AN ABSTRACT OF THE THESIS OF

Lee J. Amberwood for the degree of Master of Science in Human Development and Family Studies presented on December 3, 2004.

Title: "No Pain, No Fear, No Regrets:" Views of a Good Death.

Abstract Approved:

Redacted for Privacy

Patricia Moran, PhD   Karen A. Hooker, PhD

Substantial research has shown deficits in the quality of end-of-life care in the U.S. In response to evidence of these deficits, efforts have been made to improve quality of end-of-life care. One approach has been to ask the question, "What is a good death?" Data on views of a good death from populations outside the health care system are nonexistent. In this exploratory study, we analyzed existing qualitative data on dimensions of a good death from a large sample to describe evidence of common dimensions of a good death and addressed whether those dimensions varied by age.

A secondary analysis of existing survey data from five U.S. states was conducted to examine adult community members' ($N = 2,295$) views of a good death. Responses to an open-ended question from the Missoula Demonstration Project Community Survey, an unpublished, 73-item survey on individual's views and experiences with death, dying, and preferences of end-of-life care, provided the data for the study. Six broadly themed domains of process-oriented elements of a good death were derived. The five domains of Physical State, Spiritual/Emotional Needs, Relationship Needs, Dying Environment, and Religious Needs concur with themes established in the literature. In addition, a new domain, Predeath Needs was identified. Physical State was overwhelmingly the most prominent theme (74%, $n =$

1,513) in the sample. Most respondents reported some aspect of a person's physical state while dying (e.g., pain management, symptom control, etc.) as a component of a good death.

Chi Square tests were conducted on frequency of themes across age cohorts. Differences between observed and expected counts for all themes, except for Religious Needs, were statistically significant ($p < .05$) suggesting that there are age differences among themes. The results of this study indicate that broad common domains of a good death can be derived from a sample of community-residing adults. The study's findings also support the prevailing view of recognizing specific individual needs for a good death, and suggest further that those themes may be prioritized differently among cohorts.

The findings on Physical State suggest a need for changes in how pain is addressed within the clinical setting, and the need to understand how pain is perceived and managed individually, culturally, and within the broader medical system. Enhancements for patient care may include improvement in current medical practices in pain management and providers' increased willingness to care for and communicate with dying individuals, and integrate those aspects in a persons' dying process.

"No Pain, No Fear, No Regrets:"
Views of a Good Death

by
Lee J. Amberwood

A THESIS

submitted to

Oregon State University

in partial fulfillment of
the requirements for the
degree of

Master of Science

Presented December 3, 2004

Commencement June 2005

Master of Science thesis of Lee J. Amberwood presented on December 3, 2004.

APPROVED:

Redacted for Privacy

Co-Major Professor, Patricia Moran, PhD, representing the Department of Human Development and Family Sciences

Redacted for Privacy

Co-Major Professor, Karen A. Hooker, PhD, representing the Department of Human Development and Family Sciences

Redacted for Privacy

Chair of the Department of Human Development and Family Sciences

Redacted for Privacy

Dean of the Graduate School

I understand that my thesis will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my thesis to any reader upon request.

Redacted for Privacy

Lee J. Amberwood, Author

ACKNOWLEDGEMENTS

I am grateful to my co-chairs and all of my committee members for their support, help, and guidance on this work. I also want to thank my fellow graduate student colleagues who also provided support and encouragement throughout this project's evolutionary process culminating in this final thesis. To my family, Jacklyn, Rosie, and Zane whose love and commitment to not only me but also to my dreams and aspirations continually helps to lift and raise me up to reach the potential to which I aspire. To my extended family on both sides of our family unit, thank you and bless you—you too, have been a great comfort to my family and me throughout this journey.

TABLE OF CONTENTS

TABLE OF CONTENTS (Continued)

LIST OF FIGURES

LIST OF TABLES

DEDICATION

I dedicate this work to the memory and lives of my parents, Helen M. & Leon J. Norwood, and my aunt, Jean C. Krasniewski. Surviving their sudden deaths as a young adult drastically altered my life's course to lead me where I am today.

"No Pain, No Fear, No Regrets:"
Views of a Good Death

Chapter 1

Introduction

As Americans live longer, dying is less likely to be viewed as something sudden that might happen at any time, but rather as something that is most likely to occur over time and in later life (Walter, 2003). As demographics drive the growing need for end-of-life care options, this phenomenon has stirred much interest and debate among researchers. Investigators seek answers to questions about not only how and why people die, but also the quality of care they receive—the findings of which have not been promising (SUPPORT Principal Investigators, 1995).

Substantial research has shown deficits in the quality of end-of-life care in the U.S. (Buntin & Huskamp, 2002; Lynn, 2002; Mezey, Neveloff Dubler, Mitty, & Brody, 2002; Sulmasy, 2002; Tilden, Tolle, Drach, & Hickman, 2002). For example, we know that most deaths occur in an acute care setting regardless of the patients' desire to die at home (Tolle, Rosenfeld, Tilden, & Park, 1999). We know that a majority of dying patients die in pain (Kayser-Jones, 2002). Interestingly, the issue of pain management has become so pervasive that a legal scholar has authored a treatise proposing a constitutional right to pain relief (Weinman, 2003). We also know that hospital nursing staff is often shorthanded and that patient-provider time is abbreviated, rushed, and often impersonal (Hanson, Danis, & Garrett, 1997; Pierce, 1999). Furthermore, we know that families often receive inadequate information about the patient from hospital staff (Kayser-Jones, 2002). Finally, we know that patient-provider communication lacks the depth needed to foster relationship building with patients and their families (Steinhauser et al., 2000).

In response to evidence of these deficits, efforts have been made to improve quality of end-of-life care (Buntin & Huskamp, 2002; Kaufman, 2002; Kayser-Jones, 2002; Koenig,

2002; Lynn, 2002; Mezey et al., 2002; Sulmasy, 2002; SUPPORT Principal Investigators, 1995; Tilden et al., 2002). One approach has been to ask the question, "What is a good death?" (Emanuel & Emanuel, 1998; Morrison & Siu, 2000; Steinhauser et al., 2000). A broad answer comes from The Institute of Medicine, which defines a good death as "...free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (Field & Cassell, 1997).

