Furthermore, her call to action around death and dying care was primarily directed at the health care professional thus validating their position as expert.

Bowlby (1982) proposed another stage theory of grief that was based on his earlier work on attachment theory. Bowlby, also, based his theory squarely within a psychodynamic perspective and postulated that at death a predictable set of behaviors occur because of the separation from an "object" of attachment. His stages include first, shock and disbelief; second, yearning and preoccupation with the deceased and the objects that remind one of the deceased; third, disorganization with feelings of sadness, resentment, and despair; and fourth, reorganization with the bereaved person redefining their life without the presence of the dead person (1982). Again the assumption is that these stages are universal and predictive. Again the emphasis is on pathological reactions to grieving.

Lastly, stages-theories state that the grieving person must break away from the memory of the deceased in order to reach acceptance and resolution (Kubler-Ross, 1968; Parkes, 1975; Bowlby, 1982; Wofelt, 1983; Worden, 1991; Rando, 1993). The first calendar year after the loss is generally accepted as a time line for this detachment. The rationale is that this first year is time enough to experience the reality of the loss, which is reinforced, at every anniversary date in which the deceased's absence is acknowledged. Also this time is sufficient to reorder the bereaved life to live on without the dead love one's presence (Crenshaw, 1991; Worden, 1991; Rando, 1993).

Consequently, from a medical model perspective, grief is foremost an assault on biological and psychological well-being that must be diagnosed and treated if not resolved within a year of the loss. The grief experience is universal and predictable. It is primarily an intrapsychic process and not a social one. Grief is painful and dominated by negative effects. The normal grieving process is time-specific and at the end of that time the person is done with the grieving process. Moreover, a key indicator of pathology in grieving is the inability to move away from the remembrances of the deceased (Freud's decathexis). Finally, knowledge about grief is still viewed as in the hands of the experts.

Some researchers have posited that many of these grief theories are based on poorly researched and unsubstantiated assumptions. These assumptions include understanding grief as a having a distinct pattern; as being finite; as being grounded in a process of shock, yearning, and recovery; and as identifying continuation of grief as "pathological" (Breen & O'Connor, 2007; Valentine, 2006: Center for the Advancement of Health, 2004). Research into these assumptions has failed to support them (Center for the Advancement of Health, 2004; Bonanno & Field, 2001; Stoebe & Schut, 2005a). Despite this lack of evidence based practices, studies also confirm that practitioners in the field continue to use these assumptions to guide their work with bereaved individuals (Center for the Advancement of Health, 2004, Lindstrom, 2002; Valentine, 2006). This lack of empirical substantiation for bereavement practices is very troublesome. Lindstrom (2002) remarked that the assumption of working through one's grief persists because it is culturally normative.

These cultural norms dictate that a lack of sadness or sense of loss offends a culture

that believes all persons must be missed and a bereaved individual owes that to the

deceased. If no work to get through the loss is evident then the deceased is

dishonored (Lindstrom, 2002). If our practitioners continue to follow unsubstantiated

assumptions, bereaved individuals may not be helped but hindered in their

bereavement.

With regard to definitions of complicated and normal grief, within these

initial theories, normal grief is simply the sadness connected to a sense of loss. From

Freud to later stage theorists the definition for normal grief has been straightforward

and consistent over the past forty years. Complicated grief, on the other hand, has

been defined and redefined (Breen & O'Connor, 2007; Rando, 1993; Prigerson,

Vandewekre, & Maciejewski (2007); Stroeb, van Son, Stroebe, Keiber, Schut, & van

den Bout, 2002). What does appear to be consistent is the assessment that if the

intensity of the grief process over time, the length of time for the process, and the

interference the process has in the bereaved life is prolonged then the grief is

pathological (Rando, 1993). The common defining element consistent in these

definitions of complicated grief is the essence of time. Prigerson, Vanderwekre and

Maciejewski (2007), proponents of including complicated grief as a diagnostic

category in the *Diagnostic Statistical Manual of Mental Disorders* (DSM), state that

Many of the symptoms of Complicated Grief are very similar to the

symptoms first experienced by bereaved persons who have normal uncomplicated

grief during the first few months following their loss. However, in the case of

uncomplicated grief, these symptoms subside over time. Due to the similarities in the manifestation of early uncomplicated grief and Complicated Grief, it is important to be conservative in diagnosing Complicated Grief to avoid diagnosing bereaved people whose grief is likely to resolve naturally with time (p.166).

In summary, complicated grief is seen as being stuck within the grief process and helping the bereaved to forget the deceased and learn to move on is crucial. This sentiment is echoed through all the stages theories. Initially intensive grief is acceptable as long as it does not last too long and as long as the person is able to "let go and move on" (Worden, 1991; Rando, 1993; Bowlby, 1982; Kubler-Ross, 1968). Therefore, if detachment does not proceed within this time frame and if many vestiges of attachment to the dead loved one continue, complicated grief develops and this is seen as a disease and problematic (Lupi, 1983, Kubler-Ross, 1968; Parkes, 1975; Bowlby, 1982; Wofelt, 1983; Worden, 1991; Rando, 1993). Within this model's approach to grieving, any lasting relationships with the decreased are incompatible with healthy grieving.

Social Constructionist Theoretical Groundings

Some grief theorists have begun to modify this medical model of grief and to introduce a grief model that reflects a social constructivism approach. Kubler-Ross opened this door when she reported that the meaning of death can be individualistic and that spirituality is an important consideration for grieving individuals (1968). Worden also theorized that there are multiple ways of grieving. His "grief task" view acknowledges not every stage must be experienced to reach a healthy resolution of

grief and that the elements of the grief process can encompass both negative

emotions such as anger and depression and positive elements such as peace and

relief (Worden, 1991). Cook and Oltjenbruns (1998) have theorized that mourning is

grounded in culture. It takes place within a sociocultural context that is displayed in

grief rituals. These rituals can be grounded in spiritual traditions or not, but they are

cultural-specific and varied. The impact of ritual is to provide an outlet for feelings

and behaviors and also invite social support and encourage mutual support for

making meaning of the death in that particular cultural context.

In addition, the emphasis on resolving grief within a particular point in time

has begun to be viewed differently. Klass, Silverman and Nickham (1996) with their

continuing bonds theory of grieving have questioned whether the work of grief is

resolution at all. They believe the bereavement process is lifelong and is the

experience of continually negotiating and renegotiating the meaning of the death

over the life span of the bereaved. One never comes to acceptance but reaches

periods of understanding that are fluid and changeable (Klass, Silverman &

Nickham, 1996).

These approaches to grieving clearly support that grieving has a cultural

context, and not a linear, stage process. Ritual and social support are validated and

grief is seen as a social *and* intrapsychic experience. Remembering the dead is not

necessarily pathological. Resolution is not the goal but understanding the process is.

Finally, the expert in their grief is the bereaved and they are the holders of

knowledge about their unique and common experiences.

In viewing definitions normal and complicated grief, social constructionists point out that these definitions mirror the culture's norms of what is acceptable and what is not. So each culture identifies "mourners who obey the rules and those who do not" (Walter, 2005). Theoreticians and researchers have pointed out that these definitions reflect primarily a North American, Caucasian, middle-class, spousal loss perspective (Center for the Advancement of Health, 2004, Stroebe et al. 2003; Valentine, 2006). Moreover, Walter (2005) contends that the "grief police are not doctors…counselors… they are ordinary family member" who label the grieving individual as sick because they do not conform to cultural/family mores (p. 76).

Social constructionists identify multiple ways of knowing about grief and multiple ways of grieving. Grieving individuals from other cultures are not mandated to move on. Many engage in ancestor worship, communication with the dead, visions of the deceased, and so on that are not troubling nor impair the functioning of the surviving loved one but enhance their lives in a positive way (Hogan, Worden, & Schmidt, 2003-2004; Walter, 1997; Goss, 1997, Raphael, 2000).

In addition, prolonged grief over time (the key indicator of complicated grief) does not necessarily impair the person's functioning in their daily lives; in fact it may improve it. Roger Kemp, whose daughter was brutally murdered on June 18, 2002 in Kansas City, states that he thinks about her "all the time", "feels" her presence with him often, and feels guided by her memory. This does not trouble him but he states that it is a source of "strength" and "comfort" (personal conversation, April 10, 2007). He feels that the creation of the Ally Kemp Foundation to teach

young girls self-defense and safety tips has made him and his life better. Also this

prolong engagement may serve to change a culture and lead to a more just society.

For example, the death of a young man because of a drunk driver led to the creation

of Mothers Against Drunk Driving (MADD) and resulted in the creation and better

enforcement of drunken driving laws (reference). The Mother of the Plaza de Mayo

(Argentine mothers of disappeared children) resulted in a change in government

(reference). There are many more examples. Perhaps complicated grief (not letting

go) can be a positive influence on individuals and on society at large.

Transpersonal Theoretical Groundings.

A transpersonal approach to grief theory has also emerged. Whereas, the

medical model focuses on the negative aspects of grieving and seeks to identify

pathologies and the social constructivist model looks to enlarge the ways people see

grief and to affirm the importance of the context of the loss, transpersonal

approaches take the discourse one step further. The process of grief is seen as having

a complex pattern of adaptation to loss, which is neither linear or in stages (Hagman,

1995). Symbolic bonds with the deceased are not just acknowledged but celebrated

as healthy experiences. Shapiro stated, "Grief is resolved through the creation of a

loving, growing relationship with the dead that recognizes the new psychological or

spiritual (rather the corporeal) dimensions of the relationship" (1996, p.552). The

impact of how bereaved individuals experience loss includes uplifts such as

spirituality, relief and comfort (or etc.) (Attig, 1996; Calhoun & Tedeschi, 1990;

Neimeyer, 2002; Singh, 1998). Grieving is also seen as a social event. How we

grieve and how well we are supported in our grief cannot be separated and can give clues to problems coping with our losses (Nadeau, 1998). Awareness emerges that grieving may not be just a negative process but also a time for post-traumatic growth, for a reassessment of the meaning of life, and for an opportunity to evaluate the important elements of life (for example, human relationships, culture, and spirituality) (Neimeyer, 2002; Singh, 1998). Attig verbalized his view of this opportunity as a "reorganization… as we relearn…we reweave the fabric of our lives and come to a new wholeness, (1996, p. 146).

This view of grieving does not discount that grief can change lives in a negative way but contends that it is equally possible that grief can be a positive, growth experience. It acknowledges that grief is a process that is long-standing and the task is to stay connected to the person in a spiritual or psychological way. We never forget the ones we love nor do we stop loving them. It is the context of the love that changes. This transpersonal perspective holds that the pain of grief has purpose and meaning; that we re-grieve through our life span and can make, reassess, and create different meanings of loss as we age; that we are the experts on our grief but it is not just a personal process but a social one. Finally, it posits that grief is an important component of life and it is trying to avoid loss and its implications that create problems for the individual (Neimeyer, 1996).

In summary, end-of-life care is deeply-rooted in three different and sometimes conflicting models of health care. These models are the medical model, which is the oldest and still most widely experienced by dying individuals; a

palliative care model, which supports comport care as just as important as curative care; and a transpersonal model which views death as a normal life event and one that is a opportunity for growth and meaning. Grief theories have also paralleled these care models. Stage theories of grief tend to support a pathology-focused medical model. Continuity and cultural theories of grief reflected the importance of ritual, community, and lasting connections to the dead as positive elements. Finally, post-traumatic growth theories view loss as meaningful and opportunities for both an individual and their community's growth and development.

<div align="center">Scale Development and Connections to Complicated Grief</div>

Many scales have been developed to address identifying grief reaction and complicated grief. Initially the scales used were depression-based scales (Beck's Inventory of Grief, for example) but grief manifests itself in depression that may mirror clinical diagnoses but is different in many ways (Jordan, Baker, Matteis, Rosenthal, & Ware, 2005). These initial depression inventories proved to be poor discriminators. Further development of grief scales sought to understand the key components of complicated grief as identified by early researchers and practitioners (Bowlby, 1982; Kubler-Ross, 1968; Lupi, 1983; Parkes, 1975; Rando, 1993; Wofelt, 1983; Worden, 2001) from normal grief experiences that will resolve over time. A sample of grief scales developed over the last twenty years are: the Risk Index (Parkes & Weiss, 1983); the Grief Experience Inventory (Sanders, Mauger, & Strong, 1985), the Texas Revised Inventory of Grief (Faschingbauer, Zisook, & DeVaul, 1987), the Inventory of Complicated Grief-Revised (Prigerson et al., 1995),

the Core Bereavement Items (Burnett, Middleton, Raphael, & Martinek, 1997), the

Hogan Grief Reaction Checklist (Hogan, Greenfield, & Schmidt, 2001), and the

Grief Evaluation Measure (Jordan et al, 2005).

 In assessing these scales the links between the conceptualization of

complicated grief's component, its applicability to practice, its reliability and validity

testing, and its ease of delivery were evaluated as to strengths and weaknesses. With

regard to this study the Inventory of Complicated Grief-Revised (ICGR) emerged as

a good choice for an instrument due to its strong connections to theory and practice.

Prigerson et al. (2006) have systematically defined the elements of complicated grief

and have critiqued the above scales in relation to this definition and the current state

of research with the above scales. Prigerson et al. definition postulates that

complicated grief has components as irritability, tenseness and restlessness that are

connected to anxiety reactions and sad mood, guilt and anhedonia that are connected

to depression reactions but have a "uniquely grief-specific profile" (2006, p. 66).

This profile includes a persistent preoccupation with thoughts of the dead person;

ruminating, yearning, and searching for dead person; disbelieving and feeling

stunned about the death and not accepting the death (Prigerson et al, 2006). This

grief profile is also persistent over time, whereas, disbelief about the death, non

acceptance, and preoccupation with thoughts about the person's last days is typical

of the newly bereaved. These elements persist past six months (Prigerson et al,

2006). In examining the 19 items of the ICGR, connections to these defining

elements are readily evident. In particular the 19 items of the scale connect to these

three groups. Table 1 reviews the particular item and its theoretical connections to

complicated grief.

Table 1

ICGR Items and Conceptualizations

Item	Concepts
Thinking about person prevents normal activities	Rumination, preoccupation
Cannot accept death of person	Non-acceptance; disbelief
Drawn to places/things associated with deceased	Preoccupation
Disbelief over what happened	Disbelief; non-acceptance
Hard to trust people	Anxiety
Lost the ability to care	Depression
Pain in body (somatic reaction)	Depression, anxiety
Life is empty	Depression (anhedonia)
Hear the voice of the deceased	Disbelief, yearning, preoccupation
See the deceased person	Disbelief, yearning, preoccupation
Feel bitter	Non-acceptance, depression
Feel lonely	Depression, yearning
Feel envious	Non-acceptance, depression
Avoidance of reminders of deceased	Preoccupation, non-acceptance, anxiety
Feeling angry	Non-acceptance, depression
Feel unfairness of death	Non-acceptance, depression
Memories are upsetting	Non-acceptance, anxiety, depression
Stunned or dazed over what happened	Disbelief, non-acceptance

| Longing for person | Preoccupation, yearning, rumination, disbelief, depression |

Furthermore, the ICGR scale attempts to concentrate on the defining elements of complicated grief versus normal grief. Depression is expected in normal grief (the loss of a loved one is sad); anxiety is expected (a death shakes our belief in a world that is predictable and controllable). Complicated grief occurring with these issues does not abate but become life altering in a negative way. Consequently in looking at Table 1, the elements of the rumination, yearning, preoccupation and negativity are contained in the items of the scale. The Risk Index (Parkes & Weiss, 1983) and the Grief Experience Inventory (Sanders, Mauger, & Strong, 1985) scales do not take into account this need for differentiation and concentrate on anxiety and depressive aspects only. The Texas Inventory of Grief contains items that theorists believe is normal bereavement. For example, one of the items states that no one will take the place of my loved one—a normal statement about grief not a pathological response to loss (Faschingbauer, Zisook, & DeVaul, 1987). Also this scale does not have the extensive validity and reliability with follow up testing as does the ICGR (Prigerson et al, 2006). Finally, Grief Evaluation Measure (Jordan et al, 2005) is very new and undergoing its initial validation testing.

Another favorable aspect of the ICGR is the links to advocacy within the grief counseling community to include this as a diagnostic category in the DSM-V. If this category is included it will help the health care professional to be more aware of the differences between normal and problematic grief, encourage a more rigorous

look at symptoms, and allow the grieving individual a billable category that may increase seeking help.

Limitations to this instrument are important to note. Despite its strengths, the ICGR is also grounded in a medical model theoretical perspective that views prolonged grief as pathological and intense grieving emotions as a disease. One could make a case that it further entrenches practitioners in the medical model. In looking at particular questions within the ICGR from a social constructivist or transpersonal model, alternative explanations (not pathology but strength-based) could be made. Table 2 looks at of the questions and postulates an alternative way of understanding these events.

Table 2

Possible Alternative Explanations for ICGR Items

Item	Alternative Conceptual Understanding
Cannot accept death of person	Acceptance not a goal (Silverman & Klass, 1996)
Drawn to places assoc. with deceased	Preserving bonds (Silverman & Klass, 1996)
Life is empty	Reordering life narrative/meaning-making (Janoff-Bulman & Berger, 2000; Neimeyer, 2005-6)
Hear the voice of the deceased	Spiritual experiences (Attig, 1996; Neimeyer, 1995)
See the deceased person	Spiritual experiences (Attig, 1996; Neimeyer, 1995)
Feel unfairness of death	Reordering life narrative/meaning-making (Janoff-Bulman & Berger, 2000; Neimeyer, 2005-6)
Memories are upsetting	Preserving bonds (Silverman & Klass, 1996)
Longing for person	Acceptance not a goal and preserving bonds (Silverman & Klass, 1996)

Seeing these items as indicative of problems, preclude other ways of knowing.

However, if the practitioner is aware of the importance of context for these items

then the validity of the instrument can be confirmed for the individual. For example,

if the sight of the deceased loved one compels the bereaved to be more depressed and

more anxious then this could lead to complicated grief. However, if the person finds

this vision comforting then possibly it is an example of the person grieving well. As with all scales they can point practitioners in the right direction in understanding the person they are working with, but they are not deterministic and are flawed if follow-up assessments are not conducted

In summary, the ICGR scale is well grounded in a conceptualization of complicated grief that attempts to address the elements of complicated grief but not normal grief. It is linked to a practitioner movement to include "complicated grief" as a diagnostic category in the DSM-V. Limitations do exist with this scale but from the available scales that assess complicated grief, this one appears to be the best available at this time.

<div align="center">Scale Development and Connections to Positive Grief</div>

Whereas there were many options to select from in deciding on a scale for complicated grief, finding a scale that addressed the positive aspects of grief was unsuccessful. Researchers and theorists point out that grief is multi-dimensional but no scale mirrored this. Consequently, a scale that reflected some of the identified elements of positive aspects of grief was devised.

In reviewing the literature about transformative, positive-growth, and developmental grief, these positive elements were identified. First, making sense of the loss in the life narrative was critical Attig (2002) postulates that we relearn "each aspect of our world" (p. 39), and points out that places and events continually challenge us to recreate their importance in the light of the loss. Each special event, our home, every picture, our church, and so on reminds us of our loss and spurs us to find meaning in

it (Attig, 2002). Other theorists concur and identify this as a milestone event in grieving well (Janoff-Bulman & Berger, 2000; Neimeyer, 2002). Another key element to post loss personal growth, in light of the loss, is that we reassess what is important to us as individual and if necessary reorder our lives (Calhoun & Tedeshi, 2002; Frantz, Farrell, & Trolley, 2002; Neimeyer, 2002). Particular examples of this process of reassessment involve qualitative studies in which persons remarked that they were less materialistic, more attached to loved ones, and proud of their accomplishments (Frantz, Farrell, & Trolley, 2002; Tarockova, 1996). Their research points out the awareness of bereaved persons of appreciating life more; more self-esteem. Bartholome echoes this in his statement that death is like sugar; it is what makes life sweet.

An awakening of spirituality is also mentioned often as a benefit of loss. Talbot (1996) and Milo (1997) reported that most of the bereaved persons they studied reported a heightened awareness of the mysteries of life and of spirituality. Frantz, Trolley and Johll (1996) studied 300 bereaved adults and found that 80% of them had a strengthened belief in spirituality, in particular life after death. Chen reinforces this with his remarks that grief has the potential to advance spiritual growth more than any other life activity (1997).

In looking to create a scale that would reflect this positive potential for grief, ten items were created that mirrored some of the reoccurring statements that bereaved people made and reported by the above researchers. Table 3 is a list of the positive grief items and their connections to elements of post-loss growth.

Table 3

Positive Grief Items and Transpersonal Theory Concepts

Item	Transpersonal Concepts
Life has more meaning	Meaning-making
Learned more about myself	Enhanced self-awareness and esteem
Gotten the important things out of life	Meaning-making
Material goods don't mean as much	Reconstruction of values
Better person	Enhanced self-awareness and esteem
More spiritually aware	Spiritual awareness
Good memories of deceased	Meaning-making
Value each day	Meaning-making; reconstruction of values
Don't fear death	Spiritual awareness/enhanced self-awareness
Live life over with few changes	Meaning-making; reconstruction of values Spiritual awareness/enhanced self-awareness

Although these items are untested, they do appear to have face validity in that they address the themes present in positive grief literature. This will be an attempt to balance the negative aspects of grief with the positive ones, looking to see grief not just from a medical model viewpoint but also to incorporate alternative ways of knowing from a social constructivist and transpersonal theoretical view.

Emergence of a Health Care Continuum of Services in End-of-life Care

As stated before, these three paradigms and theoretical approaches currently exist within end-of-life care policies, practices and research queries. At present they are in flux. The medical model is beginning to incorporate elements of a social constructivist model to address the criticisms by consumers and professionals about the defects of a strictly medical model approach to end-of-life care. The palliative care model is appearing in health care venues, from hospitals and nursing homes to dialysis units, but its approach is limited by its willingness to be physician-centered and physician-controlled. The transpersonal care model, which resides primarily in hospice-based venues, continues to see death as part of the life experience to be embraced, celebrated, and supported.

Health Care Continuum of Services

A health care continuum has emerged. The medical model forms the first anchor, since the medical care setting almost always forms the basic initial intervention for end-of-life care. Moreover, few people with a life-limiting illness do not avail themselves of treatments available to them within the medical model's framework. Moreover, many of the interventions that are fundamental to good palliative care originated with medical model interventions and research.

The healthcare providers at this anchor (the medical model healthcare providers) have also professional standards for good end-of-life care that mirror the best practices identified in research studies. These standards include the EPEC for

physicians (Emanuel, Von Gunten & Ferris, 1999), the ELNEC for registered nurses (English & Yocum, 1998), the NASW Standards for social workers (NASW, 2003).

However, these professional standards are prioritized differently depending on the medical model's theoretical and practice paradigms. Medical care paradigms emphasize information on the disease, treatment options, plans of care, respect for the individual and their culture and listening. Availability of the health care provider, emotional support, and referrals to services are next in importance with spiritual support, information on dying, and information on bereavement of lesser importance.

As the disease progresses and if symptoms become problematic, the medical care model can move to incorporate a palliative care model. This model is embodied in the work of the palliative care team. This team shifts the emphasis to plans of care that involve palliation (drugs, alternative therapies, and so on), treatment options with regard to comfort care, emotional support with particular concentration on culturally competent support, and spiritual support as the team works to provide comfort. It is important to note that palliative care teams provide services to those persons wishing to continue to have aggressive treatments or do not wish hospice services. Referrals to the palliative care team for services are ordered by the primary physician and vary in intensity and time of services. Services such as referrals to additional services, information on dying, and information on bereavement are secondary concerns. In addition, information on disease, listening, respect and availability have been established in the first tier of medical care services and should be continued into the palliative care services. Palliative care team services also

acknowledge that services to the caregivers and loved ones of the ill person are important. Palliative care teams are encouraged to include a caregiver's need assessment and to provide support to them. As the disease progress and if the ill person wishes hospice services, then the emphasis shifts to the transpersonal needs. Building on the services from the medical care model and capitalizing on them, hospice care continues with plans for care, treatment options that do not include aggressive treatments, listening, availability, and needed referrals. More emphasis is put on the meaning needs and include emotional support, spiritual support, respect for culture and the meaning of loss and death in the person's culture, inclusion in plans for care so that those plans promote comfort and are meaningful, information on the dying process, and information on bereavement. Only in the hospice model is the mandate for services to caregivers and loved ones included. Hospice in theory and practice sees the client as not just the person who is ill but also the surrounding loved ones.

In summation, by conceptualizing a Continuum of Health Care Services at End-of-Life, the key best practices are all included at each level but the emphasis on the order in which these practices are delivered or if they are delivered are dependent on the model of care involved. Figure I displays the general emphasis that each model brings to end-of-life care services.