One limitation of the current understanding of what defines a good death is that data have been gathered mostly from those within the health care system; that is, patients, family members and/or caregivers of the dying, spiritual/clergy caregivers, and physicians, nurses, and other medical caregivers. These studies have found that, whereas physicians' description of a good death are "uniformly more medical in nature" (Steinhauser et al., 2000 p. 829), patients, families, and other healthcare professionals provide a broader range of attributes (Steinhauser et al., 2000). Some of these are pain and symptom management, clear decision making, preparation for death, contributing to others, and affirmation of the whole person.

Data on views of a good death from populations outside the health care system, that is, community samples, are nonexistent. Recommendations on future areas of research in quality of end-of-life care have called for gathering data from community members (Knebel & Buckwalter, 2002). Researchers suggest that such responses, not yet constrained by the health care system, are self-determined and therefore may have greater validity (Kayser-Jones, 2002). Furthermore, a community sample of prospective end-of-life care consumers might best represent the future demand for improved quality of end-of-life care.

The practice of community-based research has been widely used in public health interventions and in campaigns on various social health problems such as heart disease (see

Lasater, Carleton, & Lefebvre, 1988 as cited in Byock, Norris, Curtis, & Patrick, 2001).

Interest has grown around the "whole community" framework of studying end-of-life care, an

approach endorsed by the Institute of Medicine Committee on Care at End of Life (Field &

Cassell, 1997). Communities provide structure and processes that carry out end-of-life

experiences. Byock et al. (2001) argued that a framework to fully understand the many

characteristics of the end-of-life experience should include both medical and nonmedical

aspects of care within the whole community setting. Therefore, comprehensive efforts to

improve quality of end-of-life experiences necessarily should include multiple research

investigations within that setting.

Purpose

A secondary analysis of existing survey data was conducted to examine individuals'

view of a good death. The objective of the study was to provide new information about the

dimensions of a good death from a population currently missing from the literature, a sample

of individuals outside the healthcare system. Moreover, because of the large sample size, this

study provides evidence of common dimensions of a good death from a sample outside the

healthcare system, which is also missing from the literature.

Chapter 2

Literature Review

Theoretical Framework

Socioemotional selectivity theory and ecological systems theory provide the

theoretical frameworks that informed this study. Socioemotional selectivity theory is pertinent

to end-of-life research because it focuses on how people perceive time and how that

perception leads to selecting and pursuing social goals (Carstensen, Isaacowitz, & Charles,

1999). In this study, these goals are viewed as the individual's needs associated with a good

death. Ecological systems theory provides a framework for understanding the influence of

multiple contexts on individual's perspectives of dimensions of a good death (Bronfenbrenner,

1986). To guide the study, both theories provide a strong foundation and underlying premise

upon which to describe and analyze similarities and differences in views of a good death.

Socioemotional Selectivity Theory. End-of-life scenarios represent a unique

opportunity to investigate the selection of social goals as a function of perceived time. The

theory's premise is that individuals select social goals depending on whether they perceive

time as open-ended or limited. Furthermore, this theory suggests that individuals' motives to

do so are for either of two specific reasons: to acquire knowledge or to regulate emotion

(Carstensen et al., 1999). If individuals perceive time as open-ended or unlimited, they are

more motivated to pursue goals related to acquiring knowledge. If they perceive time as

limited, goals related to regulating emotion take priority. This theory fits with the proposed

study because it suggests the feasibility of an examination of differences in perspectives of a

good death as a function of age. Closeness to death because of age may reveal variations in

community members' social goals that may be reflected in their views of a good death.

Ecological Systems Theory. Bronfenbrenner's (1986) ecological systems theory

provides a useful framework to understand views of a good death from multiple contexts and

settings. Bronfenbrenner's theory emphasizes the importance of how events and changes

occur in both immediate and larger social context settings and how they influence individual development. In this study, this framework helps to illustrate how a person's interaction with multiple contexts, or types of end-of-life care might influence his or her view of a good death.

Within the ecological framework, (see Figure 1) settings and contexts are arranged on expanding concentric rings of the model, with the individual in the center. Proximal settings are placed closer to the center whereas distal settings are placed further away. Dying individuals and those within the surrounding settings comprise the *microsystem*. The *mesosystem* is comprised of the interrelations and exchanges between settings within the microsystem (Bronfenbrenner, 1977). Therefore, theoretically, through the exchanges within the *mesosystem,* views of caregivers in multiple settings serve to influence the views of a good death of those individuals within the microsystem. Some of these influences can be seen in various end-of-life issues such as location of dying (Tolle et al., 1999), the use of palliative care as reflected in pain management and end-of-life medical decision making (SUPPORT Principal Investigators, 1995), and the frequency of spiritual/emotional support from families and caregivers (Hanson et al., 1997; Pierce, 1999).

The *exosystem*, is a system in which the dying individual is not directly involved, however, it includes the social structures that can affect or influence views of a good death by their relation to contexts within the mesosystem. Exosystem influences can therefore determine or delimit what occurs in those direct settings (Bronfenbrenner, 1977).

In this study, the exosystem includes community members' views of a good death and community-based allied health systems and structures. As argued earlier, community members can be seen as future consumers of end-of-life care. They participate in the dialogue around end-of-life care through their experience as caregivers of a dying loved one or managing their own health care. In that light, one could propose that community members' views of a good death would impinge on the dialogue of end-of-life care options. The opposite may also be true. That is, it is reasonable that community-based organizations serving the needs of dying

Figure 1.