Figure 1. Continuum of Health Care Services in End-Of-Life Care
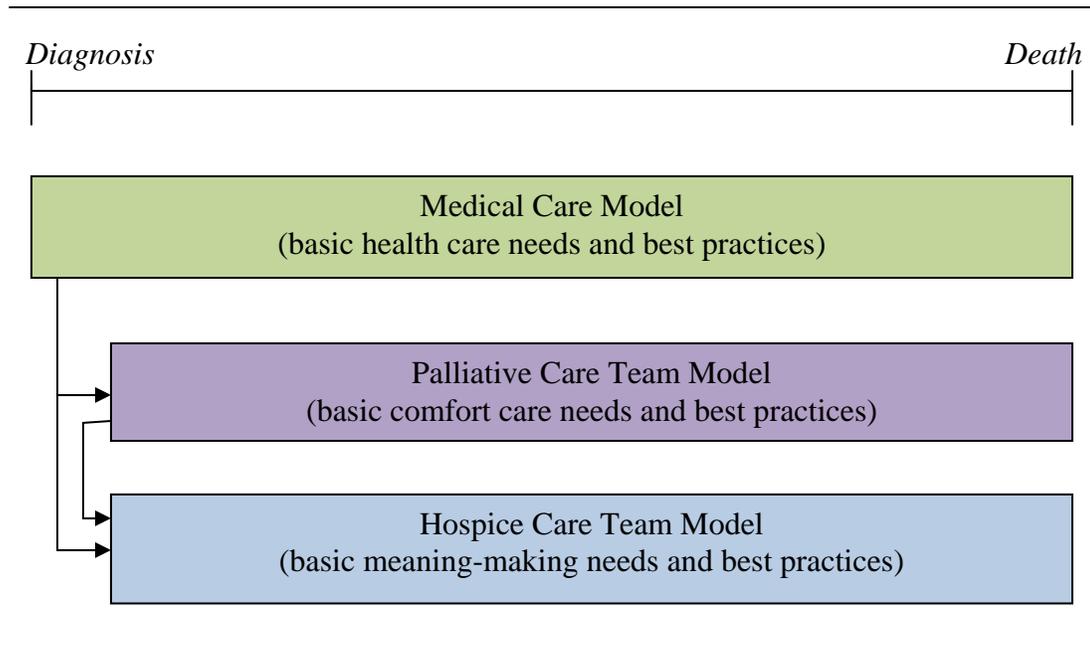
The figure reflects that each model of practice is capable of provide good end-of-life care, yet each prioritizes vital needs at particular times in people's lives and deaths. They all build on one another and good end-of-life care cannot exist without each element. Good treatment and symptom management are necessary for people to attend to connections and relationships as well as fulfill their desires to extend their lives if possible. Good comfort and connections allow movement to understand how we fit in the scheme of life, what is missing that we wish to address, and what is to be celebrated. In addition, this figure points out that medical care model controls the entry into both palliative care and hospice services. Also a person and their loved ones might also experience all three models in their healthcare experience. A person may continue to receive medical, aggressive care with palliative care team

consultations and then later choose to forgo aggressive care and enter hospice services.

Additional Considerations Regarding End-of-life Research

Conceptualizing the integration of the three theoretical models as building one upon another may be seen in both policy and practice. However, this does not negate the problems of end-of-life research has encountered. Certainly, research studies grounded in the distinct paradigms have contributed to our knowledge base, just as research from each paradigm has served to contribute to the lack of rigor and clarity. One can point to methodological flaws in all these approaches but these are flaws that can be corrected with better methodological designs. However, since each paradigm has a distinct language and viewpoint, end-of-life research can seem like comparing apples and oranges. This disjuncture is not easily solved. One way to help disentangle this problem is for researchers to be clear which theoretical paradigm is driving their study. Clear operational definitions will also help. Moreover, researchers can begin to be sensitive to the impact of the findings from a study in one paradigm influencing studies that are grounded within others.

For example, the SUPPORT study has been considered the seminal research study conducted within the medical model and clearly stated this positivistic grounding. It is of broad scope, large sample size, and methodological rigor and involved a control (experimental) research design. Briefly it explored the experience of dying in 9,000 patients with life-threatening illnesses in multiple hospitals throughout the United States. The researchers gathered data from ill persons, their

physicians, chart information, and cost analyses to record key therapeutic decisions, patient outcomes, and the efficacy of a nurse and physician treatment team approach to advanced planning. Results from this study failed to substantiate the efficacy of the treatment team in facilitating patient decision-making and communication of those decisions. It did spotlight the current experience of dying in these hospitals. Key finding from this study are as follows:

- Over 50% of the patients experienced moderate to severe pain during the last few days of their lives;

- Fifty-three per cent of physicians were not aware or were unclear as to their patient's preference for end-of-life care (especially CPR status);

- Thirty-eight per cent of the patients experienced what was defined as prolonged suffering; and

- Over 50% of the family members of the dying patients experienced some form of concurrent major life stress as loss of job, depleted savings, or loss of their own good health (SUPPORT, 1995).

Although this study appeared to confirm that the current medical model of end-of-life care was not working well for consumers or their families, it did spur further research on ways to improve end-of-life care. From this study, many additional quantitative and qualitative studies on decision making, pain management, emotional and physical suffering, and family burden directly cite the SUPPORT study as the impetus for their research (Steinhauser et al, 2000a; Steinhauser et al, 2000b; Steinhauser et al, 2001; Teno et al, 2004). Moreover, this research has

spawned research within a medical model framework (Kwak & Haley, 2005;

Wenrich, Curtis, Ambrozy, Carline, Shannon, & Ramsey, 2003) and also within

palliative care models (Pizzi & Briggs, 2004; Winston, Leshner, Kramer, & Allen,

2005) and transpersonal/hospice models (Block, Billings, & Andrews, 2005). This

study exemplifies how information gleaned from one theoretical model informs the

other models. Although these models might appear to be conceptually separate,

research appears to support that they are interdependent.

<div align="center">Additional Impacts on This Study's Methodology</div>

<div align="center">*Theoretical Implications*</div>

Each theoretical paradigm has embraced a research methodology of choice.

Positivistic

research is generally quantitative in structure and social constructivist and

transpersonal research is usually qualitative. However, the topic for this dissertation

does not lend itself easily into any one paradigm. This researcher's contention is that

current end-of-life care is a mélange of all three paradigms and the best way to

capture this mélange is to include aspects of each paradigm in the research.

<div align="center">*Special Challenges of a Bereaved Population*</div>

Although the number of both qualitative and quantitative research studies

have grown dramatically over the last ten years, ethical and design issues continue to

be evident in end-of-life research. Challenges include ethical mandates of

respectfulness for each individual and their loss, confidentiality, sensitivity, and clear

connections between risks and informed consent (Phipps, 2002). In addition,

compliance with the national standards to protect privacy in personal health information codified in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) (US Congress, 1996) has enacted more safeguards to the consumer and required more documentation by the researcher. This translates into increased rigor in designing methods so that clear operationalization of concepts and methodology are spelled out and validated and reliable measures are used when possible so that implications can be drawn as accurately as possible and limitations known (George, 2002). Moreover, this population is not easily identified and not particularly accessible. Agencies that deal with end of life issues are very protective of their consumers and need assurance that confidentiality and sensitive research practices will be used. This study attempts to address these concerns, specifically in the subsections of survey construction and confidentiality.

Overview of Researcher Bias

Although the positivist paradigm does not validate the importance of the researcher's value stance, disclosing one's conceptual paradigm is important to the clarity of the research study. The positivistic medical model has excelled in its acquisition of knowledge about disease and its causes. However, this model approach has been reluctant to address well-being and quality of life concerns. The limits contained within the medical model, for example, allow only observable, testable events as knowable. This places the quest for knowing within sharp boundaries and encourages a tunnel vision that hampers alternative ways of viewing development and growth.

The social constructivist/palliative care model, on the other hand, acknowledges multiple ways of knowing and celebrates diversity. It expands the vista of knowledge and encourages exploration. However, the lack of a value stance within social constructivist thought that all possibilities have equal weight, can be a severe limitation. Growth as a part of the change process happens but considering it as non-directional and haphazardness discounts the possibility for upward movement to greater understanding and development.

A transpersonal paradigm includes multiple ways of knowing; acknowledges that there are many individual truths; and postulates that there is an all encompassing Truth that we strive to grow towards. It acknowledges that well-being is grounded in physical and mental health, but expands that to spiritual and social health as well. It embraces measurable, observable data, as well as values non-measurable data as awareness, inspiration, and insight. As social workers, our professions is committed to assisting people to reach their fullest potential and to striving to create societies that support personal growth without oppression and social injustice. The tenets and mission of social work is firmly entrenched within a transpersonal paradigm. This has been highlighted earlier in the paper in the Social Work Standards for Professional Practice in End-of-life Care and the support for a transpersonal paradigm in end-of-life care is included within these practice standards. From this researcher's professional experience as a hospice social worker, growth occurs throughout the life span even as a person nears their death and that growth at the end of the physical life can be transformational for both the dying person and their loved

ones. Thus, a transpersonal paradigm is confirmed by social work's professional

standards, and this researcher's personal values, and practice wisdom.

Chapter 2 Summary

Within our current health care system, three ontological and epistemological models co-exist. The medical model is based on positivism and focuses foremost on aggressive medical intervention. This medical model has guided health care throughout the twentieth century and is still the dominant discourse. A social constructivist model has made some inroads into end-of-life care and has shaped the palliative care movement. Within the health care systems, palliative care teams have emerged in hospitals and extended care facilities to offer consultation and support. The third model is a transpersonal model that is best reflected in hospice philosophy and services. This model honors the positive contributions of aggressive care and palliative care while adding components of meaning making that encourages living fully until death. Although often treated separately, the need for integration of these three models is imperative. From this discourse on these three models of care, a Continuum of Healthy Care Services is proposed. This conceptualization describes the co-existence of these models but also shows their interactive nature and developmental potential.

Each of these models has conceptualized grief in a particular way. Of particular interest is the way in which normal grief, complicated grief, and positive grief are viewed, since these conceptualization guide practitioner's interventions. It is important to understand interventions that decrease complicated grief and increase the growth of positive grief. Although complicated grief scales have emerged from these models, no measures of positive grief have been developed. The rationale for

the choice of a complicated grief scale was discussed earlier as well as the rationale

behind the creation of a positive grief scale.

CHAPTER 3: Study Method

Death teaches us...that the time is now.
Death teaches us the joy of the moment.
It teaches us we don't have forever. Death says, "Live now."
---. Leo Buscaglia

Methodology

In reviewing the relevant literature, a case can be made that end-of-life care has benefits for the person dying and the family and friends during the life of the person and throughout bereavement. The extent and quality of these benefits will reflect the experience of the service model—aggressive care, palliative care, or hospice care. It is possible and even probable that through the course of a life-limiting illness a person would experience all these service models. For the purpose of this study, only the model that the person was receiving at the time of their death is of interest. Death is such an overwhelming event that the services and the support health care professionals give at this time will be memorable and likely to influence the surviving caregivers and loved ones.

Quantitative Study

This study was predominately a quantitative study of the impact of the model of care received at the time of death on the grief reactions of surviving family/friends. This quantitative study involved a mailed survey to surviving family and friends to assess whether the model of care they experienced with their dying loved one was associated with their current grief experience. Additional questions addressed demographic data and self-reported satisfaction with health care professional support. Open-ended questions were included at the end of the survey to specifically assess what health care providers did that was helpful to the loved ones in their grieving process and to ask for any other comments.

Research Questions and Hypotheses

The research questions were as follows:

1. Is positive grief associated with the model of end-of-life care received by a loved one at the time of his or her death?

2. Is complicated grief associated with the model of end-of-life care received by a loved one at the time of his or her death?

3. Does any particular demographic factor place persons more at risk for complicated grief? (Are any associated with positive grief/)

4. Are any services or supports (identified best practices), delivered by health care professionals, more present in a particular model of care or rated as more helpful in a particular model of care?

Specifically my hypotheses are:

1. With regard to the models of care and positive grief

A). Surviving loved ones of a hospice client will display significantly greater positive grief scores than palliative care and aggressive care clients.

B). Palliative care clients will display significantly greater positive grief scores than aggressive care clients.

2. With regard to complicated grief

A). Surviving loved ones of a hospice client will display significantly less complicated grief than palliative care and aggressive care clients.

B). Palliative care clients will display significantly less complicated grief than aggressive care clients.

3). Persons who are female, older (age 60 and above), and non-majority ethnicity will display more complicated grief than men, persons under 60, or persons of the   majority ethnicity.

4). Length of engagement in the model of care will impact grieving well.

A). Short length of stays in hospice will have an inverse relationship with positive grieving.

B). Few consultations with palliative care teams will have an inverse relationship with positive grieving.

5) Ratings of health care professionals will be positive in all models of care.

A). Hospice professionals will have greater positive scores than palliative care professionals.

B). Palliative care professionals will have less positive scores than hospice professionals but greater positive scores than aggressive care professionals.

Rationale for the Research Design

The research methodology was primarily a quantitative survey design. Although the literature review highlighted both quantitative and qualitative studies that explore patient care and family and friend support in end-of-life care, my research questions sought to explore the effect of a particular model of end-of-life care on two dimensions of grief reactions. The strengths of survey research included

the ability to ask a variety of questions on a particular topic; the ability to analyze multiple variables; and the ability to reach many people with a standard instrument. For this particular population, this method was felt to be less intrusive (it comes to the person's home) and would be less intensive (it can be stopped if strong feelings arise). Tennstedt (2002) in her commentary on the "state of the science" in end-of-life research clearly advocated the use of quantitative methods "to investigate the effect of different treatment interventions or models of care" (p.101).

Protection of Human Subjects

Approval of the study by the Human Subjects Review Committee—Lawrence of the University of Kansas was obtained before any data collection. The participants were assured that they and their loved one's names would remain confidential. Only I have the master list that delineates which survey was completed by which participant. That list and the response cards are locked in a cabinet and no one but this researcher has access to the key. Data recorded on my computer was also protected since my computer is also password protected. Further protections for the participants included partnering with Cancer Action to provide bereavement follow up services if necessary. With the survey instrument, a card listing the agency's name, phone number, and contact person was included with instructions to contact the agency if negative feelings or concerns arose because of the survey items or memories

Study Design

Sample Size and Power Calculations

A sample size calculation was conducted using Sample Size Calculator

(Creative Research Systems, 2003) to see how large of a sample size was required to

ensure that statistical tests would have adequate power. A power analysis is of

benefit for this study since it reduces the possibility of committing Type II errors

(not rejecting the null hypothesis when you should). Power is dependent on four

things: sample size; the effect size (beta), the Type I error rate (alpha) specified, and

the variability of the sample (Cohen, 1990). A sample size of 232 or more is

necessary to have alpha at .05 and beta at the .80 level. Through this power analysis,

the sample size will not be as large as for everything to be determined statistically

significant and not so small as to have real differences go undetected.

Sampling Plan

The sample was obtained through a partnership with a local cancer support

agency. This agency provides a wide range of services. They provided services to

over 4000 consumers in 2006 and received referrals from eight major hospitals

(Agency Annual Report, 2006) Available through their databases was information

on whether clients received hospice, palliative, and/or aggressive care services, date

of death of the ill client, age of deceased at time of death, and identified primary

caregiver. The contact persons at this agency were their executive director and their

program director. The program director was the contact that secured the database

names and supervised the mailing of the letter of invitation to possible respondents.

In order to reduce sampling error and decrease confounding variables, the sample was matched on the following variables: all the survivors cared for a loved one with cancer; had a close degree of affinity (spouses/partners, siblings or children) to the deceased; and identified themselves as "caregivers". In addition, the survivors lost a loved one more than six months but less than three years ago (person died between May 2005 and January 2008). Scale developers of the ICGR scale have suggested that it be used at least six-months after the loss. Their research, including a DSM-V field trial, indicated that complicated grief symptoms (after) six months were more valid than assessments made earlier (Prigerson et al, 2008). Moreover Rando (1993) and Tedeshi et al. (1998) also consider six months or longer post death as an indicator as to whether or not the person is experiencing complicated grief. Other studies have sought to clarify when is the best time to administer any grief scale and concur that waiting at least six months to a year is preferred (Zhang, 2006; Stroebe, 2005; Silverman, 2000; Rando, 1993). By waiting at least six months to access grief, there will be less likelihood of false positive diagnoses (Type 1 errors). From the database available through the host agency, a total of 2175 persons died between May 1, 2003 and January, 2008). Of those, sixty-one percent listed a "next of kin" contact (personal communication with program director, 6-2-09). Therefore 1327 were possible study participants.

In following the initial sampling methodology, the first wave of letters (encompassing those who were bereaved from May, 2006 to May, 2007) was sent out in early May, 2008. This initial mailing was to 627 individuals. As of June 26,

2008, only 61surveys were returned. Because of this poor response rate, this researcher spoke with the methodologist and also with the coordinator of the mailings at the host agency. The decision was made to send out the second wave to all the persons who lost a loved one from May, 2005 through January, 2008. This deviated from the initial plan to conduct a random sampling of those who had medical care, palliative care, and hospice care.

Therefore, 700 letters of invitation were sent out in this second wave in July, 2008. In total, I sent out 1327 letters of invitation to the host agency's consumers which represented all the bereaved persons in their database from May, 2005 through January, 2008. However, even with this expanded sampling plan, the response rate remained very low with only 180 individuals completing the survey (this will be discussed later in the findings section).

Survey Type

A mailed survey design was chosen. This survey design allows the researcher to address sensitive topics and reduce possible social desirability biases (Dillman, 1999). The host agency's director wrote a letter of support for the study that was sent to the potential sample participants. The response cards were sent directly to this researcher and surveys were sent out within five days of receipt of the response card. Follow-up reminder post cards were sent two weeks after the initial survey mailing. At one month, if no survey had been received, I sent a second survey mailing. These documents are in the Appendix.

Procedures

Survey Booklet

Following the suggestions of Dillman (1999), attention to how to reduce the "costs" of completing the survey was considered. The survey construction took into account the possibility that the respondent was older. Therefore, the type was a larger font (14) and white space was used to make the survey appear less lengthy and easier to complete. The booklet itself with the cover, title, cover letter, and instructions was meant to be inviting, colorful, and respectful of their grief and their memories. An informational letter introduced the study and providing informed consent information that accompanied the mailed survey. Respondents were not asked to return a signed copy of a consent form due to the fact that completing and returning the survey implied consent.

The survey instrument itself was comprised of four sections. The first section asked demographic questions. The second section sought information on the survivor's perceptions of support and inclusiveness of certain services by health care providers. These services have been identified in the literature by consumers to be best practices in end-of-life care. The third section included a tested scale, the Inventory of Complicated Grief Scale (revised) [ICGR] and a series of questions derived from the literature to assess positive grief. Finally, the fourth section included questions about the type of model of care, satisfaction with the model, and the open-ended questions. The outline for the survey is as follows:

Table 4

Survey Component and Corresponding Questions

Section	Question
	Number(s)
1. Demographic questions	1-9
2. Services received & best practices	10-22
3. a. Inventory of Complicate Grief Revised Scale	23-25-26-28-29-31-32-34-35-36-38- 40- 41-43-44-46-48-49-50
b. Positive Grief Scale	24-27-30-33-37-39-42-45-47-51
4. Model Confirmation, satisfaction ratings, and Open-end questions	52-57

Copies of the survey instrument are in the Appendix.

Survey Pilot

Before disseminating the survey questionnaire to participants seven experts were consulted to critique and to provide comments about the questionnaire. Three experts were persons who had lost loved ones during the past three years. Four experts were health care professionals.

Consumer Experts

The surviving loved ones were recruited from an aging network group that meets monthly in North Kansas City. The facilitator of this group distributed a business card and an informational flyer to the group members. Two women and one

man responded. The ages for the pilot participants were 66, 69, and 70. The average

time from the loss of their loved one was 1.3 years and none had lost a loved one less

than one year ago. All were Caucasian, and all were caregivers for their loved ones at

the time of their death. Two had not used hospice; and none had a palliative care

consultation. One person's deceased loved one had died at home; one in a nursing

home; and one at the local hospital.

The questionnaire was mailed to them and they were asked to call within two

weeks when they were able to complete a telephone survey. Comments from the

individuals were obtained by phone and this researcher took notes about their

critique. The questions to them included:

1) What is your overall impression of the questionnaire?

2) How long did you take to complete it?

3) Did you understand the questions? (Were they clear?)

4) What suggestions do you have for me about the questionnaire?

Overall, the persons remarked that the survey was very "interesting" in that it

asked them to think about what the health care providers did that helped them grieve.

All remarked that they had not really thought about how support at end of life

influenced how they might cope with their loss. However, all also remarked that in

thinking about it, they thought that it had. The loved one associated with hospice

particularly remarked that health care providers had helped her "immensely". The

two non-hospice loved ones remarked that questions about spiritual support,

respectfulness, and community referrals were interesting since they had not received and had no expectations of the health care professionals to address these needs.

In looking at the grief questions, all felt that the question about seeing the deceased stand before them should be deleted (one remarked that it was just "too creepy" and two reported that "seeing" their loved one was a "blessing"). All also stated that the questions about material goods and changing almost nothing in their lives gave them as one person said "a lot to think about". But they all agreed that these were questions that should remain in the questionnaire. All of the pilot participants requested a copy of the dissertation's findings and analysis when it was completed.

The mean time to complete the study was 23.6 minutes with one completing it at 18 minutes; one at 23; and one at 30. All remarked that the questionnaire was a little long but not burdensome to complete. Two persons remarked that the questions around clarity of palliative care services were a concern, since they did not know what they were or if their loved one had received them. No other question was identified as unclear. None offered any further suggestions.

<div align="center">Discussion of Consumer Expert Critique</div>

In analyzing the information received from these three consumer experts, the consumers potentially mirrored the demographics from the sample from the agency. Most of the sample would be over 65; most would be Caucasian; and no one would be sampled within one year of the death of their loved one. Also all were hands-on caregivers for their loved one before their death. Luckily the three volunteers also

had varied experiences with end of life care (one hospice) and had varied experiences with health care professionals at the time of death (one at home; one in a hospital; and one in a nursing facility). For the above reasons, this researcher felt that the consumer experts would be able to critique the questionnaire well.

In addressing these questions, the consumer experts had remarked that the questionnaire was engaging and the questions made them think. They all stated that it was generally clear. Since consistency in following the findings of the components of a "good death" as identified by researchers as Steinhauser et al. (2001), Pierce (1999), Chochinov (2003) and others was important, no questions about cultural respect, spirituality, and community referrals were deleted. It was also important to preserve the integrity of the complicated grief scale, so none of these items were deleted. In addition, the comments about the positive grief scale suggested no deletion of any of those items.

The comments about the palliative care questions were also of concern. This researcher did ask follow up questions to the consumer experts about the experience of caregiving for their loved ones. The first concern was about symptom management (palliative care services are geared to controlling symptoms). All stated that their loved ones' pain was under control. Two remarked that constipation was a problem at times. All remarked that their loved one was restless and agitated at times. One remarked that she felt her husband was "awfully depressed" for at least a year. From this information this researcher felt that all of the deceased loved ones had needs for palliative care interventions (physical and mental discomfort). The

second concern was about the care providers and their settings. The hospice

consumer had heard of palliative care and was aware that hospice was to provide

comfort care services. All the participant's loved ones had been in the local hospital,

within one year of their death. This local hospital has a very active palliative care

team (which routinely leaves business cards with loved ones identifying themselves

as the "Palliative Care Team"), so there was some assurance that none of them had

contact with that team or they would have acknowledged this. This researcher also

checked with the nursing home that served one of deceased and they confirmed that

they do not have a palliative care team but that the nurse "handles patient problems".

Even though there was little evidence of palliative care services, these items were

still retained. Nevertheless, this researcher was aware that there was the possibility

that identification of palliative care providers may be difficult by consumers.

Finally, the consumer experts were asked if the questionnaire and talking to

this researcher about their deceased loved one was troublesome to them or awakened

negative feelings. All responded that they had seen this as an opportunity to "do

some good" and did not have negative reactions to the questionnaire.

Professional Experts

The professional experts were all recruited due to this researcher's contacts

within the health care community. These professionals were experts in hospice,

palliative care, and medical care services. These experts were strategically chosen

due to their connections to the three basic health care models of interest. Two were

connected to hospice care (one as a social worker for over twenty years in hospice

and the other a hospice director and a listserv facilitator for the National Hospice and Palliative Care Organization (NHPCO). One was a seasoned social worker at a local medical center and the final expert was the director of the palliative care team at a local hospital. Three experts were female and one male. No information about age or ethnicity was asked of the professional experts.

The information provided to the professional experts explained the study and asked them to critique the questionnaire. The questions were open-ended and just encouraged the professionals to feel free to say anything they felt was pertinent to improving or critiquing the questionnaire. The questionnaire was faxed to them and they were asked to respond via email or phone within two weeks. Three of the professional experts responded in writing; one was interviewed over the phone.

Other than typographical errors, the comments grouped around issues of time, format for the questionnaire, closed-ended questions, consistency and palliative care. All respondents stated that they thought the survey was very "current" and "topical". As with the consumer experts, all remarked that they found it interesting and were interested in receiving information about the results.

Two respondents stated that the questionnaire was a "little long", but all responded that it was "easy" to complete. One advised me that with her work on the NHPCO Family Bereavement Services survey, it "too is long but (that) has not seemed to affect the rate of return compared to the one page ones folks used prior to that, "because the layout was conductive to completing it, like yours". The palliative care expert stated that his team looked at the survey and felt that it was easy to

complete. Furthermore, he remarked that the survey looked long because of the 14 point font but really was not that lengthy.

With regard to format, one expert felt that the questionnaire should be bound on the left side to make it easier to open and more like a booklet. Another remarked that he felt that the format was good in that easy to answer questions were at the beginning ("helping the person ease into the survey") and at the end ("when they are ready to be done"). Also one remarked that the format had a "good flow" and was respectful and non-threatening.

Other comments centered on question construction and question wording. One of the hospice experts wanted to have more options (other than yes and no) for questions 12-22. The other hospice expert stated that she wanted more open-ended questions but she felt that might add too much to the length of the questionnaire. Another suggestion was that that the choice of words was consistent. In some places, "deceased loved one" was used and in others "person who died". She felt that the grouping of the questions and the repetitive use of the Likert scale were strengths. She remarked that older persons need this consistency and frequency to help them "navigate" the survey.

Finally, only one person critiqued the palliative questions. She stated "The only concern I have…are the questions regarding Palliative Care. That's a term that's used a lot, but people seem to have different definition of what that entails".

Discussion of Professional Expert's Critique

In examining the critique by the professional experts, this researcher decided to keep the number of questions but noted in the postcard insert the information that it took 20-25 minutes to complete the questionnaire. The questionnaire bound on the left so it would be in booklet form. The discrepancies in word use were corrected to mirror the ICR scale. The repetition of the Likert scale values were kept per suggestion, even though it did make the survey appear longer.

With regard to the comments about palliative care questions, one of the professional experts brought this issue up (as had two of the consumer experts). This researcher opted to leave these questions in, again fully aware that these questions might be problematic.

In general, the professional feedback reinforced the belief that the questionnaire would be easy to complete, coherent, and clear. Also the awareness of the professional experts that the questionnaire appeared respectful and non-threatening was appreciated.

In summary, the experts (consumer and professional) who reviewed the questionnaire gave concrete feedback as to both its format and substance. Corrections and clarification were made to the questionnaire in response to their suggestions. The experts did question some of the items specifically regarding the ICGR scale but these items were retained to assure the integrity of the scale. This researcher also opted to retain questions regarding palliative care teams even though some experts questioned whether consumers would be able to identify these teams.

Operational Definitions and Measurement

Independent and Dependent Variables

Independent variables were the models of end-of-life care (aggressive care, palliative care, or hospice care) that the dying person received at the end of their life. Dependant variables were the grief indicators of "positive" or "complicated" grief. Gender, age, ethnicity, length of stay and ratings of health care professionals helpfulness were additional independent variables and were examined in regard to the dependent variables of grief indicators and family satisfaction with health care professionals..

Demographic and Time-Sensitive Variables

Respondents self-report of demographic variables (age, ethnicity, relationship with deceased, and location of death) were gathered. Length of stay was considered to be the amount of time in days from admission to hospice to death of the client. This variable was self-reported and recorded as a continuous variable. Length of contact was deemed to be the number of times that the palliative care team consulted with the family or person about their care. This was also self-reported and recorded as a continuous variable.

Complicated Grief Scale (ICGR scale).

Complicated grief was accessed through the use of the Inventory of Complicated Grief Revised (ICGR). This scale developed in 1995 allows respondents to rate the frequency that they experience each item on a 5-point Likert scale ranging from "always" (1) to "never" (5). Scores can range from 19 to 95.

Scores that are 25 or less indicate "complicated grief". The ICGR has been used in

its original or revised form in research studies since 1995 (Prigerson, Maciejewski,

Reynolds, Bierhals, Newsom et al, 1995). With this scale psychometric properties

have been established. High internal consistency on the 19-item scale was

determined (Cronbach's alpha=.94). Test-retest reliability was also obtained and the

follow-up research found this reliability to be .80.

The ICGR also correlated highly with other scales that measured complicated

grief. With the Texas Revised Inventory of Grief (TRIG), the correlation was .87,

with the Grief Measurement Scale, it was .70, and with the Beck Depression

Inventory, a scale that assessed depressive symptoms, the correlation was .67. Later

studies have found high correlations between scores less than 25 on the ICGR and

scales that assess post-traumatic stress disorder and major depressive disorders

(Prigerson et al., 2007) thus adding to the data supporting concurrent validity. This

scale has been recommended by other researchers for both its concurrent and content

validity and test-retest reliability (Stroebe & Schut, 2005, Zhang et al. 2006, Roach,

2000). In addition, scores indicating complicated grief on the ICGR correlated

positively with scales that identify high degrees of physical pain, social isolation, and

generally poor physical or mental health (Prigerson et al, 1995).

Positive Grief Scale Development

Previous researchers have found that grief is not one-dimensionally negative,

but includes positive growth elements (Attig, 1996; Calhoun & Tedeshi, 2002;

Frantz, Farrell, & Trolley, 2002; Janoff-Bulman & Berger, 2000; Milo, 1997;

Neimeyer, 2002; Silverman & Klass, 1996; Talbot, 1996; Tarockova, 1996). Positive

or transformative grief literature, as discussed before, posits that the loss experience

can lead to a greater appreciation of one's life, an awareness of the important

elements of one's life, and a validation of never ending love within relationships.

However, no scale has been developed to try to assess this construct termed "positive

grief". This researcher's goal was to create a scale that incorporated the findings

from other studies (primarily qualitative) that had reported positive grief experiences.

In constructing scales it is recommended that the researcher generate items that

appear to relate to the concept (Crano & Brewer, 2001). Specifically, other

researchers have reported that positive aspects of grief include:

1) continuing bonds with the deceased that reflect that these bonds give the griever comfort (Calhoun & Tedeshi, 2002; Neimeyer, 2002; Silverman & Klass, 1996) and this is reflected in the question about good memories;

2) positive growth in spirituality (Attig, 1996; Milo, 1997; Neimeyer, 2002; Talbot, 1996) and this is reflected in the question about greater spiritual awareness;

3) self awareness and self esteem (Janoff-Bulman & Berger, 2000; Neimeyer, 2005-6; Tarockova, 1996) and this was reflected in the questions about learning more about one's self and being a better person;

4) value reconstruction and meaning-making (Frantz, Farrell, & Trolley, 2002; Janoff-Bulman & Berger, 2000; Milo, 1997; Neimeyer, 2005-6);

and this was reflected in the questions about greater meaning of life, valuing each

day, and meaning of important things.

Thus positive grief was assessed by ten additional questions developed from the

literature and tested in this study. Since there was no psychometric information for

this untested scale, the data was examined in consultation with the methodologist.

In explaining the development of this scale certain criteria were important to

address since they were guiding elements in the scale's construction. These criteria

were validity, reliability, item clarity, age competency, and coherence.

Validity was dependent on the degree in which the items mirror the elements

described in the literature as indicating the positive elements of grief (Krentzman &

Townsend, 2008). This constitutes the initial formulation of construct validity. As

stated before themes that have emerged in grief literature around positive elements of

grief were used to direct the choice of items. Also face validity was established by

the pilot study and consultations with the methodologist. This is only the first steps

in establishing the construct of positive grief.

Reliability of the scale included the interconnectiveness of the scale as well

as consistency over time (Krentzman & Townsend, 2008). The internal consistency

will be measured through the Cronbach's alpha and an alpha score of .70 or greater

is preferred. Research informs us that in the social sciences it is widely believed that

the minimum Cronbach's alpha is 70 for a set of items to be considered a scale.

Statistics tell us that at that level the standard error of measurement will be over half

(0.55) a standard deviation (Miller & Salkind, 2002).

Further testing will be needed to shed light on this scale's consistency over time.

Item clarity was confirmed by the feedback from the pilot study and also in consultation with the methodologist. Items were worded simply and consistent terms, as person who had died, were used.

Age competency was very important to this scale. It's format with large type was decided to facilitate use with an older population. As stated previously, with an older bereaved population special attention was made to the length of the scale, word clarity and appropriateness, and its ease of completion.

Coherence was also assured through the feedback of the pilot study and the methodologist. The items and response choices were consistent throughout the scale. Also, a Likert format was used since it is the preferred format to assess attitudes and feelings (Crano & Brewer, 2001). A five-point format was used because it was a typical format that might be familiar and thus less confusing or anxiety provoking to the older adult (Jacelon, 2007). The repetition of the Likert items was also seen as helpful for an older population.

<div style="text-align:center">Statistical Analyses</div>

<div style="text-align:center">*Analysis Technology and Quantitative Coding Decisions*</div>

The analyses was performed using SPSS.15.0 This program is well suited for statistical analyses (Green, Salkind & Akey, 2000). This researcher completed all the data entry.

Hypotheses 1 and 2 (associations between model of care and positive or positive grief) were answered with the data obtained in Section 3. The ICGR scores

on questions 23-25-26-28-29-31-32-34-35-36- 38- 40- 41-43-44-46-48-49-50 were summed and mean scores obtained. Since the scale's Likert scale was reversed the recommended cut off score indicating complicated grief was 89. Confirmatory factor analysis of the ICGR scale as well as Independent Sample *t*-tests were performed.

Since the positive grief questions (24-27-30-33-37-39-42-45-47-51) are untested, an exploratory factor analysis was conducted to assess whether any question did not appear to be correlated positively with the remaining questions and whether the questions all appeared to be related to the construct, positive grief. Independent sample *t*-tests were also performed

Hypothesis 3 (associations of demographic variables with complicated grief) were determined through computing frequencies of all demographic information included in Section 1 (questions 1-9) and means of the age and importance of spirituality and religious activity questions. Hypothesis 4 (associations of length of engagement and positive grief) were answered through data obtained in Section 4 (questions 51, 52(a), 53 (a), and 54 (a). Hypothesis 5 (satisfaction ratings of health care professionals) were assessed through the responses to questions 10 through 22. Frequency scores reflecting the answers to whether these services were given and a mean score reflecting the helpfulness of that information was obtained. Crosstabs and chi-square tests were conducted to analyze any significance between the model of services and the presence of the helpfulness variables.

In addition, questions 52(b), 53 (b), 54 (b), and 55 (c) yielded additional satisfaction scores that evaluated the particular model of care. The mean scores of

these questions were then examined to see any connections to positive or complicated grief scores or demographic data were evident.

Finally in Section 4, the responses to the open-ended questions (52(c), 53(c), 54(c), 55, and 56) were recorded and reviewed. Grounded theory principles were employed to provide a process for identifying common themes, similarities and differences in responses (Strasser & Corbin, 1990). The researcher compiled the responses in a Word document and then highlighted the themes and differences using a color coding system. Influencing the thematic headings were the already identified components of positive and complicated grief referred to earlier. As a type of rater reliability measure, the researcher then cut and pasted the qualitative comments on note cards and then analyzed them again independent of the computer coding. Then comparisons as to the color coding and hand coding schemes were made by the researcher. The study's methodologist also viewed the qualitative data and coding schemes. The methodologist consulted with the researcher to determine themes and differences and coding decision were reached through consensus. No member check was employed with participants. Information gathered here informed the answers to hypothesis 5.

Coding Decisions on Quantitative Data

Data was entered in SPSS 15.0. A total of 75 variables were entered from the initial questions. If the question was left unanswered, no coding value was recorded. The respondents for this study were remarkably willing to complete this

questionnaire. With the quantitative data, 92% of the respondents answered every one of items. No respondent failed to complete more than five items.

With regard to the answers about length of time receiving hospice (53 a), medical care (55 a) and number of times of palliative consultation (54 a), a specific time (i.e. 1 day) was recorded. However, two hospice respondents recorded the time in hours and these were rounded up to a day and recorded as such (.003 of a year). Whenever a range was given the higher number was recorded. For example if the range was 4-5 times, 5 times would have been recorded.

Variables were created that compiled the scores on the complicated grief scale identified as "ICGR total" and the positive grief scale identified as "Positive Grief total". Length of stay in hospice was also a recoded variable. Dummy variables were created to use in comparison around demographics (age, ethnicity, relationship).

Response Scoring

The methodology for scoring the questionnaire is as follows:

- Answers to the Section 1 (the demographic questions) were compiled and frequencies and/or means were calculated.

- Answers to Section 2 (the models of care and helpfulness questions) were scored by frequencies on Questions 10 and 11 through 22. In addition, Questions 12 through 22 were scored both by frequencies and Likert scale (1= "very helpful"; 2= "somewhat"; 3= "a little"; and 4= "not at all"). Means were obtained from the Likert scale data.

- Answers to Section 3 (the ICGR and positive grief scales) used a 5-pt. Likert scale and were scored 1="always"; 2= "often"; 3= "sometimes"; 4="rarely"; and 5= "never". Means were obtained.

- Answers to Section 4, Questions 52-55 were scored both by frequencies and Likert scales (1="very satisfied"; 2= "satisfied"; 3= "dissatisfied"; and 4= "very dissatisfied" and the comments question responses were listed.

- The final questions of Section 4, the global assessment question listed helpful services identified by the surviving loved one and compiled commonalities and differences. Question 57 asked whether the survey respondent had any additional things that they would like to say.

Sample Coding Error

Two errors occurred with the survey distribution and both had to do with the numbering on the survey. The researcher failed to completely enter the identification number. Each of these surveys was completed. Since identification numbers were partially missing, substitute numbers were given to them (12XX and 138X). All other surveys were numbered from 1222-1414 and these numbers correspond to the response card from the participant. The starting point of 1222 was randomly chosen by the researcher.

Chapter 3 Summary

In summary, this study was a first look at possible long-standing outcomes on survivors of loved ones who experienced three different models of end-of-life care. Goals included examining whether any service model had a differential impact on grief reactions. The sample included all the persons who died between May, 2005 and January, 2008 that received services from a local cancer support agency and that had an identified caregiver. It was limited to surviving loved ones of cancer patients who had provided caregiving. The survey instrument included a validated complicated grief scale, a newly created positive grief scale, assessment of health care professionals and their services, and demographic information. Statistical analyses included factor analyses, *t*-tests, Crosstabs, simple correlations and frequencies. Qualitative data was also analyzed using a grounded theory approach. Coding decisions were discussed with the study's methodologist and agreed upon common themes and differences were identified. The next chapter will discuss the findings from this study.

CHAPTER 4: Findings

"He who was has gone,
we but cherish his memory, abides with us,
more potent, nay, more present than the living man."
--Antoine de Saint-Exupéry

Quantitative Findings

Sample Response Rate

The total number of letters of invitation with response postcards sent out was 1327. Of this, 192 persons requested and were sent a questionnaire. Of the sent questionnaires 182 were returned. Two were not completed. One was just blank and one had a note attached that in looking at the questionnaire the person felt that it would be too hard emotionally to complete it. That resulted in 180 completed questionnaires or a 13.6% response rate. There were multiple mailings to the 192 persons who agreed to participate in the survey. Follow-up postcards were mailed at two weeks and a complete resending of questionnaire at one month. This was an attempt to capture as many responses as possible. The effectiveness of these follow up efforts is confirmed in that only 12 persons who volunteered to be in the study did not eventually complete the questionnaire.

In attempting to understand the poor response rate, a plan to subsample the non-respondents to inquire why they didn't respond was considered. In consultation with the methodologist, the plan was to send out postcards with four questions on them. The goal was to attempt to tease out the reasons for the poor response rate. Since the mailing had been on the host agency's stationary, was the letter assumed to be a report or a request for funds and simply tossed away? Or did the study itself and the emotionally laden topic of loss and grief deter possible participants? Although this information would not have confirmed the presence of complicated grief in the non-respondents, it would have given some crucial information as to whether

misconceptions about the mailing or difficulty in addressing questions about loss

were associated with the response rate.

The postcards would have read:

1. (Name of the agency) recently sent you a letter from their director, did

   you open the letter?   YES   NO

2. Did you believe the letter was a request for donations?   YES   NO

3. Did you read the invitation to be part of the research study?   YES   NO

4. Did you feel that participating in the research study would

   bring back troubling feelings?   YES   NO

However, the host agency personnel were unwilling to allow follow-up letters to the

sample. The program director responded on behalf of agency and stated that "We do

not want our families to feel pressured to complete the survey and we are concerned

that another letter might give them that sense." (personal communication with

program director, 10-7-08). She also remarked that from their experience a 13.6%

response rate was higher than the 8% response rate they usually experience (personal

communication with program director, 10-7-08). In conforming to Dillman's

research, this response rate is very poor. However, for a direct mailing for a request

for funds, a response rate from 2% -10% (Brownlee & Schultz, 2007; Squires, 2003)

is expected. The host agency is partially funded through direct donations solicited

through direct mail and it is possible that the letter of invitation to participate in the

study was assumed to be a request for funds. Without additional data, this remains

conjecture on the researcher's part. In the end, the study's response rate was only

13.6% and the implications of this will be discussed further in the limitations section.

Initial Findings

Sample Demographics

The average age of the participants was 61.88 (median age=62.8 yrs.). The youngest participant was 20 yrs. and the oldest was 88. Participants were generally women (70%), Caucasian (87.2%); and spouses (68.9%). Table 5 summarizes the gender, ethnicity and family relationship of the sample.

Table 5

Gender, Ethnicity and Family Relationship (n=180)

Gender	Ethnicity	Relationship
70% female	87.2% Caucasian	68.9% Spouse
30% male	6.7 % African-American	16.1% Other*
	3.3% Native American	15% children
	1.1 % Asian American	
	1.1% Hispanic American	
	.6% Other	

* includes siblings and significant others

Additional demographic information was collected on type of support for their loved ones, location of the death of their loved one and responses to items pertaining to spirituality and religious involvement. Ninety-six percent of the participants stated that they had provided both physical and emotional support to

their dying loved one The majority had cared for their loved ones in their home and the loved ones died there (60.6%). Table 6 reports these statistics on these additional indicators.

Table 6

Degree of Caregiving Support and Place of Death (n=180)

Caregiver Support	Place of Death	
96% both physical/emotional	Home (60.6%)	4
4% either physical/emotional	Hospital (23.3%).	
	Nursing Facility (4.4%)	

Responses rated the importance of spirituality for the surviving loved ones. Most rated spirituality as "very important" (77%). Religious involvement was also assessed. Sixty-seven percent stated that they were religiously active. Table 7 reports these statistics on spirituality.

Table 7

Spiritual Connections (n=179)

	Very	Somewhat	A little	Not
Importance of Spirituality	77%	20%	3%	.6%
	Active	Not active		
Religious Activity	67%	33%		

In summary, the sample was predominately older (over 62 yrs. old), white, with more than 2/3 female. A little more than 2/3 were spouses, with children and others

almost equally distributed. Less than one-fourth of the deceased died in a hospital with the most frequently listed location of death as "at home" or a home-like setting (nursing facility, hospice house). Also, over 2/3 of the respondents reported strong spirituality and active religious participation.

Model of Care

Of the total of 180 participants, 134 or 74.4% had received hospice care; 41 or 22.8% had received only medical care; and 5 or 3% had exclusively received only palliative care. The answer responses for palliative care services, however, were not straightforward. In total 64 people or 35.6% of the sample marked responses in the palliative care section. Of these 64, one appeared to not understand the question and responded about hiring a private caregiver. Of the remaining 63 persons, 47 answered questions in both the palliative care and hospice sections; 11 answered in both the palliative care and medical sections, and only 5 answered exclusively in the palliative care section. Since palliative care can be associated with both medical and hospice models, it appeared that the persons were associating the term not with a consultation with a palliative care team but with the treatment afforded in each model. The five that answered exclusively in the palliative care section were clearly receiving services from a palliative care team by the statements they gave.

In summary, the sample was dominated by those receiving hospice. Exclusive palliative care services were minimal. The sample reported strong spiritual connections and religious activity. As expected, the sample was predominately

female, Caucasian, and spouses of the deceased. All the respondents provided

emotional and/or physical caregiving support.

Hypothesis 1 and the Positive Grief Scale

Hypothesis 1 posits that surviving loved ones of a hospice client will display

significantly greater positive grief scores than palliative care and aggressive care

client and that palliative care clients will display significantly greater positive grief

scores than aggressive care clients.

Positive Grief Scale

Statistics for the Positive Grief Scale were examined in light of Hypothesis 1.

Initially the scale had ten items and with these items the potential scale range was

from 10-50. The positive grief scale was created to reflect the findings of

transpersonal researchers. Specifically the items address meaning-making,

continuing positive bonds with the deceased, increased spirituality and value

reconstruction, and finally, increased self-awareness and self-esteem of the griever.

Scores closer to 10 indicate less positive grief; scores closer to 50 more positive

grief.

Scale Psychometrics and Exploratory Factor Analysis

Since this scale was developed by this researcher for use in this study and

was untested, an initial two solution factor analysis was performed on all ten items.

Factor analysis was important to determine since this scale was newly developed and

untested. Factor analysis statistically determines the validation a scale or index by

demonstrating that its constituent items load on the same factor, and it is also use to

make determinations to drop proposed scale items which cross-load on more than one factor. A confirmatory factor analysis would show that based on transpersonal theories of grief certain elements as continuing bonds, meaning making, enhanced self-awareness and esteem, and reconstruction of values were definitive of positive grief. With regard to loadings, some researchers have stated that they should be .7 or higher to confirm that independent variables identified a priori are represented by a particular factor. Since this follows the rationale that the .7 level corresponds to about half of the variance in the indicator being explained by the factor (Kim and Mueller, 1978). However, others have argued that the .7 standard is a high one and real-life data may well not meet this criterion. In particular, researchers that have used this for exploratory purposes have been encouraged to use a lower level such as .4 for the central factor (Hair, Anderson, Tatham, & Black, 1998). Hair et al. (1998) label loadings above .6 "high" and those below .4 "low". Consequently, in looking at the factor loadings in this study, any loading .4 and above was retained. Table 8 describes the Rotated Factor Matrix and highlights the poor loadings for these three variables.

Table 8

Rotated Factor Matrix for 10-item Positive Grief Scale

Item	Factor	
	1	2
Life has more meaning	.607	.221
Learned about myself	.459	.888
Important things in life	.569	.007
Material goods don't mean a lot	.102	.029
Am a better person	.487	.421
More spiritually aware	.561	.050
Have good memories	.497	.043
Value each day	.739	.011
Don't fear death	.030	.163
Change almost nothing in life	.210	.069

Employing a maximum likelihood factor analysis method, it took three iterations to

result in a two factor analysis. However, three items loaded poorly on either factor

(had loadings less than .4). They were "material goods don't mean a lot to

me";"don't fear death"; and "change almost nothing". In conducting a reliability

analysis for the 10-item scale, the Cronbach's alpha was .70. As stated in the

methods section a Cronbach's alpha of .7 or greater was preferred. Consequently,

item-total statistics were calculated and examined to determine if deleting these

items would improve the reliability analysis of the scale. These items were deleted in a step-wise fashion beginning with "don't fear death" (Cronbach's alpha =.75); then "change almost nothing" (Cronbach's alpha= .764); and "material goods" (Cronbach's alpha=.792). In conducting a factor analysis on this seven-item scale, maximum likelihood factor analysis was performed and all 7 items loaded on two factors. The internal consistency of the items was high since most of the standard deviations and means were close to equal within the scale. The item "Have good memories" does have a higher mean and lower standard deviation than the other scale items. Table 9 lists the descriptive statistics for the 7-item scale.

Table 9

Means and Standard Deviation Scores for the 7-item Positive Grief Scale

Item	Mean	Standard Deviation
Life has more meaning	3.0349	1.23731
Learned about myself	3.5930	1.02028
Important things in life	3.6221	1.04975
Am a better person	3.8430	1.26297
More spiritually aware	3.4709	1.14671
Have good memories	4.4128	.85050
Value each day	3.8837	1.08599

The goodness of fit test resulted in a chi-square analysis. The results of the test were significant x^2 (8, N=180)=17.044, p=.030. All of the factor loadings with this amended scale had loading of .4 or more. Table 10 displays the 7-item's factor loadings.

Table 10

Rotated Factor Matrix for 7-item Positive Grief Scale

Item	Factor	
	1	2
Life has more meaning	.544	.368
Learned about myself	.212	.977
Important things in life	.524	.160
Am a better person	.344	.537
More spiritually aware	.523	.195
Have good memories	.497	.043
Value each day	.739	.197

The Cronbach's alpha of .792 was determined and no additional deletions would improve this score. The amount of variance explained by this solution was 46.6%. Consequently the subsequent analyses regarding the positive grief scale use this seven-item scale. Thus the amended range of score is 7-35. A score closer to 7 indicated less positive grief and a score closer to 35 more positive grief. In contrast to the ICGR scale which is designed to provide diagnostic information, no "cut-off" or absolute score that would connote "positive grief" was determined. Conceptually a cut off score for positive grief is contrary to the theory of grieving posited by transpersonal theorists. This will be addressed later in the discussion section of this dissertation.

In looking at the model of care and comparing mean and median scores, hospice scores are more positive than medical care scores and palliative care scores are least positive. However, none of these variations between medical and hospice models of care are statistically significant. Palliative care was not compared due to its small sample size. If the palliative care sample had been greater *t*-tests would have been performed.

However the mean and median scores as well as the range were computed. These are listed in Table 11.

Table 11

Central Tendency Scores for Positive Grief Dependent on Model of Care (n=179)

	Mean	Median	Range
Overall score (n=179)	25.72	26	7-35
Hospice care (n=134)	25.64	26	7-35
Medical care (n=41)	25.54	26	15-35
Palliative care (n=4)	28.75	28	15-35

Individual Means for Positive Grief Scale Items

Individual means for each of the items were also analyzed. No item had a mean score of higher than 4.4. Table 12 lists those individual means.

Table 12

Positive Grief Scale Items and Means (n=179)

Item	Mean*
Life more meaning	3.04
More spiritually aware	3.46
Learned more about myself	3.60
Gotten important things	3.63
Better person for caregiving	3.85
Value each day	3.89
Good memories	4.40

*   Likert scale 1="never"; 2="rarely"; 3="sometimes"; 4=" often"5="always"

With this scale there was little variance with most people responding "sometimes" to most questions. Only the item "I have good memories…" had a mean response score over 4, which indicated often to always. Incidentally for the deleted items on this scale the means reflected mean scores in the "rarely" to "sometimes" range. "Don't fear death" had a mean response of 2.76; "Change almost nothing" had a mean response of 3.08 and "Material goods don't mean a lot" had a mean of 3.34.

In summary, there were no significant difference between any model of care and positive grief scores. The overall means of the individual items were very similar and lacked marked variability in general and between the particular models of care. Therefore, Hypothesis 1 was not confirmed.

Hypothesis 2 and the Inventory of Complicated Grief-Revised

Hypothesis 2 posits with regard to complicated grief, that surviving loved ones of a hospice client will display significantly less complicated grief than palliative care and aggressive care clients. Also palliative care clients will display significantly less complicated grief than aggressive care clients.

Complicated Grief Scale

Statistics for the Inventory of Complicated Grief Revised were examined in light of Hypothesis 2. Hypothesis 2 states that complicated grief will be more prevalent with persons using the medical model and least prevalent with hospice consumers. The potential ICGR scale range was from 19-95 and since the scoring was reversed, a score of 89 or more would indicate complicated grief. (Scores closer to 19 indicate less complicated grief; scores closer to 95 more complicated grief). The range of scores for this study was 21-80. Since no person in this study received a score higher than 80, no person would qualified with the ICGR's criteria for having complicated grief.

In looking at the model of care and comparing mean and median scores, hospice scores were more positive than medical care scores and palliative care scores were least positive. Table 13 reviews these scores.

Table 13

Score for Complicated Grief Dependent on Model of Care (n=180)

	Mean	Median	Range
Overall score (n=180)	45.2	44	21-80
Hospice care (n=134)	44.3	40	21-80
Medical care (n=41)	46.8	44	23-76
Palliative care (n=5)	50	50	43-59

In comparing hospice care means and medical care means for complicated grief scores an independent sample *t*-test was performed and no significance was found. No significant findings were found comparing overall score and hospice and medical models. Since the sample size for the palliative care group was so small, no statistical comparison was made.