Ecological Model of Views of a Good Death
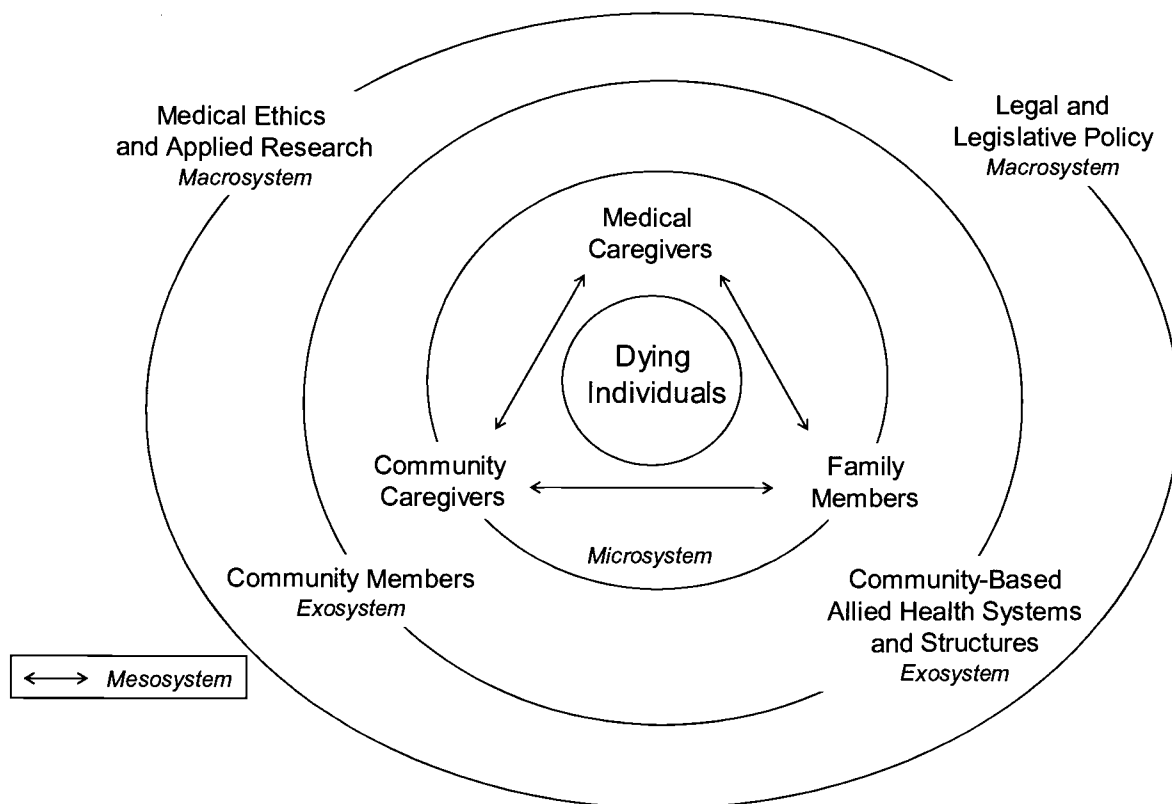
individuals and their families might influence individual's views of a good death by providing

needed services in response to consumer demand. Some of these might include home health

care, community-based support groups, respite care, and complementary therapies.

Finally, ecological systems theory states that changes in one setting create ripple

effects in all other settings. The *macrosystem* contains the broader influences of county and

state-level professional organizations, and state and federal level changes to healthcare policy

and programs that may have implications for views of a good death. Two examples are the

ongoing debate over physician-assisted suicide and the federal regulations on dispensing pain

medication. As these issues change and become more clearly defined, they may also influence

how one defines a good death.

Additionally, medical ethics and applied research efforts share the role of increasing knowledge about the dying process. Evidence-based practices in formal medical care settings necessarily tie in the obligatory ethical considerations when caring for the dying.

Although the purpose of this study was not to test this theory, ecological theory provides a useful framework to illustrate the influence of multiple settings involved in identifying dimensions of a good death.

<div align="center">Views of a Good Death</div>

The findings of these studies are expressed in two ways: Some are a direct result of asking a form of the question, "What is a good death?" and other findings are by way of participants suggesting improvements to end-of-life scenarios.

Although there is expected overlap in categories and age groups among various studies, the literature is categorized according to the groups being asked: individuals (patients and nonpatients) and caregivers. These two groups represent smaller segments of specialized groups: individual patients and families of deceased patients (nonpatients), and family, medical, and community caregivers respectively.

The literature included in this section is from various cultures and assumes the influence of cultural differences within their conceptual designs, measures, and analyses. Specifically, studies from Canada, China, Korea, Sweden, the U.K., and the U.S. are included in this review. Because the intention of the proposed study is to examine the views of a good death of a community sample from the U.S., with implications limited to the U.S., cultural variations on a good death will not be discussed in detail. Rather, similarities among dimensions of a good death will be pointed out.

Individuals: Patients and Nonpatients

In a study of older adults with nonterminal medical illnesses (outpatients), Vig, Davenport, and Pearlman (2002) explored attitudes about end-of-life to determine if end-of-life preferences could be inferred. In interviews with 16 older adults about aspects of their

perception of their own good death, themes arising from qualitative data included no pain/suffering, quick death while asleep, wanting no knowledge about impending death, being prepared, and the importance of religion. In contrast to most empirical data on a good death, they also found a reduced need for family when dying and a concern for burden to family, which, taken together, is logical. Overall, they found heterogeneity of views about a good or bad death that can limit informing end-of-life care experiences. Still, they suggested that end-of-life preferences would be useful in developing patient-centered care plans at end-of-life. Although participants seemed to differ greatly in thematic groupings of characteristics of a good death, it may be that the limited number of participants (N = 16) prohibited a broader understanding of specific responses or conceptual commonalities.

Heterogeneity of views among individuals is a common finding in all of the literature on a good death, which may add to the burden of its implementation, measurement, and testing. Cicirelli (2002) found that individual differences could be a result of many contextual aspects within a life lived, suggested that views of older adults are highly variable, and influenced by many factors including health status, presence of disease/disability, socioeconomic status, personality, family, and culture. He concluded that older adults develop personal meanings of death such as death as afterlife, death as a loss of physical function, loss of personal relationships, and release from life's troubles. In contrast to Vig et al.'s (2002) finding about decreased family closeness, Cicirelli (2002) found that family and close relationships remain important at end-of-life and relate to an older adult's view of death.