Individual means for each of the items were also analyzed. No item had a mean score higher than 3.7. Only four items (longing for the person, loneliness, drawn to places, life is empty) were answered on the average 3 or over on the Likert scale and indicating an answer of "sometime" to "often". Seven items (pain in the body, seeing the person, hearing the voice, feeling of unfairness, avoidance of reminders, loss of caring, and less trust) were answered on the average of 2 or less on the Likert scale indicating an answer of "never" to "rarely". Table 14 lists those individual means.

Table 14

ICGR Item Means (n=173)

Item	Mean*
Pain in body	1.32
See the person	1.41
Hear the voice	1.71
Feel unfair	1.82
Avoid reminders	1.86
Lost ability to care	1.90
Hard to trust	1.99
Feel angry	2.19
Envious of others	2.24
Cannot accept death	2.28
Bitter over death	2.35
Memories upset	2.39
Feel stunned	2.52
Disbelief over happening	2.79
Hard to do normal things	2.98
Life is empty	3.09
Drawn to places	3.20
Lonely	3.46
Long for person	3.64

* Likert scale 1="never"; 2="rarely"; 3="sometimes"; 4=" often"5="always"

Confirmatory Factor Analysis of ICGR

Finally, validation of the ICGR was conducted to analyze the results of the factor analysis and two factor solution, the goodness of fit, and the Cronbach's Alpha. A maximum likelihood factor analysis was performed and all 19 items loaded on two factors. The goodness of fit test resulted in a chi-square analysis. The results of the test were significant x^2 (135, N=180)=209.79, p=.000. The Cronbach's alpha of .76 was determined. The amount of variance explained by this solution was 59.6%.

The ICGR has been used with similar and diverse grieving populations. Prigerson's earliest validation studies (1995), Ott's longitudinal study of grief (2003) had similar samples to this study. Most of the participants were bereaved older spouses and the alpha scores were .94 and .92 respectively. The scale has also been used with African American bereaved with an alpha score of .85 (Laurie and Neimeyer, 2008). International studies using this scale included Dutch (Boelen and Van den Bout, 2007 ; and Pakistani (Prigerson, Ahmed, Gilverman, Saxena, Maciejewski, Jacobs, Kasl, Aqueel & Hamirani, 2002) studies but they reported on specific psychiatric populations (Boelen and Van den Bout, 2007) or violent loss (Prigerson et al). Also this scale has been used in a number of studies of younger persons and traumatic loss (Melhem, Day, Shear, Day, Reynolds & Grent, 2004; Schneider, Elhai & Gray, 2007) and adult survivors of suicide (Mitchell, Kim, Prigerson& Mortimer, 2005). These later studies examined populations with specific risk factors for complicated grief i.e. non-majority ethnicity, mental illness, and

traumatic loss and are not easily comparable to this study. Nevertheless, these other

studies reported Cronbach alpha scores between .9 and .96. In summary, no person

in the study received a score that would qualify them for a complicated grief

designation. In comparing the mean scores for hospice and medical care there were

no significant differences between these groups as to complicated grief scores.

Individual item scores did demonstrate some variability but few persons answered

"often or always" to most of the items. Hypothesis 2 was also not confirmed.

<div align="center">Hypothesis 3 and Grief Associations</div>

Hypothesis 3 posits that persons who are female, older (age 60 and above), and non-

majority ethnicity will display more complicated grief than men, persons under 60,

or persons of the majority ethnicity.

<div align="center">*Demographics and Grief Scales*</div>

In examining gender, age, and ethnicity indicators with complicated grief, the

respondents' answers were analyzed in relation to the mean scores for the ICGR.

The mean score for those who are female, 60 and older, and non-majority were

compiled and compared to their counterparts (male, under 60, and white). Table 15

reports these demographic indicators and the respective mean scores.

Table 15

Mean score on ICGR and Demographic Indicators (n=180)

Demographics		ICGR means
Gender	Female	45.30
	Male	44.90
Age	60 and over	45.91
	Under 60	44.59
Ethnicity	Majority	45.74
	Non-majority	41.43

Independent Sample *t*-tests were performed comparing ICGR means and the demographic variables. No significant differences were found either with gender and ICGR; age (under 60 and 60 and over) and ICGR; or ethnicity (majority ethnicity and non-majority). Table 16 displays the demographic variable as the grouping variable and *t*-score.

Table 16

Comparing ICGR and Demographic with Resulting t-Score

Demographic	*t*-Score*	*p*-value
Gender	$t(177)= .184$	$p= .854$
Age	$t(175)= .682$	$p= .496$
Ethnicity	$t(177)= 1.542$	$p= .125$

(Equal variance assumed and two-tailed)

Although not a part of this hypothesis, the comparison between positive grief scores and these same demographics were also made. Independent Sample *t*-tests were performed comparing Positive Grief Scale means and the demographic variables. Again none were significant. Table 17 lists those means and Table 18 the results of the *t*-test comparisons.

Table 17

Mean Score on Positive Grief Scale and Demographic Indicators (n=180)

Demographics		Positive Grief Scale means
Gender	Female	26.13
	Male	24.76
Age	60 and over	34.58
	Under 60	34.93
Ethnicity	Majority`	25.60
	Non-majority	26.52

Table 18

Comparing Positive Grief Scale and Demographic with Resulting t-Score

Demographic	*t*-Score*	*p*-value
Gender	*t*(177)= 1.641	*p*=.102
Age	*t*(175)= -.348	*p*=.729
Ethnicity	*t*(178)=..802	*p*=.423

(Equal variance assumed and two-tailed)

In summary, neither the ICGR nor the positive grief scale was significantly associated with any of the identified risk demographics for complicated grief. Hypothesis 3 was not confirmed.

Hypothesis 4 and Length of Stay

Hypothesis 4 posits that length of engagement in the model of care will impact grieving well. A short length of stay in hospice will have an inverse relationship with positive grieving and few consultations with palliative care teams will have an inverse relationship with positive grieving.

The association of grief with the effects of length of stay in hospice was also explored. The length of stay in hospice has been an important consideration with researchers over the last twenty years. Median length of stay has remained stable for the last five years at around 26 days. However, 25% of all hospice patients have hospice services for one week or less (Neigh, 2008). The concern is whether the full "hospice experience" can be delivered with short lengths of stays and thus the positive aspects of hospice support can be fully realized by patients and their

families. Since persistence of engagement with hospice is a issue of debate, the

length of time with hospice was re-coded into two variables that reflected a stay in

hospice of one week or less (25.9% of the sample's total hospice population), a stay

in hospice of two weeks or less (40% of the total hospice population), and the rest of

the sample (60% of the total hospice population). A one-way ANOVA was

conducted to see if the differences in the positive grief scores were impacted by

length of stay. Testing the scores on the positive grief scale with those of the one

week or less and the remaining sample approached significance with F= (2) = 3.567,

p=.062. No significance was found with those that had two weeks or less of hospice

services and the remaining sample.

Independent sample t-tests were performed to compare the length of stay of

one week or less and the rest of the sample with the scores on the complicated grief

scale. This yielded no significant results. Independent sample t-tests comparing two

weeks or less of hospice services and the rest of the sample with the scores on the

complicated grief scale also yielded no significant results. Since the sample of

exclusive palliative care recipients was so small (n=5) no tests were conducted with

regard to positive or complicated grief scores.

In summary, length of stay on hospice did not appear to impact the scores on

either the positive or complicated grief scales. Having one-week or less of hospice

did approach significance, p=.062. But none was significant at the p=.05 level.

Hypothesis 4 was not confirmed.

Hypothesis 5 and Best Practice Ratings

Hypothesis 5 posits that best practice ratings of health care professionals will be positive in all models of care. Hospice professionals will have greater best practice ratings than palliative care professionals. Palliative care professionals will have less positive best practice ratings than hospice professionals but greater ones than aggressive care professionals.

As the literature review pointed out a number of qualitative and quantitative studies conducted in the mid 1990's and after have attempted to glean from surviving loves ones what they considered to be best practices in supporting them and their loved ones as they coped with the dying process. Basically, these identified best practices are: awareness of treatment options; inclusion in plans for care; availability of health care professionals; being listened to; respectfulness of consumer's culture and ethnicity; emotional support; referrals to community resources; spiritual support; information about the dying process; and information about loss and bereavement (Barry et al, 2001; Chochinov et al, 2002; Cohen & Koenig, 2002; Kelleher, 2000; Pierce, 1999: Kutner et al., 1999; Lo, 1995; Reese, Melton & Ciaravino, 2003; Schneider, 1995; Steinhauser et al., 2000a; Teno et al, 2004; Thorton, 1997;Vanderweker & Prigerson, 2004; Wenger et al., 2001). Table 8 reports whether the participant ratings on presence of these best practices. If the best practice occurred then surviving loved ones rated the practices on a Likert scale from 1= "very helpful" to 4= "not helpful at all".

Overall statistics for the entire population as to the presence of these best practices and their helpfulness means are included in Table 19.

Table 19

Best Practices and Helpfulness Ratings (n=180)

Best Practices	Presence (% of "Yes" replies)	Helpfulness Mean*
Listened to	92.8%	1.31
Respected culture/ethnicity	90.6%	1.51
Availability of providers	86.7%	1.27
Information on disease	86.7%	1.15
Inclusion in plans of care	85.5%	1.20
Discussed treatment option	79.4%	1.24
Emotional support	76.6%	1.38
Information on dying process	71.7%	1.21
Referrals to resources	71.1%	1.47
Information on bereavement	57.8%	1.46
Spiritual support	52.2%	1.49

* All ratings fall between "very helpful" (1) and "somewhat helpful" (2)

Further breaking this population down into the model of care, the percent of persons who identified the presence of these best practices are recorded in Table 20. Palliative care results are not reported due to the small sample size.

Table 20

Best Practices and Presence within the Model of Care

Best Practice	Present in Model of Care (% of "Yes" replies)	
	Hospice (n=134)	Medical (n=41)
Listened to	93%	95%
Respected culture/ethnicity	90%	95%
Availability of Providers	93%	76%
Information on disease	84%	89%
Inclusion in plans of care	88%	76%
Discussed treatment options	78%	85%
Emotional support	78%	29%
Information on dying process	83%	35%
Referral to community resources	78%	51%
Information on bereavement	73%	17%
Spiritual support	60%	29%

Since the palliative care sample size was so small (n=5) they were not included in further comparisons. However, chi square tests were conducted to see if there were significant differences between the hospice and medical care samples. Significant differences were found in six of the eleven items. Hospice in all instances included the best practice more often than the medical group. Table 21 lists the statistical results.

Table 21

Significant Differences between Hospice and Medical Care Samples

Best Practice	Chi-square	p-value
Listened to	x (2, N=179) = .442	*p*=.506
Respected culture/ethnicity	x (2, N=179) = 1.315	*p*=.518
Availability of Providers	x (2, N=179) = 13.656	*p*=.001*
Information on disease	x (2, N=179) = .273	*p*=.601
Inclusion in plans of care	x (2, N=179) = 5.658	*p*=.059
Discussed treatment options	x (2, N=179) = 2.032	*p*=.362
Emotional support	x (2, N=179) = 20.518	*p*=.000*
Information on dying process	x (2, N=179) = 48.276	*p*=.000*
Referral to community resources	x (2, N=179) = 11.478	*p*=.001*
Information on bereavement	x (2, N=179) = 46.103	*p*=.000*
Spiritual support	x (2, N=179) = 13.557	*p*=.001*

* Significant values*, p≤ .001*

Inclusion in care plans for the loved one approached significance (x (2, =179)=5.658 *p*=.059. With regard to information on the disease, treatment options, respectfulness, and being listened to there were no significant differences between the two models of care.

Each item in this section of the questionnaire not only asked whether the intervention or service was experienced by the surviving loved one but also their ratings as to its helpfulness. Exploring these comparisons of medical and hospice

care was the next step. The data on the ratings of helpfulness of these interventions were examined and *t*-tests performed.

Table 22 lists the mean helpfulness ratings for the hospice and medical care groups. Since the palliative care group was so small, it was not included in this analysis.

Table 22

Best Practice Helpfulness Means and Model of Care

Best Practices	Helpfulness mean*	
	Hospice (134)	Medical (41)
Listened to	1.24	1.55
Respected culture/ethnicity	1.41	1.84
Availability of providers	1.24	1.41
Information on disease	1.10	1.29
Inclusion in plans of care	1.15	1.40
Discussed treatment option	1.19	1.34
Emotional support	1.38	1.43
Information on dying process	1.22	1.33
Referrals to resources	1.49	1.42
Information on bereavement	1.46	1.38
Spiritual support	1.42	2.00

* All ratings fall between "very helpful" (1) and "somewhat helpful" (2)

In comparing the hospice and medical group means of helpfulness indicators by conducting an independent sample *t*-test, no significant difference was found in

information on disease, discussed treatment options, Information on dying process,

information on bereavement, emotional Support, referrals to resources, inclusion in

plans of care, and availability. Significant differences were found with regard to

spiritual support, and respected culture/ethnicity. With all these variables, hospice

was rated as more helpful than medical care. Table 23 reports these significant

findings.

Table 23

Significant Mean Differences between Hospice and Medical Care Samples in

Helpfulness of the Best Practices

Best Practice	*t*-test	p-value
Listening (equal variances not assumed)	*t* (59.698) = -2.887	*p*=.012*
Spiritual support	*t* (99) = -2.14613.557	*p*=.034
Respectfulness	*t* (157) = -2.858	*p*=.014*

* Equal Variances not assumed.

The assessment of the item "helpfulness of inclusion in the care plans"

approached significance with equal variances not assumed, t(39.965)= -1.870,

p=.069.

In summary, Hypothesis 5 was confirmed in that all the models of care had

some degree of presence of the identified best practices. The range for this presence

was 29% to 100%. The hospice model was significantly more likely to have

presented information on dying, information on bereavement, emotional support,

spiritual support, community referrals, and provider availability. The hospice model was significantly more likely to have higher helpfulness ratings on the best practices of listening, spiritual support, and respectfulness of culture and ethnicity.

<center>Additional Quantitative Findings</center>

<center>*Types of Health Care Services*</center>

In looking back on the last three months of the dead person's life, the surviving loved ones were asked what types of health care services they had received. The options available for them to circle included hospice services, chemotherapy, radiation, hospital stay, palliative/comfort care, home health services and nursing home care. Comfort care services as hospice and palliation were experienced by the majority of the deceased. This is not to be confused with services from a palliative care team which was poorly represented. Next in frequency was aggressive care as chemotherapy. Both palliative and aggressive care could be associated with radiation and hospital stays and almost 60% of the sample had had a hospital stay. All of these indices confirm the extensive use of the health care system within the last three months of the person's life. In looking at the use of home health services and nursing home care, only 4.4% of the respondents were in nursing homes and only 8.9% were receiving home health services. Consequently, only 13% of the surviving caregivers were receiving help in caring for their loved ones. This attests to the intense degree of involvement of these caregivers both emotionally and physically to the care of their seriously ill loved ones. Table 24 records the variety of care services identified.

Table 24

Care Interventions Received During Last Three Months of Life (n=178)

Intervention	Percent Receiving
Palliative services	74.4% (hospice); 35.2% (palliation);
Aggressive services	48.4% (chemo); 20% (radiation); 59.3% (hospital stay).
Caregiving Assistance	
Home health services	8.9%
Nursing home	4.4%

In summary, the surviving loved ones were in general experiencing extensive caregiving responsibilities with their loved ones who were very ill and requiring extensive caregiving.

Use of Multidisciplinary Team

The type of multidisciplinary team was also of interest. Multidisciplinary teams have been identified by dying individuals and their caregivers as best practices for end-of-life care (Pierce, 1999; Sulmasy & McIlvane, 2002; Steinhauser, et al., 2000b). As stated before, multidisciplinary teams usually are considered to include at least a physician, nurse, and social worker. Additional members of the team could be chaplains, home health aides, volunteers and representatives of therapies. Consequently a full multidisciplinary team would include at least three members. Some studies have defined the multidisciplinary team as just a physician and nurse (SUPPORT, 1995). However this narrow definition has been criticized and findings

have confirmed that the best consumer satisfaction rests with a team that includes not just medically focused members but also those that attend to social, psychological, and spiritual support (MacDonald, 1991; Moore & McCollough, 2000; Sulmasy & McIlvane, 2002; Steinhauser, et al., 2000b; SUPPORT, 1995). For this study the two person team was most likely a physician and nurse (64%); the most common three person team was doctor, nurse and social worker (25%) or doctor, nurse and home health or nurse's aide (25%); and the most common four or more person team was doctor, nurse, social worker, and home health or nurse's aide (75%).Table 25 reports the type of teams that the participants described as providing services to them.

Table 25

Types of Team Providers (n=179)

Team composition	Number of responses
Nurse-physician only	54 (30.2%)
Three person teams	54 (29%)
Nurse-physician-social worker (27)	
Nurse-physician-home health aide (27)	
Four or more person teams	71 (40%)
Nurse-physician-social worker-home health aide	

For this sample approximately 69% of the teams were multidisciplinary and had at least three members. For further analysis, a team of 1-2 persons will be compared with a multidisciplinary team of 3 or more persons.

In looking at the association with complicated grief scores and positive grief scores and the multidisciplinary team, there was no significance found between the number of persons in the multidisciplinary team and the grief scores.

The association with the presence of best practice and composition of the team was determined by conducting chi-square tests. Significant differences were found for the following items: Information on dying, Information on loss, Provider availability, Emotional support, and Referrals to resources. Table 26 reports the significant findings.

Table 26

Team Composition and Respondent's Report on Receiving Best Practices (n=180)

Item	Chi-square	*p*-value
Information on dying	x (2, N=180) = 18.493	p=.000*
Information on bereavement	x (2, N=180) = 10.674	p=.005*
Emotional support	x (2, N=180) = 6.018	p=.049*
Referrals to resources	x (2, N=180) = 6.534	p=.015*
Provider availability	x (2, N=180) = 7.492	p=.024*

* Significant values, $p< .05$

Thus the larger the multidisciplinary team the more likely the best practice of information on dying and bereavement, emotional support, provider availability, and community referrals was present.

In analyzing the helpfulness of the best practices and the composition of the multidisciplinary team by conducting a *t* test, two items were significant. They are

information on dying (t [180]= -2.213, p=.029) and listening (t [81.091]= 3.1542, p=.002). Since the t test for listening did not meet Levine test for equality of variances, the statistic for "equal variances not assumed" was reported. The three or more person multidisciplinary team was most likely to have better helpfulness scores on the best practices of information on dying and listening.

In summary, most of the respondents had received services from a three or more person multidisciplinary team (69%). With this multidisciplinary team, the presence of five (information on dying process, information on bereavement, emotional support, referrals to resources, and provider availability) best practices was more likely. There were no differences in the delivery of the following best practices with reference to teams: information on disease, discussed treatment options, information on dying process, inclusion in plans of care, spiritual support, and respected culture/ethnicity. Respondents reported that teams of three or more disciplines were more helpful in providing information on dying and to listening to them. The remaining "helpfulness" comparisons were not significant.

<div align="center">Duration of Illness and Model of Care</div>

Final data was collected on the model of care used and the length of the illness experience by the deceased loved one. The mean length for the loved one's illness was 4.1 years (n=180). The median length was 4 yrs. Table 27 reviews time the caregiver knew of the deceased loved one's illness prior to their death.

Table 27

Duration of Illness (n=180)

Length of Time	Percent of persons reporting
One week or less	1.7%
1-4 weeks	2.8%
1 month to six months	29.4%
Six months to one year	17.8%
More than one year	48.3%

From these responses, only 4.5% of the participants knew about the life threatening illness less than a month and the majority (almost half) was aware of the illness more than a year.

Medical Care

Despite the predominance of lengthy illnesses, for those that received only medical care the mean length of time for this medical care was reported at 2.2 years and the median length was 1.5 yrs. Table 28 reviews this in relation to time.

Table 28

Length of Treatment for the Medical Illness (Medical Care Only) (n=41)

Length of Time	Percent of persons reporting
One week or less	4.3%
1-4 weeks	2.2%
1 month to six months	21.7%
Six months to one year	17.4%
More than one year	54.3%

The range length of treatment went from less than a week to 12 years. Fourteen individuals reported knowing about the illness for 1-2 years; eleven knew for 2-6 years; one for 10 years and one for 12 years.

Satisfaction scores for medical services were also obtained. Satisfaction scores for these services were gauged on a Likert scale (1="very satisfied" to 4= "very dissatisfied). The medical care mean satisfaction score was 2.0 or "satisfied".

Hospice Care

In reviewing length of hospice contact, the average person who had hospice received hospice services for 2.5 months or 76.5 days. The median length of stay on hospice was 29.2 days. Table 29 reviews these times and percent of persons receiving services.

Table 29

Length of Hospice Services (n=134)

Length of Time	Percent of persons reporting
One week or less	25.9%
1-4 weeks	26.7%
1 month to six months	40%
Six months to one year	5.2%
More than one year	2.2%

The range of time for services went from less than one day to two years. Three individuals reported receiving hospice services for two years and five for one year.

Satisfaction scores for hospice services were also obtained. Satisfaction scores for these services were gauged on a Likert scale (1="very satisfied" to 4= "very dissatisfied). The hospice care mean satisfaction score was 1.33 or between "very satisfied" and "satisfied".

Palliative Care

Palliative care scores were calculated in reference to the number of times the deceased loved one received palliative care services at either the hospital or with home health. Overall, 64 of 171 participants (9 missing) or 37.4% reported contact with a palliative care team. Of this overall group, the mean number of contacts was 3.4 times and the median number of contacts was 2. Five participants reported palliative care with no hospice or medical care reported; forty-seven reported

palliative care and hospice services; and eleven reported palliative care and medical

services. In comparing the number of times the respondents stated they received

palliative care, the palliative care only and palliative care/hospice group reported

very similar experiences. The medical group reported more contact with palliative

care Table 30 lists these scores for the different palliative care groups.

Table 30

Palliative Care Model Scores (n=63)

Type of Palliative Care	Mean Score	Median Score	No. of Contacts
Palliative Care only (n=5)	3	2	1-8
Palliative /Hospice Care (n=47)	3	2	1-12
Palliative/Medical Care (n=10)*	5	3.5	1-10

*one case missing

Although a small sample, some information is worth noting. With regard to

demographics, 80% of the five palliative care recipients died in a hospital (one died

in a nursing facility); and this group was younger than the medical or hospice groups

(mean age =57.7 yrs.). With regard to gender, ethnicity, relationship, caregiving,

spirituality, and religious activity they paralleled the other groups. With positive

grief, their mean responses were slightly higher than the other two groups and their

range of responses mirrored medical care. With complicated grief, their score was

slightly higher than the overall group (50 and 45 respectively) and the range of the

complicated grief scores had less variability than the other groups. The scores on

best practices were also different. The palliative care group score higher on respect

and treatment options and lower on emotional support and information on dying than the other two groups.

Satisfaction scores were also calculated. The satisfaction rating with the palliative care groups were very similar. Satisfaction scores for these services were gauged on a Likert scale (1="very satisfied" to 4= "very dissatisfied). Table 31 lists the satisfaction scores.

Table 31

Mean Satisfaction Scores with Palliative Care Services (n=63)

Palliative Care only (n=5)	1.80
Palliative /Hospice Care (n=47)	1.53
Palliative/Medical Care (n=10)*	1.8

*one case missing

Summary of Quantitative Findings

In summary, this sample was predominately white, female, older, and widows/widowers. Most had hospice services and all of them provided emotional and/or physical support to their deceased loved ones. Most saw spirituality as important and most were active in a religious organization.

Hypotheses 1, 2, 3, and 4 were examined and were not confirmed. No model of care was significantly different in associations with positive grief or complicated grief. Demographic risk factors for complicated grief such as older age, female gender, and spousal relationship were not confirmed. Also within the hospice model

of care analyses, short lengths of stays in hospice were not significantly associated with positive grief or complicated grief.

However, statistical significance was confirmed in Hypotheses 5. Seven best practices (information on dying; information on bereavement; emotional support; spiritual support; community referrals; provider availability) were more likely to be included in the hospice model. The hospice model was significantly more likely to have higher helpfulness ratings on the best practices of listening, spiritual support, and respectfulness of culture/ethnicity.

Additional quantitative data was analyzed with regard to types of health care services, use of multidisciplinary teams and length of illness. This sample's loved ones made extensive use of health care services three months prior to their deaths and that alludes to the degree of care they required. Evidence emerged that the makeup of the multidisciplinary team did impact the delivery of best practices. The larger the multidisciplinary team the more likely the best practice of information on dying and bereavement, emotional support, provider availability, and community referrals was present. In addition, with the three or more person multidisciplinary team the helpfulness scores on the best practices of information on dying and listening were significant. Also the median length of illness of the deceased loved ones confirmed that medical services were provided for four years and that hospice services median length of stay was 29 days. Finally, satisfaction scores concerning the models of care were not significantly different and all models of care received scores on average of "satisfied" or better.

Additional information was obtained through the open-ended questions included in the survey. The wealth of the information received is explored next.

Qualitative Findings

Within the questionnaire, there were three open-ended items that gave respondent's opportunities to voice comments, identify helpful interventions, or give more information. The comments opportunities were after each model of care set of questions. The comment questions were 53(c)—"Any other comments about hospice services?" 54(c)--"Any other comments about palliative care services?" and 55 (d)— "Any other comments about medical services?" The identification of helpfulness was addressed in question 56, which stated "In looking back, what did the health care providers do during the time of your loved one's illness that has been most helpful to you as you grieved your loss?" The additional information question was question 57 that asked "Is there anything else that I haven't asked that you feel is important for me to know?"

Remarkably, most of respondents answered not only these questions but many commented throughout the questionnaire on other items and some enclosed letters and notes to me to talk more about themselves and their experience with loss. Of the 180 respondents, 159 entered responses to at least one of the qualitative questions; 94 responded to at least three items or qualitative questions; and 10 respondents wrote a personal note to the researcher. Of these 10 notes, the smallest note was a paragraph and the largest a two-page, single-spaced letter. One of the respondents sent an informative article for my benefit and one an inspirational poem.

These respondents were extremely generous with their time and efforts to add to the meaningfulness of the questionnaire.

In examining the model of care and who responded, 22 persons with medical care responded (n=41); all 5 palliative care recipients responded; and 132 (n=134) hospice recipients responded. Of the hospice respondents, 52 had hospice less than two weeks. Each respondent will be identified with reference to their comment as "H" for hospice recipient; "M" for medical care only; and "P" for palliative care only recipient. This alphabetic identifier will be coupled with the number assigned to the survey itself.

Analysis of this qualitative data will roughly follow the format for the quantitative data. Themes emerged from the data and are grouped according to their association with positive grief and complicated grief. Other associations of these grief responses with model of care will also be discussed. Connection with all the already stated elements of best practices, as well as, possible additions to best practices will be listed. And finally, general comments about the importance of "small things" and satisfaction with the model of care will be reported.

Positive Grief Statements

Statements attesting to positive grief were a central theme that emerged from these responses. Forty-nine respondents wrote comments that were coded as positive grief. The responses reflected continuing positive bonds with the deceased loved one; enhanced self-awareness or self-esteem; meaning making of the death or of continuing life; and value stances that appear to be more important in the light of the

death. The responses were identified as positive grief if they contained statements about meaning, enhanced self-esteem and self-awareness, spiritual awareness, and reconstruction of values. Also any comment that looked at memories or persistent attachment to the deceased that were identified as good things in the life of the surviving loved one were also coded as "positive grief".

Meaning-making

Statements were written that displayed that over time the respondents thought about their loss and the meaning it had in their lives. A greater appreciation of life was voiced. Twenty-four respondents wrote this meaning making. A sampling of these responses is as follows: "I choose to take each day as happy and thankful that I'm still about to get up each day and go on with my life" (1414H); and "I don't know how to answer questions (about grief). Life will never be the same. We have to make a new normal. We will always miss him" (1368H). Meaning around the grief experience was also noted, "Perhaps the grieving process is a direct equation to the love between survivor and deceased (1222M).

Spiritual Awareness

The next most common theme that emerged had to do with spiritual awareness and growth. Twenty-one respondents mentioned spirituality or their faith in God was a strong support for them during the time that they cared for their loved one. Typical of these statements was the one made by a respondent (1244H) whom had lost her husband. She wrote, "The comfort of the Lord kept me in peace through all the difficult time". However, the importance of a spiritual supportive awareness

was also present in bereavement. Another (1326M) stated, "Belief in God is central to my feelings about death. I mourned the loss, then left that behind me. His will be done". So this trust in a higher power helped with their grief.

Alternative spiritual practices were also mentioned. One respondent (1274H) confided that "I visited a medium—although skeptical, it surprisingly helped me. I felt reassured my husband was happy and in a good place with other loved ones and that he is still with me". Other spiritual connections that were not based in a deity or practice were also discussed. "I have also noticed that I'm a lot closer to NATURE—and notice wild animals such as birds, turtle, insects, rabbits, fish, and a lot more" (1280H). Pets also bring solace and a spiritual type of support. One man wrote,

> My recovery from her death is eased because of our pets—they are helpless for food/care without me and their love and companionship with me has kept me from spiraling into a black hole where I think I would have hidden—instead I walk with Teddy, meet people and talk to folks at dog parks. Spend time outside, gardening so we both can get some fresh air. I told someone this week that without my dog I do not think I would have been able to go on as I have (1296H).

Memories as Comfort

Memories and the persistent awareness of the deceased person was also a major theme. Fourteen mentioned memories as comfort. The memories did not harm or hamper the lives of the loved ones but enriched them. "The memories of my past with my wife are all good and that's one of things that keep me going. I feel from

time to that I'm able to continue to be happy with my life just and hope to do so for the rest of my years on this earth" (1413H); "I think of her and I will always think of her from time to time but death is just life and life continues to go on. (1414H);

Personal items also brought solace. One respondent (1267H) talked about giving her mother's things away and mentioned that she kept one item, "the pillow cases are the only thing I kept from the 'deathbed' and they are very special to me". Another wrote, "Things that were Mom's give me wonderful memory reminders" (1295H).

The awareness that love never dies and that bond is never broken was also mentioned. "My husband was young and full of life. I miss him with all my heart each and every day, even two years later" (1353M). "I think about mom quite often but it does not keep me from living life to the fullest…I miss her dearly. She was an important part of my life, but my life is not empty" (1295H).

Enhanced Self-awareness/Self Esteem

The bereavement experience for these respondents also resulted in comments about their personal growth in understanding about relationship and grief and about the pride of caregiving. Six respondents mentioned this enhanced awareness. One respondent (1239H) remarked how she was very aware of the type of relationship she had with her mother,

> We were fortunate. We had a great relationship, no regrets and she died
> surrounded by the ones she loved. My experience would have been much

different if it was not like this. I know that from experience and losing other

loved ones when I was much younger.

Another wrote about her new self-awareness of grief and her family. "The loss of a

loved one results in grieving for that loss and for me; it reopens grief for other losses

that have not been fully grieved yet" (1245H). Another saw the impact on her family

with new eyes, "It's a 'family' loss—even for little children. WE all grieve; we all

need a hand to hold, an ear to listen, a heart to understand" (1289H).

Also self-pride about caregiving was mentioned, "The hardest part was

watching my mom suffer. There are days I wish I wouldn't know so much about her

suffering. But I am grateful I was there to take care of her" (1389P). And another

wrote, "I do feel like I'm a better person because of the example he gave to us with

the way he handled his cancer—all I can say is I've been so blessed" (1368H).

Reconstruction of Values

Values were also reflected upon. Only a few respondents (10) mentioned

enhanced awareness of what they value in life and only four appeared to have

actually reevaluated their lives. An example of enhanced awareness were comments

like "When I see a couple around our age I just smile and say to myself "enjoy each

moment" (1368H). For others, death and illness had a different meaning. One

(1388M) wrote, "I fear death even less than I did before mom died".

In summary, many of the respondents to the open-ended questions wrote

about the positive aspects of life that were spotlighted because of their loss. These

comments were made by approximately 31% of the persons who answered the open-

ended questions. Grief statements that supported the negative aspects of loss were also evident.

Complicated Grief Statements

Hallmarks of complicated grief are those activities that prevent a person from living their lives happily. Twenty seven respondents made comments about the pain of loss. The qualitative comments were examined to identify elements of rumination, preoccupation, yearning, depression, anxiety, isolation, non-acceptance, and other statements that are associated with the negative aspects of grief. Generally these negative elements were couched in terms of disbelief, regrets, loneliness, sadness, and yearning.

Sadness and Constancy of Loss

Eleven respondents remarked about the constant sense of loss. "Loneliness is persistent—no one can take her place…" (1279H); "It's been a year and a half since losing my husband and each day is a struggle. The question is how do I go on? I can't find an answer" (1311H). Another comment that stresses the current pain of loss was "I cried through the whole survey" (1249M). Finally the reality that the loss of a loved one may be the harbinger of losses in other areas was voiced (1247H)--"It was a very rough time, we were very close. I lost my husband, home, and car. I'm now living with my son.

Disbelief and Regrets

Disbelief was voiced by one respondent (1412H). She wrote, "Sometimes it doesn't feel "real" yet. Regrets were a theme for nine respondents. Respondent

(1404H) wrote "I wasn't able to be there before she slipped into the drug induced coma…I'll regret it forever. I also wish I could've have been more brave when she was alive to talk to her about death—her death." Missed opportunities to talk were also expressed when she said, "It's been over a year since I lost my mom and I still feel there was still so much I should've talked to her about" (1405H) Difficulty thinking about the loss was also noted by one respondent (1413M). She stated "It is hard for me to think of that (what had been most helpful) since my husband passed away".

Identification of Persons Appearing to have Complicated Grief Indicators

In reviewing the qualitative comments, many individuals voiced grief particularly the sadness and loneliness of loss. Most of these respondents also in their comments made statements about going on with living, finding peace, relying on friends, and spirituality, and other indicators that they were coping well with their grief. However, two individuals appeared to display a continued intensity of grief that could be indicative of complicated grief.

One respondent (1249M) remarked to the question asking any last comments with this, "I just turned 44. I've lost two husbands to cancer in less than 5 yrs. I've tried counseling and meds. Neither helped." Within the statement the intense sadness of the grief and the "stuck" quality of complicated grief is evident.

Another respondent (1404H) also displayed indicators of complicated grief. Initially on the front of the returned questionnaire was written "Sorry it has taken me so long to respond. It was hard to open the envelope". In the response to the last

question, she wrote, "I wasn't able to give my mom a proper death and I'll regret it forever. With this statement the intense feelings of regret are still present as well as the sadness and self-reproach of complicated grief. These two persons will be discussed more in the discussion section.

In summary, approximately 17% of the persons who answered the open-ended questions voiced the negative aspects of grief. So both the positive aspects and negative aspects of grief were verbalized by this sample.

<div align="center">Model of Care and Grief Statements</div>

Of the above positive and negative grief responses, each model of care is mentioned with regard to its assists or hindrance to their grieving process. Hospice care was singled out 24 times as helping with their grief. One (1371H) simply wrote, "Hospice was a big help with the grieving process". Others wrote about the follow-up grief support, "I received grief counseling through XXX Hospice after the death of my grandmother and it was so nice to grieve with other people in the same situation" (1324H). One (1280H) remarked that "The follow-up hospice grief counseling helped the most. Saved my sanity." An interesting addition to the grief experienced by the surviving loved ones was also the comment that "some of the grief was also due to "losing" those health care folks we had became so familiar with…that connection is also gone" (1261H).

For medical care, there were three statements that medical services helped the grieving process. "They (XXX Hospital) wrote me a wonderful note after she died that it was an honor to care for her. I really like that and it helped (with grief)"

(1404M). However, one respondent (1281M) stated bluntly that "the health care people did nothing to help me grieve my loss".

For the palliative care persons, no statement was made that related the palliative care services received by the deceased and the grieving process. However the majority of the responses focused on particular services that were helpful or not to the surviving loved ones.

<div align="center">Statements about Best Practices</div>

Within the qualitative responses, many comments were made that confirmed the earlier research about the importance of certain best practices in end of life care. These reported best practices were awareness of treatment options; inclusion in plans for care; availability of health care professionals; being listened to; respectfulness of consumer's culture and ethnicity; emotional support; referrals to community resources; spiritual support; information about the dying process; and information about loss and bereavement (Chochinov et al, 2002; Cicirelli, 1997; Kayser-Jones, 2002; Kagawa-Singer & Blackhall, 2001; Macdonald, 2003; Mor, 1989; Nakashima & Canda, 2003; Nelson-Becker, 2006; Pierce, 1999; Mulder, 2000; Reese, 2001; Schwartz et al. (2002); Shrens, Uancey & Kollef, (2003); Steinhauser et al, 2000a; Steinhauser et al, 2000b; Sulmasy & McIlvane, 2002; Teno et al, 2004; Vanderweker & Prigerson, 2004; Vig, Davenport & Pearlman, 2002; Viser, 2002; Wenger et al., 2001; Zhang, El-Jawahri, & Prigerson, 2006).

Comments about these best practices were frequent with approximately 53% of the respondents pointing out the benefits or lack of a particular practice. The most

often mentioned practices that were appreciated by the respondents were support (emotional or financial) information delivery, listening, physical signs of the dying process, and availability. One respondent (1278H) typified the responses about emotional support when she wrote, "We couldn't have done it without them…We were guided through a stressful time with compassion and a lot of support". Another typical response (1390H) singled out particular services "Help with the payment of medications-insurance help-support for (getting) supplies".

Listening was also mentioned frequently (13 respondents). A usual comment (1233H) was "Explained everything in detail—answered my questions—listened well to my complaints and concerns".

Another frequently (12 respondents) mentioned best practice was information about the dying process. Persons (10) wrote about how important this was to them and others (2) wrote how missing this component was problematic. A hospice respondent wrote how important this information was to them and stated, "What helped the most was them telling us the signs of death so we would know the time was near so we could help her pass" (1240H). Others wrote about this impact of this missing information, " I would have appreciated more input as what was happening the last week in bed and I would wanted to have (that) …tell me more (1385H).

Availability was also mentioned by nine respondents. "It is very important to have a doctor you can call at any given moment and he is always there to answer questions or meet you at the hospital, or to help with whatever you need" (1238H).

Other common responses to the other best practices were also mentioned. The range in which these practices were mentioned by respondents was from 8-2 times. For inclusion in the plans for care, one respondent (1350H) wrote, "Health care providers have the attitude 'I know best'. They should consult with the patient and/or family. I believe we should have some input and choice regarding kinds of treatment available and their results before staring treatment." For respectfulness, one wrote that she was most appreciative of the "Respect for the ill patient and sincere concern for her comfort" (1295H).

Spiritual support was also valued. Respondent (1261H) stated what was most appreciated by their family was that the hospice "Created a personal connection with Dad and Me. I/we really felt they were our partners on this path; talking candidly about their perspective, especially about the spiritual aspect of death/dying and cancer in general." Treatment options were another important practice. An example of this is "They (palliative care team) made us understand every step. They gave us options. THEY gave us HOPE!!!" (12XXP). Referrals to community services was least mentioned with only two respondents citing this. One stated, "I was directed to various support services throughout the community" (1231M).

Additional Best Practices

Additional practices also were brought up in the qualitative measures that were identified by this sample as important for health care providers to do. The most

mentioned (11 respondents) was a "personal connection" with the family and the dying individual. Samples of comments in this area are: "The little hugs and the sweet way they (the health care providers) talked to him. Because of these people I felt he was in a very <u>safe</u> place and we weren't going this struggle, life changing event, alone" (1313H); and "They treated LXX as an important person …They talked with her and not around her…" (1295H).

"Honesty" was also mentioned by respondents (5 times). "They (health care providers) were blatantly honest (didn't sugar coat). This helped to know how hard to fight the illness" (1382H). Others talked about how they wished (4 times) for more honesty, 1409H) wrote, "Drs. Should be more honest with patients…and it still hurts."

Another important practice (7 respondents) to this sample simply knowing they were not alone in their care. It was simply the "presence" of the health care provider. "They were THERE—I wasn't alone" (1351H).

"Pain control" was identified by some (5 respondents) as a vital practice. One respondent (1357H) wrote a typical observation, "They kept him comfortable and pain free".

The final additional best practice was follow-up services that would fall under the best practice of attention to needs of family and friends. Hospice bereavement services (4 respondents) were singled out as important. "The hospice sent me books and called me once a month to see how I was doing and getting along, This helped me" (1315H). For one person (1301H), "I am most appreciative of the

continued bereavement counseling."

From these comments, the importance of the presence of the identified best practices in end-of-life care was evident. Also mentioned frequently were comments about the level of satisfaction loved ones felt about the service delivery models experienced.

<div align="center">Satisfaction with Model of Care</div>

Questions 53 (c), 54 (c), and 55 (c) all asked the respondents to any other comments about the particular model of care that they had received. In total, 117 persons wrote some comment about their satisfaction or dissatisfaction with the services they received from the model of care. For hospice, 101 statements were written (85 positive statements; 16 negative). For medical care, 13 statements were made (6 positive and 7 negative). Palliative care had four positive statements.

<div align="center">*Hospice Care Satisfaction Comments*</div>

For hospice, many statements were global ones of satisfaction and others honored particular support or services. Typical global responses were, "I can't say enough for the comfort it gave me, my wife who died, and our 3 daughters. Hospice has become an entity, not something I associate with death but with life" (1382H). Particular services were also mentioned. For example certain persons were spotlighted. One (1236H) related," the bath lady was so wonderful to my mother… That may seem small, but it meant a lot to my mother." Another respondent (1330H) wrote, "The two nurses from hospice were very helpful and willing to do whatever

was needed to help my wife and me and my family through this time". Particular

care services were also highlighted."I had VXXX Hospice. I had around the clock

care. This was most helpful" (1284H). Another (1313H) talked about the inpatient

facility in the area,

> "Hospice house provided a calm, soothing environment where my family
>
> and I were allowed to make the most of the time my husband had left to be
>
> close, talk share memories. The stress of medications and care removed,
>
> so we could just concentrate on each other."

Timeliness of response was also a common theme. "It was unbelievable how they

made the process simplified if we called and needed something they took care of it

the same day" (1382H).

There were comments that were negative about hospice services. These

comments appeared to be grouped into poor services response, personal concerns,

and a global response. Service problems that were written about all appeared to have

a connection with timeliness of the hospice's response. One person's (1393H)

comment was " At the end when he was dying, I called frantically trying to get them

to come and it took them 2 hours to respond by that time he was gone. I wish I had

known of their slow responses". Problems with personnel were also mentioned, "too

many different nurses—poor chaplain, didn't adequately provide information on

death, did not help much at death or afterwards" (1375H). The only global comment

that was dissatisfied with hospice services was, "They were no good stole his

money" (1125H).

Medical Care Satisfaction Comments

All the positive satisfaction comments for medical care recipient focused on personnel exclusively and did not talk globally or about particular services, timeliness, or benefits. Here are examples of typical responses. "Our doctors were superb; always helpful and supportive and encouraging." "All the medical teams always kept a positive outlook on our situation and were very supportive to our entire family" (1222M).

Dissatisfaction with medical care comments was also made. Common themes in this area were around global statements about medical services and helpfulness and support from medical providers. One (1400M) stated, "Traditional medical care is not geared specifically to the individual's welfare."

Palliative Care Satisfaction Comments

The palliative care comments that expressed satisfaction with this model of care were "The care and kindness they showed my mom made me somewhat more comfortable when I could not be there" (1314P); and "They treated us as if we were the only ones they had to worry about!" (1316P).

In summary, in each model of care recipients of those services made comments identifying satisfaction or dissatisfaction with the care they and their loved one received. Since the sample was skewed and included more hospice care recipients most of the comments made were about this model. Of the 134 total hospice recipients approximately 75% of the care providers wrote their opinions. Of the 41 medical care recipients, approximately 32% contributed comments and 80%

of the palliative care recipients expressed their opinion. Both the hospice care model and medical care model had positive and negative comments. The palliative care model had only positive comments.

Additional Findings

Social Support Statements

Eight respondents singled out social support as crucial for them. A hospice respondent summed up the gist of most of these comment when she wrote, "The health care providers were very nice but I gained strength and support from family and friends" (1360H). A medical care only respondent also commented on the persistence of this support, "My family, friends, and church were my support and they are still there for me even today" (1281M). One respondent chided this researcher when he said, "You didn't ask about the importance of support by friends, and in what ways they helped. Seems to me those questions should be critical to your study" (1327H)

Timely Hospice Referral/Service

Six respondents did address the timeliness of their hospice referrals. Four persons remarked that they should have been referred to hospice sooner. Each of these people had hospice services for 3 days or less. One reflected the general feeling of this group when she wrote, "Should have gotten it (hospice) MONTHS before—didn't know enough about it." (1269H). Three medical care recipients also voiced concern over hospice referrals. One remarked, "I wish we had hospice in to help me in his final days so I could have known more at his death." (1266M).

Summary of Qualitative Findings

In summary, many of the respondents answered one or more of the open ended questions in the questionnaire and some enclosed additional statements about their caregiving and grief experiences. With these qualitative statements common themes emerged. These themes centered on elements of positive and complicated grief, models of care and grief support, identified best practices, satisfaction ratings for the models of care and social support. With reference to positive grief, elements of positive grief (meaning making, spiritual connections, enhanced self awareness/self esteem, and value reformulations were all present in the qualitative comments. Negative grief statements also appeared but not as frequently as the positive comments. Many respondents made both positive grief and negative grief statements. However, two individuals had predominately negative grief statements and may have had the potential for a complicated grief diagnosis.

Comments about the model of care supported hospice as providing more of the identified best practices and that these best practices were important to the respondents. A preponderance of hospice respondents voiced satisfaction with this model of care over all and with grief support in particular. Palliative care services and hospice services also appeared to have the most statement of consumer satisfaction. Finally, some of the comments spoke to the importance of social support to the caregiving and grieving process.

Chapter 4 Summary

Demographically this sample was predominately homogeneous. Most respondents were white, female, older, and widows/widowers. Approximately three-fourths had hospice services and all of them provided emotional and/or physical support to their deceased loved ones. Most saw spirituality as important and most were active in a religious organization.

Hypotheses 1, 2, 3, and 4 were examined and were not confirmed. No model of care was significantly different in associations with positive grief or complicated grief. Demographic risk factors for complicated grief such as older age, female gender, and spousal relationship were not confirmed. Also within the hospice model of care analyses, short lengths of stays in hospice were not significantly associated with positive grief or complicated grief.

However, statistical significance was confirmed in Hypotheses 5. Seven best practices (information on dying; information on bereavement; emotional support; spiritual support; community referrals; provider availability) were more likely to be included in the hospice model. The hospice model was significantly more likely to have higher helpfulness ratings on the best practices of listening, spiritual support, and respectfulness of culture/ethnicity.

Additional quantitative data was analyzed with regard to types of health care services, use of multidisciplinary teams and length of illness. This sample's loved ones made extensive use of health care services three months prior to their deaths and that alludes to the degree of care they required. Evidence emerged that the

makeup of the multidisciplinary team did impact the delivery of best practices. The larger the multidisciplinary team the more likely the best practice of information on dying and bereavement, emotional support, provider availability, and community referrals was present. In addition, with the three or more person multidisciplinary team the helpfulness scores on the best practices of information on dying and listening were significant. Also the median length of illness of the deceased loved ones confirmed that medical services were provided for four years and that hospice services median length of stay was 29 days. Finally, satisfaction scores concerning the models of care were not significantly different and all models of care received scores on average of "satisfied" or better.

Common themes emerged with the analysis of the qualitative data. These themes centered on elements of positive and complicated grief, models of care and grief support, identified best practices, satisfaction ratings for the models of care and social support. With reference to positive grief, elements of positive grief (meaning making, spiritual connections, enhanced self awareness/self esteem, and value reformulations) were all present in the qualitative comments.

Comments about the model of care supported hospice as providing more of the identified best practices and that these best practices were important to the respondents. A preponderance of hospice respondents voiced satisfaction with this model of care over all and with grief support in particular. Palliative care services and hospice services also appeared to have the most statement of consumer

satisfaction. Finally, some of the comments spoke to the importance of social support to the caregiving and grieving process.

Key findings to be examined in the discussion section concern the lack of palliative care team data, response rate, and other limitations. However, strengths of this study that need to be discussed in depth are the presence of positive grief statements and their association with best practices, the way the different models of care build on one another and any barriers to that, and implications for social work practice, policy, and further research.

CHAPTER 5: Discussion

Dying is surely the most profound of life's challenges.
We speak of growing up and growing old;
perhaps, we can refer to those who emerge from suffering
into a subjective sense of wellness in their dying as "growing on."

--Ira Byock

Death affects not only the person who is dying but the family and friends who grieve the loss. How people die impacts societal norms that grapple to define what a good death is, and challenges the community to support quality of life for its members. Never before has the global society been in such a position to care well for those that are dying in a biological, psychosocial, spiritual, and personal way. The opportunity to improve the lives and deaths of its members is clear and present. Studies like this one are necessary to improve support for the dying and their loved ones so that this seminal event will not be remembered in solely negative terms but that the positive aspects of dying and the search for life's meaning can be nurtured and advanced.

Included in this dissertation is a review of the changing face of dying and grief. These changes are directly connected not only to the changes in health care delivery, but also in the changing awareness of the importance of best practices in end-of-life care. These best practices not only benefit the dying person but also appear to support positively the grieving process of surviving loved ones.

The dominating philosophical paradigms are also examined in light of their approach to end-of-life care. The positivist paradigm that has governed medical practices (the medical model) for the last one hundred and fifty years is being profoundly influenced by new ways of conceptualizing knowledge itself and alternative ways of knowing. A transpersonal theoretical approach has emerged as a counterpoint to the medical model. This theory has envisioned death as a natural, normal occurrence full of potential for growth and transformation (Kubler-Ross,

1968). Also, a social constructivist paradigm supports the belief that the ill person has a right to determine the course of his or her treatment (Reb, 2003). In this paradigm's conceptual framework, the ill person is the only one who truly understands the meaning of his or her life and needs in the dying process.

These three theoretical stances coexist today within society and within the health care system. Confusion and miscommunication can result as health care professionals and consumers try to provide and receive good end-of-life care without realizing that basic conceptual frameworks and goals are divergent. However, the multiplicity of frameworks in which to view death and dying does not need to be a key barrier within end-of-life research. All three frameworks have the potential to provide good end-of-life care to ill persons and their families.

Study Goals

The goals of this study were three-fold. The first goal was to test whether the model of care received by a dying person facilitated the ability of surviving loved ones to grieve well. The second goal was to examine previously identified best practices in end of life care and rate how helpful these practices were to the study participants. The presence of best practices within the services of a particular model of care was also of interest. The final goal was to explore the interaction of the demographic variables as gender of ethnicity, relationship to the deceased, age, and length of stay in hospice to the experience of grief of the surviving loved ones.

The models of care that were explored included the medical model, which was exemplified by a traditional medical approach; a social constructivist model

embedded in a palliative care team approach, and a transpersonal model inherent in a hospice care approach. Additional components of this dissertation included a conceptualization of a continuum of health care needs at the end-of-life and of a bi-dimensional grief framework that included positive growth enhancing elements as well as complicated grief. The continuum of health care services at the end of life theorized that each model of care experienced by persons at the end of their lives could and did build upon all other models of care experienced by the dying persons and their loved ones. Additional concepts that were key to this study included the identification of positive grief as a category that encompassed positive grief experiences and personal growth through loss.

<div align="center">Lack of Data on Palliative Care Services</div>

In beginning the analyses of data for this study, the lack of definitive information about palliative care team interventions became evident. The initial intention was to attempt to see how palliative team interventions at the end of life compared with the efforts of medical care and hospice care. However, this was unable to be determined. Most of the palliative care team results are reported but since the sample was so small (n=5) they were not included in the major analyses. This non-inclusion is identified throughout the findings section. Consequently, the study became essentially a comparison between the medical model and hospice care.

Feedback from the pilot study did allude to the possibility that clear data about palliative care team services may be difficult to obtain. The information from the consumer experts was inconclusive. One of the pilot study's expert reviewers had

cautioned that palliative care was not clearly defined in her experience. The consumer who had experienced hospice identified palliative care as a function of hospice not as a separate entity. The other two consumers denied contact with a palliative care team even though their loved ones had experienced poor symptom management. Certainly the findings of this study confirm that palliative care as a concept is used with many different services and professionals in the health care setting. The data from the palliative care team respondents did not appear to be reliable or readily identifiable.