Some older adults' perspective of a good death may also be influenced by caregiving experiences in later life. Wilson (2000), in a study of Canadian older adults with caregiving experience of someone at end-of-life and who had considered their own deaths, identified two relevant concepts: how to cope with dependency while dying and appropriate end-of-life care. Participants selected home as the preferred location of dying contingent on the availability of

family member caregivers. Appropriate end-of-life care included no prolongation of dying, no loss of control in treatment decision making, and most participants favored euthanasia.

The difficulties in defining a good death for older adults seem to increase when they enter the medical system for ongoing care (Kaufman, 2000). Some would suggest part of the reason for this is because of how medical science views the person as a patient (Sulmasy, 2002). Rather than considering *persons* as individuals who exist within a matrix of relationships, *patients* become "an object amenable to detached, disinterested investigation" (p. 24). Moreover, Sulmasy suggested that becoming a patient drastically alters the person and that illness has a disrupting effect on all the relational aspects within the self (i.e., physical, psychological, social, and spiritual) that constitute the patient as a human person. Therefore, patients' may not base their responses to end-of-life care preferences from a whole person perspective, but an altered one. Caregiver recommendations to include person-centered care to improve end-of-life care also support this idea (Hanson et al., 1997; Pierce, 1999; Steinhauser et al., 2000).

Kaufman (2000) expounded precisely on the role of institutions within this dilemma, in her exegesis on what she terms "the problem of death in America" (p.1). In describing the notions of a good death or a "death with dignity," she cites widely held cultural ideals, some of which include dying people who can (a) freely reject use of medical technologies to sustain life, (b) can manage their own pain, and (c) can choose their own location of dying. As a result, Kaufman contends that the medical system provides a confused model for older adults at end of life. Care is confounded by old age, disease, and decline. When all of that is negotiated with the medical technological imperative to extend life, it presents an operational and conceptual predicament for improving end-of-life care.

Of all possible settings of the dying process, hospice is the closest model to what is thought of as a good death. Scholars have used the hospice concept as a synonym for a good death (Ternestedt, Andershed, Eriksson, & Johansson, 2002). Indeed, definitions of hospice go

so far as to mimic those of a good death: "symptom control, social relationships, psychosocial and existential concerns" (p. 154). As well, hospice philosophy reaches beyond the discrete aspects of a good death to include a broader dimension of integrating "all general aspects of human life as well as specific aspects brought to the fore by impending death" (p. 154).

It is not surprising that some scholars are moving beyond the preliminary understanding of the dying process and its relationship to life. In a Swedish study using retrospective data from nurses, Ternestedt et al. (2002) developed six criteria for evaluating a good death: symptom control, self-determination (autonomy), social relationships, self-image (whole person perspective), synthesis (life evaluation) and surrender (acceptance of death). Their goal was to develop further a model for care planning and documenting, and for evaluating quality of care. Their analysis employed the criteria mentioned above to answer the question: Did patients have good deaths? Previous work by these researchers originally identified these criteria.

Ternestedt and her colleagues operationalized these end-of-life criteria for a good death into their current model of hospice care. By translating evaluative criteria about a good death into operationalized concepts, they formed the structure to make concrete changes within hospice care standards and practices. Furthermore, this empirical evidence is unique in accomplishing that goal. Successful adaptations to models of end-of-life care might positively influence the direction of similar future investigations in the U.S.

Most if not all research examining perspectives of a good death are qualitative studies. In a study from the United Kingdom, Masson (2002) used storytelling to explore perceptions of a good death from hospice day care patients and family members of hospice decedents. Specifically, participants were asked to provide two stories about deaths of people known to them—one they viewed as a good death, and one they viewed as being "not good" (p. 194). Through storytelling, his participants articulated dimensions of a good death reflected within real life contexts. Participants' stories revealed not only aspects of a good death consistent

with those in the literature, (i.e., physical comfort and distress, at peace, normality, patient and family control and preparation), but exemplified the context of dying as "rooted in living" (p. 200). Future research may reveal more about the underlying meaning of individual dimensions of a good death, and the ideal dying scenarios for patients and their families.

Caregivers: Family

There is ample retrospective data on deceased patient's families and family caregivers' perceptions on quality of end-of-life care of their loved one (Braun & Zir, 2001; Hanson et al., 1997; Lynn et al., 1997; Masson, 2002; Pierce, 1999; Steinhauser et al., 2000). The focus of this body of research is to examine families' perceptions of deficits of end-of-life care, and thus limits its ability to answer the question "What is a good death?" directly. Nevertheless, their perspectives support the need to improve end-of-life care and family caregivers' specific suggestions on improving care provides another important way to learn more about the aspects of end-of-life care that may coincide with the dimensions of a good death.

Researchers have noted that family perceptions regarding patient's pain, level of care, and treatment preferences may not be accurate (Hanson et al., 1997; Lynn et al., 1997) Even so, studies on families' perceptions have noted a secondary benefit to gathering data from this population. These studies may aid in a families' grief process (Masson, 2002) because they are often conducted relatively soon after the death of a loved one (Lynn et al., 1997; Steinhauser et al., 2000).

Another aspect of this subset of the literature is that some studies examined only the perceptions of bereaved family members (Hanson et al., 1997; Lynn et al., 1997; Pierce, 1999), while others included family members as a subgroup among other groups, such as, caregivers, (see Masson, 2002; Steinhauser et al., 2000; Wilson, 2000). A prominent commonality of these studies is their clinical context. Not surprisingly, most deaths occur within an acute care hospital. Nevertheless, this fact emphasizes the critical need for

evaluative data on the in-hospital dying process. Moreover, it could be argued that clinical, postmortem research could be said to present notions of what a good death is *not*.

Among these studies, most notable is the follow up work of Lynn et al. (1997) for the SUPPORT Investigators. From interviews with surrogate family decision makers, Lynn and her colleagues found that most of the elderly and seriously ill patients in the study died in an acute care hospital, often in severe pain, with shortness of breath, confusion, and other symptoms patients found hard to tolerate (p. 103). Moreover, even though most patients preferred treatments that focused on comfort (even if they shortened their life), over half of the patients were treated aggressively (p. 103).