Possible explanations for the lack of discrimination among palliative care and medical and hospice care may be attributed to the confusion about the use of words "palliative care" and the lack of uniformity in its implementation. First, this ambiguity around palliative care services may reflect the lack of an agreed on definition of palliative care in end-of-life settings (Critchley, Jadad, Taniguchi, Woods, Stevens, & Whelan, 1999; Wachter, 2003; WHO, 2005). Palliative care as a nomenclature is commonly referred to by many different providers. Medical care personnel talk about delivering palliative care services when they address pain and some physical symptom management (Critchley et al, 1999; Miller & Walsh, 1991; Reb, 2003). Some consider alternative therapies as massage as palliative care (Reb, 2003). Hospice care personnel see palliative care as extensive services that encompass symptom management of not only physical but also emotional and spiritual angst (Reese et al, 2003). As a result, palliative care in these venues has no consistent meaning. Also palliative care can also refer to different models in

hospitals and nursing facilities.

Second, the implementation of palliative care team services is not standardized. This lack of standardization was a significant barrier to capturing data that was palliative care specific. Palliative care teams in hospitals can be only consultants who are only called in when a primary physician requests them. They report directly to that physician who decided whether or not to implement the care team's suggestions (Morrison et al, 2005). Another option is that might be very autonomous and be connected with palliative care units in hospital and nursing facilities where the full range of services are supervised by the palliative care team at the end of life (Morrison et al, 2005; Viney, Walker, Robertson, Lilley, & Ewan, 1994). With this range of services available under the umbrella of "palliative care" and the many different uses of this term, consumers may not be sure what palliative care means in practice or be able to identify if this is an independent team. This appears to contribute to the ambiguity of the palliative care results. As stated above, due to the lack of consistent data on palliative care teams the analysis became limited to only hospice and medical care services.

Hypothesis 1

Hypothesis 1 stated that surviving loved ones of a hospice client will display significantly greater positive grief scores than palliative care and aggressive care clients and that the palliative care clients will display significantly greater positive grief scores than aggressive care clients. This hypothesis was not confirmed. The sample of palliative care clients was not analyzed due to the explanations given

above. The remaining data did not find any significant differences between hospice care and medical care clients on the positive grief scale. However, evidence of positive grief was reflected throughout the responses to the survey.

Positive Grief and Team Composition, and Demographics

In addition to the lack of differences found with regard to their positive grief scale scores with regard to model of care, there was no significance found between the number of people on the multidisciplinary team and positive grief scores. There were also no significant findings between demographic variables (gender, age and minority ethnicity) and positive grief scores and no difference in short length of stay in hospice and positive grief scores. In short, the strength and presence of positive grief occurred through all models of care within all demographic groups and with short and long term hospice services.

Understanding the Incidence of Positive Grief Responses

Although there is no significant difference between positive grief and model of care, it is clear that the respondents voiced positive grief experiences. Moreover these displays of positive grief did mirror the key indicators identified by other grief researchers. Specifically the key indicators of positive grief are: continuing bonds with the deceased, positive growth in spirituality, greater self awareness and self esteem, value reconstruction, and meaning-making (Attig, 1996; Calhoun & Tedeshi, 2002; Frantz, Farrell, & Trolley, 2002; Janoff-Bulman & Berger, 2000; Milo, 1997; Neimeyer, 2002; Silverman & Klass, 1996; Talbot, 1996; Tarockova, 1996). The items of this seven-point positive grief scale mirrored these indicators with "good

memories" reflecting continuing bonds; "greater spiritual awareness" addressing spiritual growth; "learned more about one's self" and "better person" spotlighting greater self awareness and esteem; and "meaning of life", "valuing each day", and "meaning of important things" highlighting meaning making and value reconstruction. In addition the qualitative comments also elucidated a wealth of positive grief indicators. From both the quantitative and qualitative findings positive grief indicators were confirmed.

Quantitative Insights

In looking at the information gleaned from the positive grief scale, no cut-off point that would determine "positive grief" was determined for this scale. First of all, a cut-off point would be inappropriate from the scale's conceptual and paradigmatic grounding. This scale is firmly embedded in a transpersonal model. Grief from this stand point is neither a constant nor exclusive. Grief work is a process in which meaning making is in flux and grows and changes as the person experiences additional life events. Moreover, the goal is not to reach resolution but to continue to treasure the relationship and grow in its meaning. The findings support that most of the participants experienced aspects of positive grief and demonstrate this element of process. Secondly, this was the first use of this scale and only face validity was initially determined by the pilot study.

Nonetheless, the strength of these positive indicators was clearly identifiable. The average score on the positive grief scale was skewed more toward strong positive grief (mean equaled 25.7 points, with the continuum of more positive

grief anchored at 35 points and less positive grief at 7 pts). Six components of the

scale had mean responses that were "often" and only one "sometimes" (life has more

meaning). In general, with the scale responses positive grief was identified and the

strength of that grief was moderately strong.

Qualitative Insights

With the qualitative analyses, the four questions that were asked were open

ended and non-leading. However, almost all the respondents took this opportunity to

acknowledged aspects of positive grief. It is more remarkable that these respondents

addressed all the indicators identified by grief expects (meaning making,

reconstruction of values, spiritual awareness, greater self-awareness and esteem, and

continuing bonds). Certainly, these findings reinforced the accuracy of the indicators

identified by transpersonal theorists. Again, recipients of medical interventions,

palliative care interventions, and hospice interventions made statements about the

positive aspects of grief. However, only one medical care recipient stated that the

medical team was helpful with the grieving process and more statements were made

about the lack of support for grieving in this model of care. For hospice and

palliative care the written responses praised.

Finally, in looking at the demographics for this study (especially the

identified risk factors for complicated grief—female gender, over 65, and minority

ethnicity—, both men and women, those over 65 and younger, and those of majority

and minority ethnicity voiced positive grief statements. In analyzing the short-stay

hospice recipients and the longer-stay recipient's qualitative remarks, both groups

expressed that hospice services, especially follow-up bereavement, were beneficial to them. From this data, it appeared that the qualitative statements mirror and support the quantitative data with reference to positive grief. However, the qualitative data mentioned hospice and palliative care services as more supportive of the recipient's grieving than medical model care. Moreover, recipients of hospice and palliative care overtly linked these services to their expressions of positive grief. Why, then, is there this distinct and pervasive evidence of positive grief?

Grief Trajectories

The previous literature review may put the positive grief statements into the context of our knowledge of the trajectory of grief. First, the literature documents that within the first six-months of the loss, negative aspects of grief appear to dominate (Prigerson et al, 2006: Prigerson et al, 2008; Rando, 1993; Tedeshi et al, 1998). However at six months or later, only about 10% of people appear to be dominated by these negative feelings (Prigerson et al, 2006: Prigerson et al, 2008). From strength's perspective, the resiliency of people that comes about through learned coping mechanisms, social support, and personal introspection may mitigate the experience of model of care, shortness of engagement with a model of care, demographic risk factors, and number of health care providers. Simply put, most people have past experiences that help them cope with and cope through the onslaught of grief. With time they are able to marshal those resources to allow them to move past overwhelming negative feelings. From a medical model, this would be viewed as using coping mechanisms and finding closure. From a social constructivist

point of view, they would be using social mores and social support to find resolution. From a transpersonal perspective they would reflect spiritual and personal growth that helped to reorder the meaning of life. So from all the perspectives they would be expected and "normal" for most people to find "an answer" to explain the loss.

Emergence of Professional Standards

Further explanations are also possible. Health care providers, regardless of setting may be providing more effective and efficient end-of-life care. This position is supported by reviewing the increase in education regarding good end-of- life care available to all health care providers. In addition, most of these educational resources and programs for health care providers have been available and used for approximately ten years. With this length of time, health care providers have had opportunities to experience training in best practices and health care systems have had opportunities to adjust policies and practices to support good end-of-life care by establishing standards for that care.

Examples of these programs are the following: physicians have had EPEC (*Education in Palliative and End-of-Life Care*) first introduced in 1999 (Emanuel, Von Gunten & Ferris, 1999); nurses ELNEC (*End-of-Life Nursing Education Curriculum*) curriculum since 1998 (English & Yocum, 1998) and also TNEET (*Toolkit for Nurturing Excellence at End-of-life*) since 2003 (Wilkie et al.); licensed practical nurses had their core curriculum, *Core Curriculum for the Licensed Practical/Vocational Hospice and Palliative Nurse*, since 2003 (Hospice and Palliative Care Nurses Association, 2003); nursing assistant's curriculum, *Core*

Curriculum for the Hospice and Palliative Nurse Assistant since 2002 (Hospice and

Palliative Care Nurses Association, 2002); social workers in 2001 had their

Competency Based Education for Social Workers (NHPCO) and also the *National*

Standards for Social Work Practice in Palliative Care and End-of-Life Care (2003);

clergy and chaplains have both the *Guidelines for Spiritual Care in Hospice*

(NHPCO, 2001) and *Statewide Clergy End of life Education Enhancement Project*

(Hospice Foundation of America, 2003); and for all health care professionals*,*

National Consensus Project for Quality Palliative Care (2004). From this wealth of

resources for all health care professionals, all key health care providers in end-of-life

care venues should be exposed to their professional standards and practices for good

end-of- life care.

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Sample Context Implications

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The composition of the sample itself influenced the quality and quantity of

positive grief statements. First is the dominance of the hospice care model (n=134).

Approximately, 75% of the recipients reported receiving hospice care. Healthy

grieving is a goal of hospice care and it is the only medical service mandated by law

to provide follow up bereavement support. Moreover, as reported in the literature

review, hospice services are positively correlated with healthy grieving by surviving

loved ones. In addition, in looking only at the qualitative statements, 97% of the

positive grief statements were made by hospice recipients. This study further

corroborates the strong association between positive grief and hospice services.

Additional clues from the survey sample that substantiate the plethora of

positive grief findings are the respondent's stated spirituality. The initial section of

the questionnaire (before any scale or before questions regarding model of care were

introduced) asked two questions in reference to their global assessment of the

importance of spirituality and their association with an organized religion. With

regard to the global assessment, 76.1% of the respondents reported that spirituality

was "very important" in their lives and 19.4% reported it was "somewhat" important.

For this sample, about 96% had a personal spirituality. In addition, 66% defined

themselves as "an active member of an organized religious group". Grief theorists

from all models of care have associated healthy grieving with spirituality. Moreover,

social constructivists point out that socially appropriate rituals around grief and

social support foster healthy grieving. The transpersonal theorists believe that

spiritual connections to the deceased are healthy and staying connected in a spiritual

sense promotes the surviving loved ones ability to go on after the death and find

happiness in life. For transpersonal theorists, connections to organized religion is

also a strength, since most religions support a belief in fostering continuing bonds

and offer meaning to the loss. Religious organizations also have a codified meaning

for death and many postulate an afterlife in which families reunite. This may

encourage people to find a meaning for the death of their loved one.

Also the sample received most of the services considered to be "best

practice" in end-of-life care that were identified by consumers in previous studies

and this may further corroborate the efficiency of these services in supporting

surviving loved ones. All these best practices but "information on bereavement" and

"spiritual support" were received by 70% of more of the recipients. In addition, five of the eleven practices were received by 85% or more of the respondents (see Table 20).

Finally, the response rate of the sample itself may have skewed the responses to reflect more positive grief. A type of "creaming" may have occurred with the poor response rate. Those persons that responded were proud of their caregiving, proud of their personal growth, and proud of stronger sense of meaning may have been more open to complete the questionnaire. Those that were mired in their grief might have found it too difficult to consider being part of the study. Evidence from this is found in the statement from the two persons that appeared to have more negative comments about their grief process; one wrote on the front cover of the questionnaire, "Sorry it has taken my so long to respond It was hard to open the envelope" (1404H) and the other wrote "I cried through the whole survey" (1249M). In addition, one of returned surveys that was uncompleted stated that it was just "too hard" to complete.

In summary, there is evidence that the strong positive grief scores and comments can be further attributed to the sample itself. This sample was overwhelmingly connected in spiritual ways, grounded in institutions that encourage finding meaning in death and socially support grieving activities, and received follow up bereavement services that promoted healthy grieving. The very nature of the sample—those who responded—may also indicate self-selection with only those that had successfully found positive grief experiences answering.

Bi-dimensional Grief Experiences

The data from this study does support that grief is not all negative. This preponderance of positive grief data supports this researcher and other researchers' contentions that grief is not one dimensional but that post loss growth occurs. People, who have experienced a loss, can and do come to make meaning of that loss, reassess their values, explore spirituality, gain added self awareness and self-esteem and treasure life.

Hypothesis 2

Hypothesis 2 stated that that surviving loved ones of a hospice client will display significantly less complicated grief than palliative care and aggressive care clients. Also, palliative care clients will display significantly less complicated grief than aggressive care clients. This hypothesis was not confirmed. No member of the sample was confirmed to have complicated grief as determined by the ICGR scale developed as a diagnostic tool by Prigerson et al (1995).

ICGR Scale Items and Lack of Complicated Grief

In looking solely at the responses from the ICGR scale, the individual items from the ICGR scale could be explored more fully. The literature review confirms that people get stuck in their grief because they are preoccupied with thoughts of the other person; they are non-accepting of the death; they avoid connections with the deceased; and they exhibit depression and anxiety. In looking at ICGR items, seven items were answered on average "rarely or never" and these included items about avoidance, preoccupation, and depression. No item's average score was in the

"often" or always" category. Only two items scored above 3.5 on the 5 point scale

and they were items about loneliness and yearning. This further substantiates that the

identified indicators of complicated grief were not pronounced within the responses.

Qualitative Insights

Although no person in this study received a score on the ICGR scale that

would indicated complicated grief, negative grief experiences were evident in the

qualitative findings. Many respondents wrote comments that indicated negative

grief, documenting the loneliness felt and the sadness that persists. However for all

the respondents but two, these negative comments were interspersed with positive

grief statements. For two persons in the qualitative section, no positive grief

statements were made and they appeared to demonstrate strong evidence of

complicated grief. Statistically this represented approximately 1% of the sample

population. Other studies have postulated that approximately 10% of bereaved

persons experience complicated grief (Prigerson et al., 2006; Prigerson et al, 2008;

Rando, 1993).

Possible Complicated Grievers

Two respondents did voice strong negative grief in their statements written in

response to the qualitative items. Statements from one respondent (1249M) reveal

indicators for complicated grief. She spoke of the continuing rumination over the

loss, the predominant negative feelings (crying and depression) and also being

"stuck" in her grief (she had tried medication and therapy and neither helped). The

other respondent (1404H) also spoke of the dominance of negative feelings and

regrets. In addition this respondent felt that the medical providers had "ended up killing her (loved one)" and her anger at the medical providers and her sense of powerlessness were evident in her comments.

With exploring in depth the first person's (1249M) responses and demographics, this person scored a 76 on the ICGR. This score was well below the 89 point cut-off but still was still in the higher range (mean score for medical care was 46.8). On the positive grief scale, the mean score was 24, which was near the mean score of 25.54 for persons receiving medical care. In looking at demographic indicators this respondent was a female, age 44, and white. She was a spouse whose loved one had received medical care only from a two person medical team (doctor and nurse). Concerning identified best practices, she received all but two of the practices and was satisfied with all that she received. The two missing best practices were bereavement information and referrals to community resources.

This respondent also remarked that this was her second spousal death in five years (M). Perhaps this is evidence of the impact that multiple losses in a short period of time can have on resiliency in the grieving process and the need for early and extended grief therapy for those who experience multiple losses (Beder, 2004; Dean, 1988; Worden, 2003).

For the other respondent (1404H), the same comparisons were made. The mean score for this respondent was 46 on the ICGR; this was slightly above the mean score for a hospice recipient (44.3). The mean score on the positive grief scale was 19 well below the mean score for other hospice recipients (25.63). With

reference to demographic indicators, this respondent was female, 52 yrs. of age, and also white. She had hospice services and reported the support of a four person multidisciplinary team. However, in looking at best practices she reported not having seven of the eleven best practices. She did not have discussions around treatment options, bereavement information, emotional support, spiritual support, information about the care plan, respectfulness, or was listened to.

This person also remarked that she regretted not being able to talk with her mother about death. This may highlight the importance of supporting communication between family members at the end-of-life and its connections to grieving well (Ahrens, Yancey & Kollef, 2003; Azoulay, 2005; Rando, 1993; Worden, 2003). In addition, other studies support the belief that the degree of communication between family members impacts the degree of communication between them and health care providers. Studies document that good interfamily communication fosters good communication between health care provider and family/dying person (Curtis, Engelberg, Wenrich, Shannon, Treece, & Rubenfeld, 2005; Hanson, Danis & Garrett, 1997; Lautrette, 2007). In analyzing the items that address communication with health care providers included in this survey, the respondent stated that although she had hospice services for about two months, she did not have discussions around treatment options, bereavement information, emotional support, spiritual support, information about the care plan, respectfulness, or was listened to by the health care providers. This is only one person but it does appear to support these findings on the need for frequent, clear, and respectful communication between, among, and with the

loved ones and health care providers.

In looking at these two persons from a demographic viewpoint, they have few of the identified demographic risks for complicated grief. Both are female which is a risk factor but neither were older (one was 44; the other 52) nor from a minority. One was a spouse (a risk factor) but the other was not. This speaks to our awareness that although risk factors are helpful to know they are not deterministic.

Follow-up with Possible Complicated Grievers

Embedded in my cover letter that was included in the mailing of the survey was a statement to contact me or their counselor at the host agency if they felt the need to contact a grief counselor due to the survey. No one to my knowledge contacted the host agency and no one contacted me. In looking at the statements made by the two individuals previously described, this researcher had their contact information from the response card and this researcher decided to call them. This researcher spoke with each individual at length, offered information and possible sources for additional counseling and even offered a pro bono visit from me. Both individuals repeated their comments about how difficult their loss had been for them; both verbalized that they were in a grief support group (one at her church and one at her local community center). Both declined my offer of services. I also offered to assist them in receiving support from the host agency's social worker. This was also declined. From these conversations I did feel that both displayed some of the elements of complicated grief but were supported by other professionals.

Sample Context Implications

Why did this sample reflect so little evidence of complicated grief? Possible reasons for this rest in the analysis given for positive grief. This sample had a preponderance of spiritual connections, the presence of a high degree of positive grief indicators on the positive grief scale, the evidence in the qualitative responses of strong family and social ties and a high number of qualitative responses that attested to personal growth, continuance of bonds, and enhanced self-esteem. The poor response rate itself may allude to the fact that few people with complicated grief would volunteer for the study (this will be addressed in the limitations section). Yet, perhaps this cross-sectional study gives insight into the nature of the grieving process.

In summary, although no person scored high enough on the ICGR scale to indicate complicated grief, two persons with their qualitative comments appeared to be exhibiting symptoms of complicated grief. They both appeared to be profoundly saddened by the loss and struggling with this sadness; both appear to display rumination, yearning, and being "stuck" in their grief over time. With a follow-up contact, I learned that both were involved in a grief support group and both declined services from me and from the host agency.

Hypothesis 3

Hypothesis 3 stated that persons who are female, older (age 60 and above), and non-majority ethnicity will display more complicated grief than men, persons under 60, or persons of the majority ethnicity. This hypothesis was not confirmed,

since no member of the sample was identified as having complicated grief.

Interestingly, this sample was overpopulated with persons with risk factors for complicated grief (female (70%), over 65 (45%), and spousal relationship (69%). Only non-majority persons were under represented in this study (13%). Yet, no person with complicated grief was identified in the quantitative data and only two respondents in the qualitative responses appeared to manifest complicated grief. Of the two who appeared to manifest complicated grief only one risk factor was consistently present and that was female gender.

This finding at first look is puzzling. However, as mentioned earlier in this dissertation, studies have confirmed that there are certain protective factors that appear to support healthy grieving. People who can verbalize an acceptance of death, a belief in a just world, and/or instrumental support appear to grieve more healthy (Bonanno et al., 2005). People who verbalize a strong sense of spirituality and strong spiritual connections also appear to cope with loss better (Michael, Crowther, Schmid, & Allen, 2003; Walsh, King, Jones, Tookman, & Blizard, 2002). And finally, those persons that experience support prior to the loss have significantly less bereavement stress even more than those that receive only support during bereavement (Bass et al., 1991). These studies confirm that certain factors as awareness of the death, strong spiritual connections, social supports, and assess to community resources decrease the likelihood for complicated grief. In this study, these elements were predominately present and this may suggest that they had moderating influence on these risk factors.

Another factor was the sample's predominance of hospice recipients. The presence of the identified best practices in end-of-life care may account have provided crucial support. In addition, the bereavement supports mandated by hospice may have been beneficial too. Studies have confirmed that hospice bereavement services are effective in helping loved ones cope with their loss (Forte, Barrett, & Campbell, 1996; Kramer, 1992). The sample was also overwhelming satisfied with the care their loved one received at their last days. Since studies have confirmed that complicated grief is also associated with dissatisfaction with the care received (Contro, Larson, Scoffield, Sourkes & Cohen, 2002; Prigerson & Jacob, 2001). Finally, it is important to point out once again that complicated grievers may have not responded to the survey.

<div align="center">Hypothesis 4</div>

Hypothesis 4 stated that length of engagement in the model of care will impact grieving well. A short length of stay in hospice will have an inverse relationship with positive grieving and few consultations with palliative care teams will have an inverse relationship with positive grieving. This hypothesis was not confirmed. People, who's loved ones had one week or less of hospice services, were not significantly different on the positive grief scale than those that had longer lengths of stay. The small response rate for palliative care services precluded the analysis of the remaining portion of the hypothesis.

An additional explanation for these findings (other than those already postulated in the above discussions) may be the awareness of short length of stays

and the quality of the response by the hospice team. Short length of stays is not a new experience for hospices. Hospice statistics for the last decade have confirmed that approximately 30% or more of hospice clients receive services for one week or less (NHPCO, 2008; Rickerson, Harrold, Kapo, Carroll & Casarett, 2005; Teno et al., 2008) and for this sample 26% received hospice less than a week. Hospices have learned to deliver core services efficiently and with the awareness that time may be very short for the dying person (Shockett, Teno, Miller, & Stuart, 2005). This study may be additional confirmation as to the effectiveness and efficiency of hospice services in short term. In reviewing the satisfaction ratings, 62.3% of the persons, who experienced seven days or less of hospice services, were very satisfied or satisfied with the services they received. Past studies have associated good services as a support for grieving well (Bradley et al., 2006; O'Brien et al, 2000). This quick response service delivery may be another support for surviving loved ones coping with grief.

Hypothesis 5

Hypothesis 5 stated that best practice ratings of health care professionals will be positive in all models of care. Hospice professionals will have greater best practice ratings than palliative care professionals. Palliative care professionals will have less positive best practice ratings than hospice professionals but greater ones than aggressive care professionals. Hypothesis Five was confirmed in that all the models of care had some degree of presence of the identified best practices. The range for this presence was 29% to 100%. The hospice model was significantly more

likely to have presented information on dying, information on bereavement, emotional support, spiritual support, community referrals, and provider availability. The hospice model was significantly more likely to have higher helpfulness ratings on the best practices of listening, spiritual support, and respectfulness of culture/ethnicity.

Evidence of Best Practices in Models of Care

In exploring the presence of best practices within each model of care and their helpfulness to the surviving loved one, restatement of those best practices is necessary. These best practices as substantiated by earlier studies included communication with the loved ones and the ill person about information about their disease, treatment options, and community resources; about inclusion of the loved ones in plans of care; about emotional, spiritual, and social support; about information on death and dying as support for their grief; and about respectfulness and availability. These best practices have been identified through research conducted in medical, as well as hospice and palliative care setting. Moreover, they have been validated in both qualitative and quantitative studies. The most influential of the studies that identified these best practices is the SUPPORT study (1995). Consumers have consistently acknowledged that these practices have aided them to caregive well because they have this emotional and concrete support from their health care providers (Chochinov et al., 2002; Kayser-Jones, 2002; Nakashima & Canda, 2003, Mulder, 2000; Reese, Melton & Ciaravino, 2003; Steinhauser, et al., 2000b; SUPPORT, 1995; Visser, 2003; Wenger et al., 2001). Professionals have

agreed with these practices and all of these health care provider training standards incorporated this common set of best practices. All included sections on communication with the patient and the family, ethical issues, emotional and spiritual support, knowledge of grief, cultural awareness, provider self-awareness, and psychological and/or physical symptom management. However, when each of these standards was examined, there were apparent differences in the degrees of emphasis and professional cultural approaches.

For example, in both, the EPEC and ELNEC standards, pain management and physical symptom management dominate information on emotional symptoms and suffering (American Association of Colleges of Nursing, 2001; American Medical Association, 1999). Concentration on the patient overshadows support for loved ones. Spiritual support is encouraged at the time of death but not mentioned as frequently during the time of terminal illness. Ethical issues reside predominantly in the completion of forms such as advanced directives and do not resuscitate orders as well as the need to be clear about their professional standards regarding active and passive euthanasia. For health care providers in the medical model, the emphasis is different. The need to prepare family members for the death and the emphasis on emotional and spiritual support for the dying person and the family equally are integral parts of good end-of- life care that is not stressed as much in the standards for the medical professions.

Other providers also emphasize some elements more than others. For example, chaplain standards highlight the aspects of spiritual support, understanding

of the grieving process, cultural competency and working with other professions to provide services. Within social work standards, the emphasis is on self-determination, serving both the ill person and their family, cultural competency, community links for support, and emotional/spiritual/bereavement support. The result in looking at these professional standards is that one profession cannot fulfill all the best practices needed and wanted by dying persons and their loved ones. That is why another known best practice is the use of the multidisciplinary team.

The multidisciplinary team has as its core members the physician, nurse, and social worker. Additional members can be home health aides, chaplains, therapists, volunteers, and so on. In looking at the multidisciplinary team, each provider standard supports at least a three-person team approach. However, in this study, the medical model services commonly were composed of a two-person team. Hospice services were most likely delivered by three or more person teams. The impact of the two-person team is clear in this study. With only this two-person approach, this sample's respondents were less likely to receive all the components of best practices. Specifically they were less likely to receive information on dying process, information on bereavement, emotional support, referrals to resources, and provider availability. Moreover, some ratings of the helpfulness of the best practices were significantly lower with the two-person team. Those persons, who had been served by three or more disciplines, reported significantly higher helpfulness rating in the areas of information on dying and to listening to them. This appears to suggest an incomplete delivery of best practices in the medical model services area and more

fidelity to the best practices standards with teams with three or more disciplines.

This finding corroborates the importance of understanding that each health care professional brings particular areas of expertise to the care plan. Because of their grounding in the medical model, medical professionals are less likely to address spiritual or love one concerns—their focus is on the ill person and solutions to the medical needs. Because of their grounding in spirituality, chaplains are most likely to address spirituality and respectfulness. Because of their grounding in a "person in environment" perspective, social workers are more likely to look to emotional/spiritual support, loved one support and bereavement, and community resources. Another strength of social work is respectfulness. Social workers are mandated by their code of ethics to be competent in persons of diversity whether that is diversity based on age, spiritual preferences, ethnicity, ability, or other factors. It might take a village to raise a child but it certainly takes a multidisciplinary team with each member's unique professional cultural perspectives, training, and specific professional standards in end-of-life care to provide comprehensive best practices to dying individuals and their loved ones.

Explanation of Significant Findings

The significant findings regarding best practices may be attributed to the reasons described above. Simply put, physicians and nurses are not trained or encouraged to address emotional support, spiritual support, or community resources. Although one could assume that information on the dying process and bereavement information would be standard in a medical model, this information is the antithesis

of the medical model paradigm that concentrates on cure. Their availability may be problematic due to high patient loads. On the other hand, social workers, and to some extent chaplains are trained to provide emotional and spiritual support and bereavement information and support. Social worker's forte is linkage to community resources. The overarching rationale for the use of the multidisciplinary team is the belief that with more professionals involved in the care of the dying person and their loved ones, there are more professionals available to them for support and consultation.

These significant findings point out the importance of a multidisciplinary team. This team may be the cornerstone of assuring the delivery of best practices as it capitalizes on the strengths of the contributing professionals and also assures more professional availability. Since hospice is the only model of care that is mandated by policy to include a multi-disciplinary approach to care, these significant findings may add to the corroboration that multi-disciplinary teams are indeed the gold standard for end of life care.

Length of Illness, Satisfaction Ratings, and Timeliness of Hospice Services

Additional findings confirm long standing problems regarding when medical care moves from curative to end-of-life care. The surviving loved ones reported that 48% of the loved ones were aware of the life threatening illness for more than a year. Only 4.5% knew of the illness for 4 weeks or less. However, 52.6% of the loved ones reported receiving hospice care received that care for 4 weeks or less. Hospice benefits are applicable to people who have a terminal illness and a projected life span

of six months or less. This six-month time frame is flexible and only a guideline. As it has been documented repeatedly, hospice referrals many times come very late in the dying process (with this sample 26% had services less than 1 week). This mirrors the statistic findings reported by the NHPCO. In 2007, approximately, 30.8% of persons received hospice services for seven days or less (NHPCO, 2008). However, many end-of-life care experts have recommended that a hospice stay of three months or less leads to less family satisfaction and inadequate delivery of the full services available through hospice (Christakis & Iwashyna, 2000; Richeson, Harrold, Kapo, Carroll & Casarett, 2005; Shockett, Teno, Miller, & Stuart, (2005).

Timeliness of the receipt of hospice services also confirmed information from other studies. Teno, Shue, Casarett, Spence, Rhodes, & Connor (2008) discussed in their national survey of hospice surviving loved ones that "the trend of unmet needs and dissatisfaction with care… (was associated with) those who reported referral that was 'too late'" (p. 124). Teno et al. also report that this "too late" referral impacts satisfaction ratings for hospice but more importantly it impacts their bereavement. In this study a small number of respondents (6) also remarked that they should have had hospice sooner or that they should have insisted that the doctor refer them to hospice. Timeliness of referrals to hospice has been a long-standing problem since hospice services began in the US in 1974 (Teno et al., 2008). This study corroborates this issue in a small way.

In this study the mean satisfaction rating for hospice services was very high, 1.3 (very satisfied=1). Only 6% or 8 of the hospice clients voiced dissatisfaction with

services (satisfaction rating of 3=dissatisfied or 4=very dissatisfied). In looking at those people who were dissatisfied, 37.5% had received hospice for 7 days or less. Only one respondent who had received hospice more than three months reported dissatisfaction with hospice services. This appears to support the earlier research that satisfaction with hospice services is associated with the length of time one receives those services.

This study also alludes to the association of best practices and consumer satisfaction ratings in particular with the medical model. In general, satisfaction ratings with medical services were also high with an average rating of 2 (satisfied=2). However, 29 % or 12 reported dissatisfaction with services. In examining the 12 dissatisfied medical care respondents, on average they reported five missing best practices. Ten of the 12 respondents (83%) did not receive were emotional support; nine (75%) did not receive spiritual support; 8 (67%) indicated they did not receive information on grief or the dying process; and 7 (58%) did not receive community referrals. This study appears to support that the lack of best practices is associated with less satisfaction with services received.

<div align="center">Snapshot of Grieving Process</div>

In summary, the majority of the hypotheses were not supported by the data obtained in this study. Neither hospice nor medical services appeared to be significantly different in supporting positive grief. Also the length of time on hospice was not correlated with stronger positive grief scores. With regard to complicated grief, no member of the sample scored high enough on the complicated grief scale to

indicate the presence of complicated grief. Consequently, Hypotheses 2 and 3 became moot. Although the majority of the hypotheses were unconfirmed, this study did provide a snapshot of the grieving process that shed light on the key concepts of positive grief, complicated grief, and the importance of best practices.

Mixed messages on the grieving process are evident in every returned questionnaire for this study. The mean score for all the respondents on the ICGR was 45 (range from 19-95). This represents that "sometimes" to "often" the respondent felt elements of complicated grief. The mean score for the positive grief scale was 26 (range from 7-35). This represents that "sometimes" to "often" the respondents felt elements of positive grief. The qualitative findings also support mixed messages in the grieving process for all but two of the respondents mirrored this mixed positive/negative experience of grief. For example, One respondent (1295H) wrote, "I miss her dearly she was an important part of my life, but my life is not empty." This exemplifies continued connections to the deceased but not impairment for the surviving loved one. So what do these mixed messages imply with reference to the three models of care and their etiological frameworks? Clearly the "mixed" message is that grief is multidimensional. Both negative feelings of loss and positive feelings can exist simultaneously. Furthermore, the same experience such as preoccupation with a deceased loved ones things can be interpreted differently. For some, this can be a comfort—a continuation of bonds. For others, it can be a haunting—an enmeshment in the pain of the loss.

Medical Model

In looking at a medical model approach, the respondents could be described as being in the disorganization stage of grief because they "sometimes--often" grapple with the feelings of despair, resentment, and despair. Clearly this sample does not display acceptance nor have they learned to move on. The participants of this study do appear to be on the average still working on their grief tasks. Yet from the medical model perspective, still working on grief tasks after six month or longer is problematic. The persistent engagement of the respondents with their grief post six months after the loss would conceptually lead us to believe that these individuals were at risk or actually experiencing complicated grief.

However, this study's findings document that although the persons are "not over their grief" they continue to live on and find joy in life. As quoted in the findings section, a respondent (1414H) exemplifies this when he said, "I do think of her and I will always think of her from time to time but death is just life and life continues to go on, so I choose to take each day as happy and thankful…and go on with my life". Others commented "I think about my mom quite often but it does not keep me from living life to the fullest" (1295H) and said, "I feel my mother is still around me at all times" (1257H). Consequently, this persistent engagement does not appear to be pathological with this group of grieving loved ones. At least from this sample, persons that voiced sadness from the loss, rumination and preoccupation, yearning, and even disbelief did not appear to be suffering from complicated grief or to be impaired in continuing on with their lives thus refuting that extended grief is

always problematic to the mental health of the grieving person.

Social Construction Model

From a social constructivist framework, the cultural mores are important to the identification of complicated grief. They contend that Western culture expects individuals to be over grief in six months to a year. However, in this sample population, no mention was made of this societal expectation. In fact, the data from this sample suggests that others were supportive of persons regardless of time. A respondent (1281M) wrote "My family, friends, and church were my support and they are still there for me even today." Another respondent (1246H) concurred "I have also become friends with other women who have reached out to me who also had lost their husband".

Social constructivists also point out that Western society is less tolerant and feels threatened by the chaos of grief. The chaos of continuing grief and its impact on living is also evident in the findings. This is reflected in the following remark: "Life will never be the same we have to make a new normal…of course, I'm lonely but I must go on that's what he'd want me to do" (1368H). Definitely mixed messages are evident that reflect continuing grief as chaotic but not necessarily impacting the quality of life after death.

Finally, present in the social constructivist conceptualization is the possibility of positive grief. Constructivists posit that grieving mores can change and loss can be reframed into an improvement for the person or society. One (1291H) has taken her loss experience and enhanced her life. She stated, "...joined hospice as a volunteer to

share my knowledge and to help others get through this time." Another said, "Hospice is a wonderful organization—I try to help people now when and where I can, because I appreciated all the help I got" (1241H). From these findings, it does appear that reframing the grief experience has allowed some individuals to offer their help to others. From a social constructivist model, this sample does mirror the importance of others (society) in supporting grieving and the importance of reframing that grief in a positive way. However, the data from this sample does not appear to substantiate that society is intolerant of prolonged grieving or the chaos of the grieving experience.

Transpersonal Model

With a transpersonal perspective, this study appears to support that continuing connections with the deceased are not problematic to the griever but positive to the griever's wellbeing; that meaning making occurs and values are reevaluated; and that enhanced self awareness/esteem occurs. This study provides evidence of continuing bonds and the positive aspects of them. A respondent (1414H) wrote, "The memories of my past with my wife are all good and that's one of things that keeps me going." Moreover, the grieving experience is supported as lifelong and one of continued renegotiation. Another (1245H) remarked "The loss of a loved one results in grieving for that loss and for me; it reopens grief for other losses that have not been fully grieved yet." And rewriting life stories to incorporate more spirituality and a greater sense of the meaning in life is also apparent with the participant's responses. Also another (1392H) exemplified this when she wrote, "My

mom lived her life as she wanted. There were consequences to that lifestyle. She never wanted to be old. Not that anyone really wants to die but she lived as she wanted to and what more can anyone ask for in life." Finally, statements were written that support grievers experiencing enhanced self awareness. For example, "I do feel like I'm a better person because of the example he gave to us with the way he handled his cancer—all I can say is I've been so blessed" (1368H).

Continuum of Health Care Services

This study appears to validate that every model of care contains similar elements of best practices. If one model of care was the "right" answer for good end of life care then it would be clear that one would have exclusive practices that would be effective only within that model of care. If these best practice frameworks were mutually exclusive these findings but would be very problematic. However, if one conceptualizes a Continuum of Health Care Services in End-Of-Life Care, these findings are expected. As stated before, "The end-of-life service continuum, thus, reflects that each model of practice is needed to provide good end-of-life care and serve vital services at particular times in our lives and deaths. They all build on one another and good end-of-life care cannot exist without each element" (pg. 69).

With the original conceptualization of the continuum of services, the medical model served as an anchored and since it is grounded in the positivistic paradigm, this model would concentrate primarily on serving the person who is ill and only secondarily on serving caregivers. Key best practices should be information about the disease process, discussion of treatment options, inclusion of the person in the

plan for their care, community resources to support the care plans, availability, listening, respectfulness, and finally information about the dying process. One would expect less information about bereavement or spiritual support services.

Palliative care services occur on the continuum after the initial contact with medical care services and these services are grounded in a palliative care/social constructivist model. They highlight the connections that are necessary to provide comfort and care to the ill person. In this phase, the caregivers are important because they are key connections that bring the ill person comfort and care. Respect, listening, availability, emotional support, information on the disease especially comfort measures, treatment options with regard to comfort decisions, and inclusion in plans for care should be key best practices at this point. Spiritual support may also be crucial in palliative care services since a spiritual basis may bring comfort. Less important would be information on the disease, community resource referrals and information on bereavement.

Depending on client choice and prognosis, hospice services may be delivered in lieu of or after palliative team services. These services focus on the transpersonal model and center on those best practices that help the ill person and their loved ones make sense out of death and bereavement. The practices should include spiritual support and information on bereavement. Here the caregivers and the ill person are equally important and their needs must equally be addressed. However, in hospice, treatment decisions, inclusion in plans for care, emotional support, listening, availability, respectfulness, information on dying, and community resource referrals

are still best practices that are important to be delivered in the hospice setting.

In summary, the differences between the medical, palliative, and hospice care models can be viewed as differences in the paradigmatic grounding of each model. For medical care, it is the preservation of life, the treatment of disease, and the focus on the patient. For palliative care, it is the awareness of the social construction of illness and pain, the importance of marshalling social support, and the respect for alternative views and answers to end of life questions. For the hospice model, it is the emphasis on meaning making as a way to understand the process of life and death, and that the gifts of loss are present just like the pain of loss. In each model certain elements are emphasized that reflect the model's approach to death and dying, However, as one moves along the continuum, these previous best practices are not lost-- it is just that the next phases emphasizes additional best practices. Therefore, each model builds on the other.

As expected, the findings from this study support that in all models, all best practices were present to some degree in each model of care. However, hospice model of care was significantly more likely to have the best practice present and also to be more helpful. There were significant differences between the medical model and hospice on the following best practices availability, information on the dying, information on loss, emotional support, spiritual support, and community referrals. Moreover, in hospice the helpfulness ratings of the best practices were significantly higher than the medical model in the areas of respectfulness, spiritual support, and listening. It appears from this data that hospice is providing not only the key best

practices one would expect from the paradigmatic model but also key best practices

one would expect to be addressed in the medical model. For example, the dying

process is well documented. Certain physical events are expected to occur as

restlessness, decrease in urine output, differences in breathing patterns etc. and one

would expect that medical model professionals would address these physical

elements and give information on the dying process to loved ones. However, the data

for this study did not support this. In the same manner, community referrals for

needed services, supplies and support services were reported more likely in the

hospice model. Certainly, in combating the life-threatening disease, community

referrals would be appropriate and just as needed from a medical model standpoint.

Figure 2 displays the significant best practice differences with regard to model of

care.

Figure 2. Continuum of Health Care Services in End-Of-Life Care

Diagnosis   *Death*

Medical Care Model
Key Best Practices include Information on Disease, Listening; Respect;
Treatment options; Inclusion in Care Plans

Palliative Care Team Model
(not assessed)

Hospice Care Team Model
Significant best practices include Spiritual Support; Information on
Bereavement; Availability; Emotional Support; Community Referrals;
Information on dying
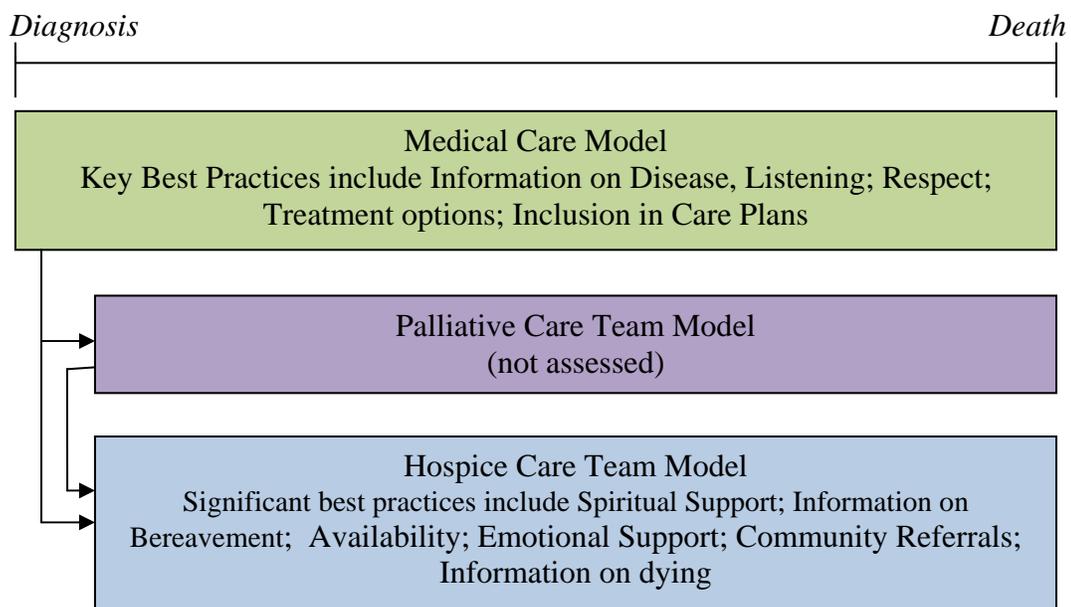
With regard to models of care, five key best practices were delivered equally well by both the medical model and the hospice model. However, this study found six key best practices that were significantly more likely to be found in the hospice model. This finding is troublesome since the medical model serves a gatekeeping function in that without referrals and documentation from the primary medical care physician, entrance to palliative care team services and hospice services are barred. The onus is on the medical care model to provide these services adequately and in this study this did not appear to occur.

Policy/Practice Realities and Best Practices

Health care in the United States is governed by national and institutional policies that gate keep access to some end-of-life services. Neither palliative care teams nor hospice services are available without physician orders. Palliative care team consultations are available only when the primary physician orders them. Moreover with our current palliative care team model, the primary physician may or may not accept the advice of the team and the patient and family would not be informed of the team's suggestions (Morrison et al, 2005). For hospice care, it is mandated in the Medicare and Medicaid hospice benefit that the primary physician certifies terminal illness (1983). For private insurance coverage for hospice this certification is also required (Moore & McCollough, 2000). With this system, the benefits of palliative care team consultations and hospice services not directly accessible to the patient or their family.

Most all persons at the end of their lives experience basic medical care. Some

die having only experienced basic medical care. In this study, approximately one-fourth of the participants had loved ones that had only experienced basic medical care and twenty-six percent of the hospice clients had only had hospice for one week or less. Forty-eight percent of all participants in this study reported that their loved ones were sick for over a year. Couple those statistics with the knowledge in the medical community about treatment effectiveness and signs and symptoms of impending death and the importance for health care providers in the basic medical setting to address end-of-life care aggressively is evident. The data from this study appears to suggest that this continues to not occur effectively and efficiently in the basic care setting. Best practices (information on dying; information on bereavement, emotional, and spiritual support) particularly geared to death and dying were significantly absent in the medical model.

Since health care providers in the basic medical services gate keep access to palliative and hospice care services, the onus for providing complete and extensive end-of-life services is on the primary and basic medical care services. The basic medical care providers have standards that include all the best practices studied in this dissertation. The knowledge is there and available to them. Also available to them in most health care settings are additional health care professionals that can be partners in supporting and supplying information. For example, all hospitals and most nursing facilities have social workers and access to chaplain support. Many cancer clinics, all dialysis clinics, and many general health care clinics have social workers on staff. Partnering with these professionals would fulfill the best practice of

a multidisciplinary team and also allow social workers to address social support, emotional support, spiritual support, and case management, which is one of their practice strengths.

From the view of the end-of-life health care services continuum, the standard is that best practices are basic needs. Palliative care and hospice can build on and expand the support and services to assist dying persons and their loved ones but basic medical care must address these issues also. As long as the health care systems has this gatekeeping function, the services of the basic health care setting must provided complete end-of-life care.

A possible conceptual framework that could be used in the medical setting is concurrent planning. Concurrent planning is a child protective services practice approach that promotes planning both for reunification with the biological family and adoptive planning simultaneously (Child Welfare Information Gateway, 2005). Lessons for the medical setting are to look at treatment toward survivorship but at the same time planning for end-of-life. Transplanting this concept would bring to the forefront the practices that are beneficial to end-of-life care and keeping them in the awareness of health care providers. It would also allow these providers to be open to opportunities to support the seriously ill person and their families when they bring up their concerns about end-of-live services. Openness of health care professionals to discussing the spectrum of care available to them from diagnosis to death is correlated with better compliance with aggressive treatments as well as more satisfaction with end-of-life care by patients and their families (Curtis, Weinrich,

Shannon, Carline, Ambrozy & Ramsey, 2001; Curtis et al, 2005). Studies exploring

this approach would be beneficial is documenting whether this would enhance the

delivery of best practices in health care settings.

In summary, this study could be seen as a "snapshot" of the grieving process

and the resulting data as substantiation that each model of care has the potential to

engage in practices that are supportive. Each conceptual framework contributes

needed elements to good end-of-life care. However, the medical model did not

deliver the same quality and quantity of best practices as the hospice model. The

importance of these best practices to good end-of-life care is well documented and

the onus for basic medical care setting to provide these practices is paramount. The

discussions are based on the data obtained from this study but this data is subject to

limitations and strengths, which will be addressed.

Limitations and strengths of the study

Limitations

Limitations to this study are clearly evident. The most serious limitations are

the response rate and its implications and the palliative care responses and their

ambiguity. Both of these limitations call in to question any attempts at

generalizabilitiy from this sample to the larger population.

Response Rate

Although thoughtful decisions were made about the type of survey and its

delivery, certain problems in the original plans are now evident. First, the researcher

believed that a mailed survey would be a less intrusive, less emotionally laden and

efficient approach to asking about the respondent's experiences. However, by allowing the host agency to mail the letters of invitation from their director in their envelopes may have resulted in potential respondents confusing this as another appeal for funds. The researcher failed to ask pertinent questions about the similarity of a letter from the director to past recipients of services and fund raising efforts. Although it is not possible to definitively state that people mistook the mailing for fund raising that is a distinct probability. That may in and of itself account for the poor response rate.

Another concern with response rate is that the respondents may have failed to represent a full gamut of persons experiencing grief and those with complicated or negative grief chose not to participate in the study. As stated earlier in this section, grieving persons may not have felt emotional able to fill out this questionnaire. Thus this study may only represent those people who are grieving well.

In obtaining background data on the sample, it was determined that 2175 individuals died within the timeframe of interest for the study. Of this 2175 persons, 39% of them according to the database utilized hospice. However, only 1327 of the 2175 had contact information listing next of kin and an address for contact. Moreover, due to the limitations of the agency's databases they were unable to query how many of the 1327 with family/friend contact information utilized hospice also (personal communication with program director June 4, 2009).

However, the researcher's practice wisdom suggests that the sample of 1327 may have had more hospice recipients than the original 2175. Hospice recipients

identify for their hospice provider a primary caregiver (usually next of kin or close friend). When the person called into the agency to report hospice involvement this information may have been disclosed. Consequently, next of kin/close friend may have been entered in the database for hospice recipients. However, this information does not allow this researcher to say with any degree of confidence whether the sample of 1327 mirrored the 2175 sample with regard to hospice use. The data on the sample of 180 participants appears skewed since 75% of respondents used hospice.

On the other hand, the sample was not skewed to include persons in support groups or those already identified as having grieving concerns. This sample was drawn from a community agency and was homogenous as to a loved one's illness (cancer), and relationship (primary caregiver). It is possible that this sample reflects good end-of-life services in all venues. Form the available data, it is not known.

However, with this response rate does not allow any conclusions to move beyond conjecture. With over 86.4% of the potential sample not responding, nothing can be asserted with any confidence and there is no generalizability to any larger population.

Palliative Care Ambiguity

The opportunity to compare the three predominant provider models for end-of- life care was also unsuccessful. In retrospect the question about palliative care, "Did your loved one receive services from a palliative care team (other than hospice) at the hospital or with home health?" was not clear to the respondents. The pilot study raised questions about the ability of consumers to differentiate among the

many uses of "palliative care" to allow them to identify a palliative care team as contrasted with just services that were palliative. This researcher should have thought through this issue (as suggested by two of my experts) and realized that with all the different meanings of palliative care and the lack of a standardized model (as with hospice) it would be very difficult to get meaningful results from a mailed survey.

Additional Limitations

Additional limitations include the use of the Positive Grief Scale that had not been validated or tested. This scale has face validity and this study seems to suggest that seven of the ten items may have content validity. However, further testing is certainly needed to make any determinations as to content and then construct validity. It is not known from this first use of the scale whether it is culturally competent since the sample was predominately white. The grieving process is certainly rooted in the practices and values of one's culture and further testing of the instrument would be necessary with people not from the majority culture.

Another limitation is the cross sectional nature of the study. Since grief is also embedded within time, the reliability of these findings is also limited to this snapshot of the grief process. A further plan for research could involved a longitudinal study of bereaved persons at six-month intervals from the death to study the progression of time and its influence on both positive and complicated grief.

Other limitations are due to the nature of the sample itself. It is heavily skewed to white women over the age of 62 that are widowed. The majority of this

group also described themselves as spiritual and approximately, two-thirds were active in a particular religion. This sample did not reflect diversity in age, spirituality, or relationship.

<center>Strengths</center>

Although there are several methodological weaknesses to this study, this study does have strengths. One strength is that it furthers the discourse about how health care professionals can support healthy grieving. Respondents confirmed that best practices as communication and listening, emotional and spiritual support, delivery of needed information, and availability aided them in coping with their grief. Follow-up bereavement services also were singled out as helpful.

Another strength was the study's confirmation that the grief process is multidimensional. The process can have both negative and positive feelings coexisting simultaneously. Strong continuing bonds with the deceased and revisiting memories can result in positive growth. These bereaved voiced their personal growth in self-awareness, self-esteem, spirituality, and the reconstruction of values and meaning in their lives.

In addition, this study presents a conceptual model that inclusively groups the major end-of-life service models. It serves to emphasize that each model is interconnected and builds upon and strengthens the delivery of best practices in end-of-life care. This conceptualization is a first look at viewing end-of-life care not as a competing array of services but as interdependent and potentially mutually reinforcing.