These findings are consistent with those of Hanson et al. (1997) who investigated perceptions of end-of-life care of family members of older adult decedents who died in tertiary care centers (community hospitals, nursing homes, and home care). Hanson and her colleagues found that even though family members reported a high rate of severe pain in their dying family member, they were concerned about compassionate and timely communication about their loved one's dying process, comfort care, and that their loved one was treated with respect. Families' recommended improvements to end-of-life care included better communication between provider and family, greater access to physician's time, and better pain management (p. 1339).

In concert with these findings are those of Pierce (1999) who studied the same population within the same context (tertiary care centers). Her results clearly reflect the complexities of the medical system and its impact on the families of dying patients. Examined from the perspective of impact of medical caregivers (nurses), Pierce gathered suggestions on improvements to end-of-life care that illustrated the real life context of standards of care within a hospital system and its challenges. She found that the rules of the complex medical system affect families' ability to care for dying loved ones. The author reported evidence of a lack of personalized care that left families feeling powerless and intimidated by the system

and importantly, hesitant to challenge those rules out of fear of reprisal in terms of the care of their loved one. Overall, this left families feeling both uninformed and distressed.

Suggestions to improve care included families' desire for more help with interactions with their dying family member. This included being physically close, touching, maintaining their loved one's hygiene, and engaging more fully with them. Many respondents reported some inhibition in initiating these behaviors because of their lack of experience and not knowing the right thing to do. Secondly, families reported the overwhelming importance of nurses' impact on the dying experience for family members. They reported that nurses were fundamental in providing individualized, whole person care and in communicating critical information to families about their dying loved ones. Families desired improvements in facilitating the progress of interactions between and among medical caregivers, patients, and families and a general environment more conducive to these types of interactions. Families overwhelmingly testified to the isolated, impersonal environment of, for instance, the intensive care unit as not conducive to facilitating a more personal experience with their dying loved ones.

These findings not only convey the aspects of what a good death is *not*, but also dramatically demonstrate the present context of the dying process experienced by many people. These data inform end-of-life care experiences through the richness of the lived context of the dying process within a formalized care setting. Together with Masson's (2002) real life context data, they generate a broader picture of end-of-life care with greater meaning, and characterizations that are more explicit.

Caregivers: Medical

> …only health-care professionals today develop sufficient experience and
> familiarity with death and dying. Hence, the promise of a good death is more
> appropriately a topic demanding the health professions' attention than it might
> have been a century ago. (Emanuel & Emanuel, 1998 p. 22)

The role of the formalized care setting as the predominant venue of death and dying brings to the forefront the responsibility of healthcare providers in facilitating and delivering end-of-life care. Complicating this responsibility, according to Emanuel and Emanuel, are the overriding and persistent social attitudes that deny death. These attitudes are pervasive within the medical care setting and are expressed through goals in treatment that are forcefully curative rather than palliative (Stolick, 2003). Moreover, the limitations in providing empathic end-of-life care exhibited by some medical caregivers may be seen as an inability to understand the patient's unique style of living and their meaning of death, which Stolick proposes is only possible by facing one's own mortality. Stolick proposes that physician's ability to face their own mortality results in their seeing the patient as a person, living a certain life with vital self-definitions based on individual experiences and relationships of meaning.

Studies on nurses' attitudes of a good death reveal much agreement with the overall literature on dimensions of a good death (Kim & Lee, 2003; Mak & Clinton, 1999). In a review of the Western literature from China, Mak and Clinton (1999) found similarities to Western definitions of a good death among the following dimensions reported: comfort/pain relief, awareness and acceptance of death, autonomy, mutual support with family, preparation for death, and location of death. From a cultural perspective, the authors also noted an apparent lack of reference to a good death within the Chinese literature, despite its use in a well-known Chinese proverb, "a good birth is not as good as a good death" (p. 100). Further research into Chinese attitudes about dying might prove enlightening.

Kim and Lee (2003), in a Korean study of nurses' attitudes about their own good death, revealed similar commonalities with the addition of no burden to family and a belief in perpetuity, with comfort as the most important aspect. Despite the similarity of results, researchers suggested that healthcare providers, families, and patients may disagree on the meaning of these dimensions and how they can be manifested within a patient's end-of-life care plan (as cited in Kim & Lee, 2003). This disagreement, Kim & Lee suggest may provoke

the question of whether individual healthcare providers' specific roles influence their level of understanding of death and dying.

In their examination of components of a good death among medical caregivers and other subgroups, Steinhauser and colleagues (2000) found that although medical caregivers overall confirmed the importance of aspects of a good death, their professional role distinctions determined more variation in responses than other demographic variables. For instance, although providers reported a fear of not knowing patient end-of-life care preferences when entering a medical crisis, Steinhauser et al. noted that providers also reported avoiding end-of-life discussions with patients for fear of removing hope. This conflict of beliefs, and whether they manifest in care, supports the notion expressed earlier, of the forcefully curative goal of medicine and the need to deny death. This was also evident in physician's descriptions of a good death as described in mostly biomedical terms rather than psychosocial terms related specifically to the dying patient (Steinhauser et al., 2000).

Additionally, Steinhauser and her colleagues' findings outlined six dimensions of a good death that are consistent with the current literature and add new knowledge. These dimensions are pain and symptom management, clear decision making, preparation for death, completion, affirmation of the whole person, and a new concept, contributing to others. This last concept refers to the importance of allowing terminally ill patients to contribute to the well-being of others, most often in the form of time, gifts, and knowledge.

Caregivers: Community

Religious/spiritual beliefs are often turned to as a source of support when people are threatened by a serious accident or illness (Ehman, Ott, Short, Ciampa, & Hansen-Flaschern, 1999). When examining quality of end-of-life care, researchers often include the role of clergy and spiritual caregivers within hospital settings (Steinhauser et al., 2000; SUPPORT Principal Investigators, 1995). Faith communities and their leaders are currently asking themselves what role they might play in improving end-of-life care for their congregants (Braun & Zir, 2001).