The respondents in this study were also intensively involved with the health care system during the last three months of their loved one's life. They experienced multiple experiences with health care providers in acute care facilities, home health service, hospice care, and nursing facilities. Moreover, they had multiple experiences with all possible members of the health care teams (doctors, nurses, aides, social workers, chaplains, and other providers. Consequently they were well acquainted with the services and the providers thus adding credence to the validity of their responses. These experiences also reflected the experience of intense caregiving for the respondents. This persistent and extensive engagement with the health care systems is another strength.

Finally, this study may actually substantiate that health care providers in all settings are actually doing a good job in supporting people through their grief (both anticipatory and post-death). Each discipline has had a set of end-of-life care standards for at least ten years and these standards have remained stable. Each discipline theoretically may have trained their members in good end-of-life care and these best practices are being implemented at a greater degree than in the past. This is certainly an assumption and cannot be fully substantiated by this study, but it is a distinct possibility that we have improved our level of care.

Implications for Social Work Practice, Policy, Theory, and Research

The findings of this study are particularly important to social workers in the health care settings. As stated before, social workers are in a unique position to provide good end-of-life services. First of all, social workers practice in all the

venues that serve persons with life threatening illnesses and their families. We are

there in the hospitals, nursing facilities, hospices, home health agencies, cancer

centers, dialysis units and so on. Our presence affords us the access to both recipients

in need of services and our fellow health care colleagues. In our roles of service in

multidisciplinary teams we can advocate for best practices in end-of-life care and

also intercede with our colleagues to deliver those best practices no matter what the

venue. Second, social workers are also involved in end-of-life policies. We can

influence the incorporation of best practices into policy. Third, as a multitheoretical

profession we strive to assure that good theoretical underpinning support our

practices. Social work values also support good end of life care and ethically

mandate us to support, advocate, and implement practices that serve to assist loved

ones in their grief. Specific suggestions for social work are evident in the findings of

this study.

Practice Implications

A number of strong practice recommendations are suggested by this study.

The array of best practices that were indentified in the mid 1990's and are contained

in all health care provider's standards are still not implemented to their fullest.

Hospice appears from this study to implement most and to a greater degree of

helpfulness than medical care. However, in both hospice and medical care, none of

these practices were implemented at 100% and some had implementation rates below

50%. Social workers can spearhead efforts to increase these rates.

Multidisciplinary teams are also a positive support for the ill person and their

families. Social workers who are likely to be members of these teams can work diligently to coordinate with their colleagues in discussing ways to support ill persons and their families and to advocate within the team that all members provide good end-of-life care. Social workers can also support the education of team members of the importance of their unique contribution to end-of-life services.

This study also points out the need for social workers to be aware of the multidimensional nature of the grieving process. Both negative aspects of grief and positive ones can exist simultaneously. This study and other research studies support that this is a normal manifestation of grief. Reassuring loved ones that they are grieving well even if they are profoundly sad on one hand and feeling wiser on another is just one example of how this can be operationalized in practice. Also supporting the strengths of positive grief can assist loved ones in identifying their own growth through the grieving process. As with other elements of a strengths perspective, persons may not be aware of their resiliency until it is spotlighted and acknowledged. Being aware of the elements of positive grief (growth in mean making, self awareness, self esteem, spirituality, and reconstruction of values) can give social workers areas to address when providing counseling to support healthy grieving.

Also, social workers are often facilitators of grief support groups. Within these groups social workers need to be aware of the warning signs of a more complicated grief experience. This way they can intervene early and help the person get timely therapeutic support.

This study also suggests that concurrent planning, a practice approach social workers are very familiar with, may be a beneficial approach to utilize in the medical setting. Social work knowledge in the policy, practice, and research arenas could assist in crafting a workable model for health care providers to employ with persons with serious diagnoses.

Social workers can also use the information suggested by this study to realize the interdependence of all the health care models. With this perspective the importance of closely working with members of each model is enhanced. Social workers could attempt to increase the communication lines between colleagues in other venues and also decrease the "turf" wars that can sometimes arise. Thus a greater level of respectfulness among the professions could emerge.

Policy Implications

Social workers are also crafters and advocates for good end-of-life policies. This study suggests some policy issues. First the Medicare and Medicaid hospice policies include provisions that make persons choose between continuing aggressive treatments and enrolling in hospice. Palliative care teams and units serve to fill this benefit gap by providing "hospice-like" services without the need to discontinue aggressive treatments. However, as stated before palliative care teams and units have no consistent or funded model that unifies and standardizes their services. This reflects another example of a fragmented health care system. Social workers can be on the forefront to amend and expand the Medicare Hospice Benefit to include palliative care services to those receiving aggressive treatments or to institute

standards of practice for palliative care teams.

Social workers can advocate with policy makers to codify the makeup of multidisciplinary teams and requiring that social workers and other non-medical persons be part of those teams. Currently hospice and dialysis units are by policy mandated to have social workers involved in the delivery of services. This should be extended to all end-of-life care/life-limiting health care services.

Another policy change that would benefit recipients of end-of-life services would be to require health systems to provide bereavement services to surviving loved ones. This is another mandatory element of hospice policy that is unfunded. By requiring other health care venues to do follow up bereavement services would enhance the early detention of complicated grief reactions and serve to support grieving well. As pointed out in this study, a number of loved ones pointed out the importance of the follow-up services to their wellbeing.

Finally, beginning the conversation about implementing a concurrent model approach in working with persons with life-limiting illnesses is also important. Concurrent plans for care (just like concurrent child welfare practices) should be mandated so that the conversation about preferences, expectations, and resources can be made earlier in the illness. This researcher anticipates that many health care providers would resist a concurrent planning approach. However, the best practices listed for end-of-life care are frankly best practices for all health care providers in all health care settings. Being open to discuss all outcomes and options with ill persons and their families is the responsibility of all health care professionals.

Conceptualization

This study can inform social workers in conceptualizing the grief process as one that is not linear and not dichotomous. Grief waxes and wanes. It is not either positive or negative but a mixture that reflects the coping assists, social support, ethnic supports, and personal strengths of the griever. The impact of time on grief is also a factor and this too is not a fixed number. Helping social workers to encourage the bereaved to understand themselves and the unique impact that loss has had on them may lead to more flexibility in our culture to support the grief process over time. Moreover, looking at the entire realm of grief and its impacts will lead to stronger and more robust grief theories.

Research Next Steps

Additional research studies could emerge from this dissertation study. First, additional validation of the Positive Grief Scale is warranted. Further steps to construct a scale that would have both content and construct validity include expanding items to include more indicators of positive grief. The literature emphasizes the concepts of appreciating life more after a loss and additional questions concerning what that meaning is and how it is manifest are warranted. Three items were deleted from the positive grief scale due to their lack of consistency with the remaining items. However, all of the three items were squarely grounded in qualitative findings. These three items were about reevaluating the meaning of material goods, fearing death, and changing the past. Since this study had a sample that was screwed toward persons with strong spirituality, another more

balanced sample may display different results. Also, reevaluating personal goals such as less work and more emphasis on family and relationship was not included in this study and should be part of additional scale items.

Another addition to the scale would be to test items included in the ICGR scale that may be connected to positive grief. The ICGR assumes that some items like "I see the person who died stand before me" as being an example of pathology. However, in reading the findings in positive grief studies, vision of the dead person can be comforting to loved ones. Further examples of ICGR items that should be included in a positive grief scale are: "I feel drawn to places and things associated with the person who died"; and "I hear the voice of the person who died speak to me." However, these three items would be rewritten to insure that they were discriminating between negative and positive grief. For example, "I see the person who died stand before me and that brings me comfort" and so on. Further reading and research by this researcher is needed to flesh out more items that would indicate positive grief. Also collaboration with other researcher in this area is needed. .

Second, using this scale to explore the grief process longitudinally would be a benefit. Identifying key times in the grief process that are particularly difficult has been done (Worden, 2003). Key times that have been identified include 3 months, six months, one year, and at key life events as weddings, subsequent losses especially deaths, and so on (Crenshaw, 1991; Rando, 1984; Rando, 1993; Worden, 2003). But pairing interventions that support positive growth at these key times has not been explored.

Another area for research is the question that remained unanswered in this study—what is the impact of palliative care teams and units and their comparison to hospice and medical services.. The lack of standardization of palliative care team services is still missing. Additional studies need to address exactly what is in the "black box" of a particular palliative care team or unit before a meaningful comparison could be done. Finally, replicating this study with just a medical and hospice focus but with a qualitative research study may lend definitive information as to whether our efforts at all levels are better supporting healthy grieving.

In summary, social workers are on the front line in the delivery of end-of-life care. Best practices have been identified and they are implemented to some degree in every model of care. However, better implementation is needed and social work can proactively encourage this. Also social workers as members of multidisciplinary teams and as support group facilitators are in a unique position to support the bereaved and to work with their fellow health care providers to improve care. Social workers can also work to stress the interdependence of each model of care and to increase cooperative efforts. Policy issues are also important arenas that social workers can influence, especially in areas to include standardization of end of life services, reduction of systemic barriers, and requirements for extended use of multidisciplinary teams. Theory can guide us to learn more about the complexities of grief and to help us educate our clients and our communities as to ways to understand the grieving process and to allow tolerance for the multiple ways in which grief is manifested. Additional research would further expand our

understanding of positive grief and how it supports healthy grieving. Further study

that addresses the effectiveness of palliative care teams and their benefits is also

needed.

Final Thoughts and Conclusions

Although there were limitations in comparing a palliative care model with

hospice and medical models, the evidence of the multidimensionality of the grief

experience was evident in the findings of this study. Positive elements of grief were

voiced by the majority of the respondents. They echoed and supported the elements

of positive grief in that growth in meaning making, self-awareness and self-esteem,

spirituality, value reconstruction, and continuing bonds. All models of care reflected

this positive grief experience. Negative elements of grief were also present but no

one experience the clinical definition of complicated grief as defined by the ICGR

scale. These negative elements of grief coexist with the positive ones and

demonstrate the non-linear and non dichotomous aspects of the grief experience.

Once again all models of care reflect negative grief experiences. This researcher

postulated that this study does appear to act as a "snapshot" of the grief experience.

Further examination spotlighted the importance of identified best practices in

end-of-life care. The hospice model does appear to more likely include these

practices and effectively deliver these practices than the medical model. A discussion

of the Continuum of Health Care Services ensued and the belief that all best

practices can be delivered in all models of care and the interdependence of these

models was pointed out. Also explored were the implications of the gatekeeping

mandates for hospice and palliative care and the resulting additional onus placed on basic medical care services. In addition, a new practice intervention, concurrent planning, may be helpful in beginning to provide more complete services to persons and their families as they live with life-limiting illnesses.

The importance of multidisciplinary teams and the presence of standards of best practices in all disciplines were examined. Also examined was the possible impact of short time in hospice on satisfaction ratings, and overall satisfaction ratings for each model.

Limitations of the study included a poor response rate, ambiguity of the palliative care data, untested positive grief scale, lack of diverse sample, and the cross sectional design of the study. Strengths include the persistent engagement of the loved ones with the health care system as they caregave for their loved ones, the evidence that good end-of-life care may be occurring in all models of care, and the complexity of the grief process itself.

Implications for social work in particular build on the extensive presence of social workers in end-of-life care and practice suggestions that arose from this study were discussed. Policy implications center on standardizing palliative care, enlarging the scope of hospice care, and the requirement for multidisciplinary teams and follow up services for all models of care. This study also suggests that social workers can use these findings to demonstrate to clients the complexity of the grieving process.

A little while and I will be gone from among you, whither I cannot tell.
From no where we came, into nowhere we go.
What is life?
It is a flash of a firefly in the night.
It is a breath of a buffalo in the winter time.
It is the little shadow that runs across the grass and loses itself in the sunset.
--Ispwo Mukika Crowfoot

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APPENDIX

"Learn to get in touch with silence within yourself,
and know that everything in this life has purpose.
There are no mistakes, no coincidences,
all events are blessings given to us to learn from."
                                    ----Elizabeth Kubler-Ross

COVER LETTER FROM AGENCY

Dear _____,

This letter comes to you and your family as those who have received support and services through Cancer Action during a very difficult time in your life, the loss of a loved one. I know that the journey through loss is a very personal journey for each of you. It is this journey that is the reason for my letter to you today. Families who have experienced the loss of someone dear to them have much to teach about their journey.

Cancer Action has been requested to assist in recruiting families who have experienced the loss of a loved one to participate in a research study looking at your experience of grief and the various support received during this time in your life.

The study will be conducted by Theresa Gordon, a doctoral student in the School of Social Welfare at the University of Kansas. Ms. Gordon has chosen this area of study for her doctoral project. If you choose to participate, you would need to complete a questionnaire, of mostly multiple choice questions, that would be mailed to you. After completing the questionnaire, you would return it to Ms. Gordon in a postage paid envelope.

Should you be agreeable to voluntary participation in this study, please complete the enclosed response card that is mailed directly to Ms. Gordon. Please remember that this is not being done for Cancer Action, and Ms. Gordon is not working on behalf of Cancer Action. Our agency is assisting her in locating families who are willing to engage in this study on grief.

Once the response card is received, she will contact you as a follow-up. All your information will be kept confidential and used only to provide information needed for this study. Thank you for your consideration in participating and assisting Ms. Gordon in her doctoral project. I know she will consider your willingness to participate in sharing this very personal experience with honor and respect as she works with you in this process.

Sincerely,

The director's signature

COVER LETTER TO PARTICIPANT

Date

Dear XXXX,

Caring for someone with a serious illness through his/her death is one of the hardest things anyone can do. The lasting memory of those days and the effect it has on the rest of our lives is not understood well. I am writing to you to ask your help in a study to explore how people who have lost a loved one looks back on those days of caregiving and how that has or has not changed their lives. I am contacting bereaved families/friends that have lost a loved one less than three years ago. Your responses will help health care professionals and others better understand how people heal through loss and how we can provide better services to those families that care for persons at the end of life.

The School of Social Welfare at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the study described below. You should be aware that even if you agree to participate, you are free to withdraw at any time without penalty. Participating in this survey is completely voluntary. Your responses will be confidential and will be released only as summaries in which no individual's answers can be identified. In the upper right hand corner of the survey, you will see a number. This number is for tracking purposes and will allow me to delete your name from our mailing list after we have received your survey. The survey itself should take about 30 minutes to complete.

As a way of saying "thank you" for your help, I am enclosing a "thank you" bookmark. This is a small compensation for your time and trouble. If for some reason, you do not wish to respond, please let me know by returning the blank questionnaire in the enclosed stamped envelope.

If you have any questions or comments, I would be happy to talk with you. Please feel free to contact me (my contact information is at the end of this letter). In addition, this study has been approved by the Human Subjects Committee of the University of KS. If you have any additional questions about your rights as a research participant, you may call them at (785) 864-7429 or (785) 864-7385 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email dhann@ku.edu or mdenning@ku.edu.
If in completing this survey you feel you need to talk with a grief counselor please contact me or your counselor at Cancer Action, Inc.

Thank you very much for helping me gain important knowledge so that we may be able to improve services to families and friends caring for terminally ill loved ones.

Sincerely,

Theresa Gordon   K. Jean Peterson, DSW
Doctoral Candidate   Faculty Supervisor
Principal Investigator   School of Social Welfare
School of Social Welfare   Twenty Hall
Twente Hall   University of Kansas
University of Kansas
 Lawrence, KS 66045
Lawrence, KS 66045   jeanp@ku.edu
tgordon@ku.edu

P.S. If by some chance I have sent you this survey in error please just return the survey in the enclosed envelope.
Thank you, again, for taking your valuable time to help.

BOOKMARK
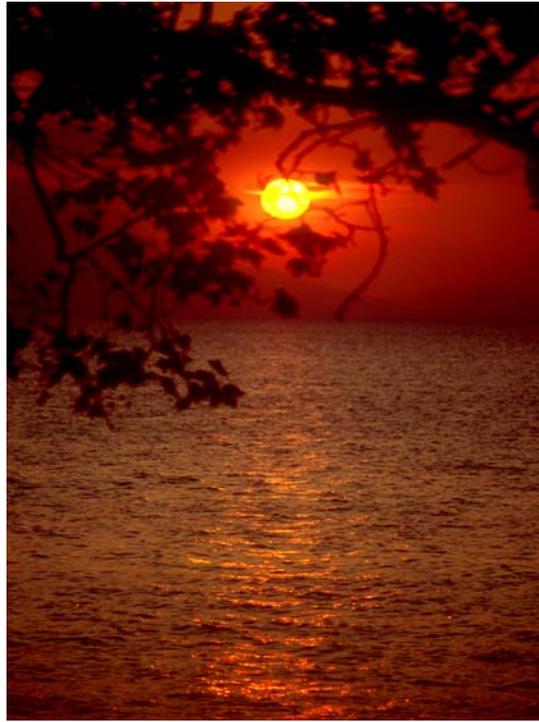
I wanted a perfect ending.

Now I've learned, the hard way,
that some poems don't rhyme;
some stories don't have a clear
beginning, middle, and end.

Life is about not knowing,
having to change,
taking the moment and
making the best of it,
without knowing what's going
to happen next.

—Gilda Radner

FOLLOW UP POSTCARD

About two weeks ago you received a questionnaire asking about
Living in the Memory of Loss. If you have completed and returned the
questionnaire, I would like to say "THANK YOU".
If you haven't, please consider doing so today and returning it. Your
responses are crucial to my understanding of how best to serve
caregivers of dying persons.

If you did not receive a questionnaire or have misplaced it, please call
913-764-2947 and I will send you another through the mail.

          Sincerely,

          Theresa Gordon LSCSW
          School of Social Welfare
          University of Kansas

COVER LETTER FOR SECOND MAILING OF QUESTIONNAIRE

DATE

Dear XXXX,

Thank you for agreeing to complete my survey about the loss of your loved one and how health professionals assisted you in coping with this loss. In seeking my PhD, I am most interested in learning how we can improve our services to surviving loved ones and this survey is my attempt to gain knowledge from you.

Consequently, getting information from your survey is very important. I'm resending you a survey and a stamped return envelope in the hopes that you can find the time to complete it and return it to me. If you have already completed and mailed the survey, THANK YOU SO MUCH.

Thank you for all your help and hope to be hearing from you soon.

Sincerely,

Theresa Gordon, PhD Candidate

913-764-2947

BOOKLET

Living in the Memory of Loss

A QUESTIONNAIRE FOR

FAMILIES AND FRIENDS

Constructed by
Theresa Gordon, LSCSW
PhD Candidate
School of Social Welfare
University of Kansas

Section 1

Before you begin the survey,
   could you tell me a little about yourself?

1. In what year were you born? _____

2. I am a (please circle)   1.Woman   2. Man

3. How would you describe your ethnic background? (circle **all** that apply)

   1. White

   2. Black or African-American

   3. American Indian or Alaska Native

   4. Asian/Native Hawaiian or other Pacific Islander

   5. Hispanic

   6. Other _____

4. What was your relationship to your deceased loved one? (please circle)

   1. Spouse

   2. Child

   3. Other _____

5. Did you provide physical caregiving for your deceased loved one? (please circle)

   1. Yes   2. No

6. Did you provide emotional support for your deceased loved one? (please circle)

   1. Yes   2. No

7. Where did your loved one die i.e. "at home", "hospital", "nursing facility", or elsewhere (please specify)?

   _____

8. How important is spirituality in your life?

        1. Very important   2. Somewhat   3. A little   4.. Not at all

9. Are you an active member of an organized religious group?

        1. Yes   2. No

Section 2

In thinking back on the last three months of your loved one's life,
        please answer the following:

10. What type of health care services was your loved one receiving?
    (circle all that apply)

Hospice Services	Palliative Care (help to decrease pain & symptoms)
Chemotherapy	Home Health Services
Radiation	Nursing Home Care

    Hospital stay (s) (including surgeries, ICU's, and so on)

11. What health care providers were providing this care? (circle all that apply)

Physicians	Social Workers
Nurses	Home Health Aides
Chaplains	Others (please list) _____

12. Did these health care providers offer information about your loved one's
    disease?   (please circle)

        1. Yes   2. No

    If Yes, was this information helpful to you? (please circle)

        1. Very important   2. Somewhat   3. A little 4. Not at all

13. Did they (the health care providers) talk to you about possible treatment options?

            1. Yes   2. No

If Yes, was this information helpful to you?

1. Very important   2. Somewhat 3. A little   4. Not at all

14. Did they give you information about the dying process?

            1. Yes   2. No

If Yes, was this information helpful to you?

1. Very important   2. Somewhat 3. A little   4. Not at all

15. Did they talk with you about your feelings of loss and grief?

            1. Yes   2. No

If Yes, was this counseling helpful to you?

1. Very important   2. Somewhat 3. A little   4. Not at all

16. Did they provide emotional support (such as listening to you and giving you encouragement)?

            1. Yes   2. No

If Yes, was this support helpful to you?

1. Very important   2. Somewhat 3. A little   4. Not at all

17. Did they offer you spiritual support?

            1. Yes   2. No

If Yes, was this support helpful to you?

1. Very helpful   2. Somewhat 3. A little   4. Not at all

18. Did they provide referrals to community agencies?

1. Yes   2. No

If Yes, was this helpful to you?

1. Very helpful   2. Somewhat   3. A little   4. Not at all

19. Did they include you in plans for your loved one's care?

1. Yes   2. No

If Yes, was this helpful to you?

1. Very helpful   2. Somewhat   3. A little   4. Not at all

20. Did you feel that they were respectful of your culture/ethnicity?

1. Yes   2. No

If Yes, was this helpful to you?

1. Very helpful   2. Somewhat   3. A little   4. Not at all

21. Did you feel that they listened to your concerns?

1. Yes   2. No

If Yes, was this helpful to you?

1. Very helpful   2. Somewhat   3. A little   4. Not at all

22. Did you feel that they were available when you wanted to talk with them?

1. Yes   2. No

If Yes, was this helpful to you?

1. Very helpful   2. Somewhat   3. A little   4. Not at all

Section 3

In thinking about today and your feelings about the loss of the person who died,

please circle the answer that best describes how you are feeling now.

23. I think about this person so much that it's hard for me to do the things I
     normally do.

     1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

24. My life has more meaning now that it ever had.

     1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

25. I feel I cannot accept the death of the person who died.

     1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

26. I feel drawn to places and things associated with the person who died.

     1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

27. I believe that I learned more about myself after caring for the person who died.

     1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

28. I feel disbelief over what happened.

     1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

29.   Ever since s/he died it is hard for me to trust people.

     1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

30. I feel that I have gotten the important things I want in life.

    1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

31. Ever since s/he died I feel like I have lost the ability to care about other people or I feel distant from people I care about.

    1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

32. I have pain in the same area of my body or have some of the same symptoms as the person who died.

    1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

33. Since the person's death, I find that material goods don't mean a lot to me.

    1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

34. I feel that life is empty without the person who died.

    1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

35. I hear the voice of the person who died speak to me.

    1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

36. I see the person who died stand before me.

    1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

38. I feel bitter over this person's death.

    1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

38. I feel that I am a better person for having provided care for the person who died.

    1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

39. Since the person's death, I am more spiritually aware.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

40. I feel lonely a great deal of the time since s/he died.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

41. I feel envious of others who have not lost someone close.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

42. I have good memories when I think of the person who died.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

43. I go out of my way to avoid reminders of the person who died.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

44. I can't help feeling angry about his/her death.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

45. Since the person's death, I value each day.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

46. I feel that it is unfair that I should live when this person died.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

47. I don't fear death since the person's death.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

48. Memories of the person who died upset me.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

49. I feel stunned or dazed over what happened.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

50. I feel myself longing for the person that died.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

51. I believe that if I could live my life over, I would change almost nothing.

      1. Never   2. Rarely   3. Sometimes 4. Often   5. Always

Section 4

Finally, I would like to know just a little more information about the type of services you and your loved one had before his/her death.

52.   How long did you know that your loved one had a life-limiting illness? (Please circle)

        1. 1 week or less
        2. 1 week to 1 month
        3. 1 month to 6 months
        4. 6 months to 1 year
        5. More than a year

53. Did you have hospice care for your loved one at the time of their death?

                1. Yes   2. No (go to Page 11, Question 54)

   If your answer is "Yes", please answer the following questions...

   A. How long did your loved one receive hospice care?

      _____   (Please identify by no. of days or weeks or months)

   B. How would you rate your overall satisfaction level with hospice care?
   (Please circle)

      1. Very satisfied   2. Satisfied   3. Dissatisfied   4. Very dissatisfied

   C. Any other comments about hospice services?

   _____

   _____

54. Did your loved one receive services from a palliative care team (other than
    hospice) at the hospital or with home health?

                1. Yes   2. No (go to Page 11, Question 54)

   If your answer is "Yes", please answer the following questions...

   A. How many times did you or your loved one meet with the palliative
      care/pain management team?   _____

   B. How would you rate your overall satisfaction level with the palliative
      care team? (Please circle)

      1. Very satisfied   2. Satisfied   3. Dissatisfied   4. Very dissatisfied

   C. Any other comments about palliative care services?

   _____

   _____

55. Did your loved one receive only medical care for their illness (no hospice or palliative care team services)?

           1. Yes   2. No   (go to Question 5)

If your answer is "Yes", please answer the following questions...

A. How long was your loved one treated for his or her life-limiting illness?

_____(Please identify by no. of days or weeks or months)

B. How would you rate your overall satisfaction level with the medical care they received? (please circle)

    1. Very satisfied   2. Satisfied   3. Dissatisfied 4. Very dissatisfied

C. Was your loved one's pain and other symptoms well controlled?

       1. Yes   2. No   3. Not Sure

D. Any other comments about medical care services?

_____

_____

56. **In looking back, what did the health care providers do during the time of your loved one's illness that has been most helpful to you as you grieved your loss?**

_____

_____

57. **Is there anything else that I haven't asked that you feel is important for me to know?**

_____

_____

Thank you so much for completing this questionnaire.
Your responses will further our understanding of the ways health care professionals can support families and friends cope with the loss of their loved ones.

Theresa Gordon
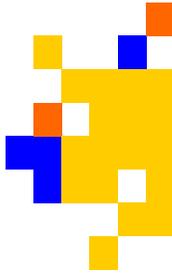
Living in the Memory of Loss

A QUESTIONNAIRE FOR
FAMILIES AND FRIENDS

If you have any questions or comments about this
survey, please address them to

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