Braun and Zir (2001) conducted focus groups of clergy and congregants in Christian churches in Honolulu. They examined the concept of a good death to identify the role of the church in improving end-of-life care. Participants' responses were in accordance with the current literature: manage pain, avoid prolonged dying, having family present and supportive, resolve conflicts, and address spiritual existential issues. The data were also operationalized into actual roles for the church: to help congregants spiritually and practically prepare for death, to facilitate conflict resolution and forgiveness, to clarify how church theology should guide attitudes and practices of death and dying, and to administer appropriate rituals and provide outreach to sick, dying, and bereaved congregants. Although these findings are solely from the perspective of those within the Christian church, they provide evidence of the increasing importance of addressing the spiritual needs of the dying at end-of-life.

Research Questions

This study provides the unique opportunity of being the first to address the question "What is a good death?" by examining large scale community data.

Two research questions were addressed.

1) What are the dimensions of a good death as defined by a community sample?

2) Do those dimensions vary by age?

Chapter 3

Methods

The methodological approach used to answer the research questions included both qualitative and quantitative analyses. The initial analysis was qualitative and consisted of a content analysis of responses to one open-ended question *"What would make for a good death, if a loved one were dying?,"* from existing data in a community survey on individuals' perspectives of death, dying, and end-of-life care preferences. The quantitative analysis involved descriptive statistics of the sample, frequencies of the themes derived through the qualitative analytical process, and cross tabulations to examine variation in theme frequencies by age.

Survey Instrument Background

The Missoula Demonstration Project, now known as Life's End Institute, is a community-based project established to study and improve the quality of end-of-life experiences in Missoula County, Montana. Established in March 1996, its primary purpose is "to research the experience of dying persons and their families and to demonstrate that a community-based approach of excellent physical, psychological and spiritual care improves the quality of life among those who are dying and their families" (Life's End Institute: Missoula Demonstration Project, 2003).

The project was conceived from discussions that took place among members of the community from various occupations including health care, elder services, faith communities, public education, university education, funeral services, and the arts who shared an interest in improving care for the seriously ill and supporting their families in their caregiving and grief. The project's goal is for individuals in communities everywhere to have self-determined end-of-life experiences that are safe and comfortable.

Part of the project's intention was to design a set of descriptive studies that would document baseline outcomes in order to improve community intervention outcomes. The

Community Profile[1] consisted of 12 unique studies. These studies employed baseline descriptive research instruments to collect objective and subjective data. The research results from the Community Profile have been used to inform a variety of community engagement and intervention projects in end-of-life experiences in Missoula.

Survey Instrument

Existing data from the Community Survey, one of the 12 studies included in the Missoula Demonstration Project's Community Profile (1997) were examined. The Community Survey is an unpublished, 73-item survey on community members' views and experiences with death, dying, and preferences for end-of-life care (see Appendix for copy of survey). In addition to open-ended questions, the survey included some questions using Likert-scale responses and others with categorical responses (e.g., income, type of insurance).

According to the Institutes' website all measures included in the Community Profile have been reviewed, pilot-tested, and used in the Institutes' research projects. However, they report that validity and reliability procedures have been completed on some of those measures, but not on all (Life's End Institute: Missoula Demonstration Project, 2003). In addition, this survey was created and implemented during the early years of this grass roots organization, which since then has experienced changes in leadership that has made it difficult to obtain certain specific information on some methodological issues and practices employed.

---

[1] The Community Profile employed a variety of methodologies to collect various types of data and included both quantitative and qualitative measures. Objective data included state death statistics, funeral records, medical chart reviews, and a community audit of pertinent services and providers. Subjective data included responses to mailed surveys of public attitudes, beliefs, and behaviors, and surveys of clinician attitudes, knowledge, and practices. One study employed structured interviews about care and end-of-life experience with family members or friends of people who had died in Missoula in a defined two-year period, and another used semistructured interviews to explore issues of quality from the perspective of bereaved family members. A participant-observer study followed nine patient-caregiver dyads during the last months of life and produced ethnographic data. A series of modified focus groups was conducted with Native Americans to explore this ethnic population's perspective on end-of-life experiences. (Byock, Norris, Curtis & Patrick, 2001)

Question Sequence

Survey question sequence, or the arranging or ordering of questions may significantly affect the study's results (Berg, 2004). The intention of the Community Survey was to gather perspectives on death and dying. As such, all survey questions, apart from demographic measures, were in some way related to the topic. Whereas questions 54 and 55 (the question under study) both ask about the death of a loved one, questions #45 – 53 ask about respondents' fear or worry of their own deaths, rated on a 7-point scale of agreement/disagreement. Views of a good death reported in the literature are from the perspective of one's own death (Kim & Lee, 2003; Vig et al., 2002; Wilson, 2000), from the death of a loved one (Braun & Zir, 2001; Pierce, 1999; Steinhauser et al., 2000), and from a more broadly defined, institutional perspective (Emanuel & Emanuel, 1998). In spite of the studies' differences in research design and research questions, respondents reported comparable views of a good death.

Dataset and Sample

Survey Distribution

The survey was distributed to a sample of community-residing adults (18+ yrs.) in each of five states: Montana, Idaho, Oregon, Wyoming, and Michigan. The survey was distributed in 1997 and then again, to different people, in 1999[2]. The 1997 sample ($N = 1,292$) included individuals living in the following geographical areas: Missoula, MT; Idaho; Oregon; and Wyoming. The 1999 sample ($N = 1,003$) included individuals living in Missoula, MT and Idaho, Wyoming and 5 counties in Michigan. Returned surveys from 1997 and 1999 comprise the total sample ($N = 2,295$).

---

[2] Michigan was surveyed in 1999 only. All other states, except for Oregon, were sent surveys in 1997 and then were oversampled for older adults in a second distribution in 1999.

Additional information on the survey's distribution has been difficult to obtain from the originators of the study because of staff changes since the data under analysis were collected. The investigators of this study have obtained certain specific information on only some methodological issues and practices employed.

We obtained limited information on how the surveys were distributed within each state. We understand that the survey process for each state was conducted by its local end-of-life care coalition. These coalitions, created and organized similar to the Missoula Demonstration Project, are comprised of community members interested in improving care at end of life within their community. The Missoula Demonstration Project, in exchange for its ability to add that coalition's results to a larger dataset compiling all coalitions' survey results, gave each coalition use of the Community Survey.

The sampling frame is unknown. All coalitions obtained mailing lists from a commercial mailing list company. However, we do not know whether samples were selected from the list or if each entire list was mailed surveys. Therefore, this study's sample is neither a probability sample nor is it a random sample. Generalizability is limited since the sampling frame is unknown.

Survey Follow-Up Efforts. Although we know each coalition used the same mailed survey, we do not know that the survey distribution and follow up processes among all coalitions were consistent with the original Missoula survey distribution process. Moreover, we do not have the number of surveys mailed per year; therefore, this raises concerns about adequate response rates and introduction of selection bias in the sample.

Follow-up Process. The first mailing included a postcard to the sample informing them of their selection to receive the survey. As an incentive to complete the survey, potential participants were told they would be entered in a drawing for a prize upon completing and returning the survey. All postcards included information for recipients to decline to participate. Surveys were then mailed to everyone in the sample who did not opt out.

Thereafter, reminder postcards were mailed to recipients who were again presented the option to decline participation. Phone calls were made to those who had not returned the survey. Finally, surveys were mailed again to everyone who had not returned a survey and who had not opted out. Combined response rates are listed in Table 1.

Table 1. *Combined Survey Distribution (1997 & 1999) Response Rates*

State	Surveys Sent	Surveys Returned	Response Rate
Idaho	1500	411	27%
Michigan	2500	732	29%
Montana	1000	596	60%
Oregon	680	100	15%
Wyoming	1500	398	27%

NOTE: Response rate was calculated for combined distributions (1997/9) of the number of surveys sent and returned for each state. Additional information about the specific response rates for each year is unavailable from the originators of the study. Response rate does not include postcards or surveys returned because of wrong address or those opting out.

Analytic Plan: Qualitative

Unit of Analysis

Individuals' responses to one open-ended question, "*What would make for a good death, if a loved one were dying?*" were examined to identify aspects of a good death as defined by respondents' views of a good death for a loved one. Analyzing response data for only one question can present both a limitation and strength. The limitation of relatively short written responses to a questionnaire rather than a personal interview may prohibit deeper, more complex thinking about the issue of a good death. Lengthy interviews may generate additional data that illustrate multifaceted end-of-life issues more clearly. However, open-ended questions also provide respondents an opportunity to express their own thoughts

individually, in their own words. This allows for richer data than, for example, responding to the question by selecting a level of agreement from a Likert-scaled response set.

Responses to this survey question were selected for this study above all other survey questions for two reasons: (a) it is the only question on this survey that directly asks for information about a good death, and (b) being open-ended, it provided respondents an opportunity to write their own thoughts and feelings about a good death free from any limitations other than their own time available and response space.

Coding Process

Each step of the proposed analysis occurred simultaneously with conversations between the researcher and her thesis advisors. The written survey provided four blank lines for respondents to write answers in their own words. The data are comprised of relatively short answers (approximately ≤ 765 characters for each response or between 1 and 150 words). The data are organized both in hard copy (in a tabulated list alphabetized by first letter of first word of response) and electronically in an SPSS data file originally provided by the Missoula Demonstration Project.

According to Berg (2004), a content analysis can include counting any of seven major elements (words or terms, themes, characters, paragraphs, items, concepts, and semantics) in written responses as the unit of analysis. To maximize the yield from a dataset of detailed responses, words or terms, concepts, and semantics were counted and included in the coding process in order to determine arising themes. The advantage of including just these three elements is that they provided an appropriate method to make the most of the variety of response length and form. In addition, the use of concepts allows for counting words grouped together into ideas while semantics allows for counting the relative strength or weakness of a word (or words) as compared to the entire statement (Berg, 2004). These units of analysis provided an optimum content analysis of the rich data on a good death.

The initial data review was conducted by the researcher and consisted of reading the data without taking notes. This review was undertaken to obtain familiarity with the data, unhindered by the additional task of thinking about themes and identifying commonalities. This method of immersion in the data is recommended (see Berg, 2004) as part of the inductive process to identify themes in the data. Next, through a process of open coding (Berg, 2004), the investigator read and reread the data to identify common attributes of a good death and to identify arising themes. During axial coding, the list was collapsed into broad themes capturing process-oriented attributes of a good death. This study employed Berg's version of Straus' (1987) axial coding, which "occurs after open coding is completed and consists of intensive coding around one category." (see Straus as cited in Berg, 2004, p. 280). This process requires successive sorting of all cases and begins with a general sorting of cases into some specific category (Berg, 2004).

To measure intercoder reliability of coded themes (Berg, 2004), an outside rater, a retired faculty member knowledgeable in qualitative analysis and trained in hospice care, reviewed the data independently to test for completeness and consistency of final categories. The rater was given a random sample of 20% of the data and a list of the domain themes identified and their descriptions. The investigator met with the rater and explained the coding process and code descriptors in detail. Complete instructions on the approach to coding were also given, to replicate the same process employed by the investigator. Once completed, the investigator met with the independent rater to review the coded data, reconcile any differences in ratings through discussion, and answer any follow up questions. See p. 30 for additional information on Intercoder Reliability.

Analytic Plan: Quantitative

SPSS was used to analyze the quantitative data. The open-ended response data rested across three text variables in the SPSS data file. Each variable allowed space for 255 alphanumeric characters (total ≤ 765 characters). Three variables permitted entry of complete

response data. Frequency of response by theme was calculated for descriptive statistics and to allow for the demonstration of magnitude.

Data analysis consisted of three levels of analysis:

1. Descriptive analyses of sample characteristics: Demographic variables included age, gender, race or ethnicity, education level, income level, marital/partnership status, and religion.

2. Sample frequency distributions of each themed category: Themes were measured as dichotomous variables in SPSS. Each theme category was a unique variable and coded as 1 if the response included the theme or as 0, if it did not.

3. Cross tabulations of themes by age cohorts: Pearson Chi-Square tests for independence were calculated and used to determine whether there was a statistical difference between observed and expected observations. For the purpose of this study, the cross tabulations described variation in theme frequency by age.

Missing Values

The Missoula Demonstration Project's Community Survey ($N = 2,130$) had 155 (7%) missing responses to the survey question selected for this study. A comparative analysis comparing demographic variables of the response and no response groups was conducted. Variables examined were age, gender, ethnicity, education, income, marital/partnership status, and religion. T-tests showed that there were no significant between group differences in any of the variables except for age, $t(2150) = 3.21, p < .001$. The nonresponders tended to be older, ($M = 52.12, SD = 15.92$), than the responders ($M = 48.09, SD = 14.95$). Although 155 participants who did not respond to the survey question chosen for this study were dropped from the analysis, it is important to temper that analysis with this age difference in mind while discussing the data.

Chapter 4

Results

Respondent Characteristics

Characteristics of the 2,295 community-residing adults in five states (ID, MI, MO, OR, WY) who completed the existing survey are shown in Table 2. Survey respondents ranged in age from 18 – 99 years with a mean age of 48 years. Men comprised 54 % of the sample. Ninety-four percent identified themselves as White. Respondents had a mean education of 15 years and 42% had annual incomes of $30,000 – $60,000. Seventy four percent identified as Married/Partnered and 71% identified a religious affiliation.

Table 2.

Survey Respondent's Characteristics (N = 2,295)

Characteristic	Value
Mean Age	48
Age range	18 – 99
Gender %	
Female	46
Male	54
Ethnicity %	
White/Caucasian	94
Native American	3
Hispanic/Latino	2
Asian/Hmong	0.3
Black/African American	0.3
Other	0.5
Mean Education	15
Annual Income %	
< $15,000 - 30,000	35
$30,001 - 60,000	42
$60,001 - >75,000	23
Marital Status %	
Married/Committed Rel.	74
Separated/Divorced	11
Widowed	7
Never married	7
Religion %	
Catholic	17
Latter-Day Saints	9
Meth/Luth/Presb/Bapt	17
Other Christian	19
Other Spiritual	10
No Religious Affiliation	29

Note. Percentages in some categories do not sum to 100 because of nonresponses. Age and education are measured in years.

Respondent characteristics are similar to each state's 2000 census population characteristics. Comparable U.S. Census Bureau statistics from the 2000 Census for the five states are shown in Table 3 (U. S. Census Bureau, 2004).

Table 3.

Comparison of Respondent's Characteristics to 2000 U. S. Census Data for Idaho, Michigan, Montana, Oregon, & Wyoming

	% Age 18 - 64	% Gender		% White	$ Median Income	% Education	
		M	F			Grad. H.S.	B.S.
Idaho	84	50	50	91	37500	85	25
Michigan	83	49	51	80	44600	83	22
Montana	82	50	50	91	33000	87	24
Oregon	83	50	50	87	41000	85	25
Wyoming	84	52	48	92	38000	88	22
Survey Respondents	83	54	46	94	Mean Range 30000 - 45000	72	25

Note. Mean range of annual income was reported here because respondents were only given income ranges to choose from and did not report individual income totals.

Of the total sample, 256 respondents were excluded from the study because they either did not respond to the survey question (n = 155) or because their responses were ambiguous and unable to be coded (n = 101). Some examples of responses from the ambiguous/unable to code group are "Am not sure," "Can't say," "Do not know," "Have no idea," "I can't think of any," "I don't know how to respond to this," " None," "Nothing," "Unsure," or a question mark "?". Also included in this group were those who reported not believing in the concept of a good death. Many of these respondents made brief, summative statements: "I don't think anything would make for a good death." "I don't think there is such a thing as a good death." "There is no way to make death good for others." or "Nothing— death is hard to deal with no matter what." A few responses were in the form of a question, "Is there a 'good death'?" "Is there such a thing?" or "What is a 'good death'?" However, a few respondents elaborated further and described what they thought might make for a good death. These responses were included in the analysis. For example, "There is no good death, [sic] the

only thing to make it better would be in knowing they were going to a better place." "I don't think there really is a "good death" when you lose a loved one, but knowing that they accept Jesus as their savior would really put things at ease."

Additionally, a small number of respondents reflected on their own experience of a loved one's death, but did not indicate whether they thought it was a good death. Although several responses in the data overall were reflective (see next section), some respondents did not include in their responses whether they thought the experience was a good death. Without respondents' subjective judgment of the experience, raters could not discern whether the respondent thought the experience was a good death. Therefore, these responses were not coded.

> My father-in-law had lived alone many years. At age 87 he called all his children home and told them he wanted to go into a nursing facility because he was tired of washing his own dishes. The children made the arrangements for him to enter Sunday evening at 4 o'clock. At 4:30 my husband and I, the last of the children to drop by because we all live a good distance away. We visited a few minutes and told him good night. He laid back on his bed so as to rest and was gone. It was like he planned it all.

> My father died suddenly -- no time for goodbyes. My mother lingered way longer than she would have chosen. She was ready to die before she actually did. Same with several other aged relatives.

Themes of a Good Death: Descriptions and Overall Frequency of Response

Six broadly themed domains of process-oriented elements of a good death emerged from the data: Physical State, Spiritual/Emotional Needs, Relationship Needs, Predeath Needs, Dying Environment, and Religious Needs. Frequency of response was calculated for each theme for descriptive statistics and to allow for, what Berg (2004) refers to "the demonstration of magnitude" (p. 286). Theme descriptions and frequency of response are listed in Table 4.

Table 4.

Themes of a Good Death: Descriptions and Frequencies (N = 2,039)

n	Theme	%
1513	Physical State References to the physical state of dying: painless, comfortable, medicated, not suffering, dying quickly, dying in their sleep, no prolonged illness, no loss of mental capacities.	74
526	Spiritual/Emotional Needs Reference to the spiritual and emotional aspects of dying: being "at peace" having resolved family/life issues, loved ones' acceptance or being reconciled with their own death, grateful for the life lived, knowing they were loved, able to bridge their fear of death, and so on.	26
485	Relationship Needs References to having family, friends, and other loved ones there at time close to death; being able to say goodbye to loved ones and express love and affection to them directly.	24
319	Predeath Needs References to events hoped to have happened before death: lived to an old age, lived a good life, accomplished professional goals, took care of financial/emotional issues (will, reconciled relationships), no prolonged illness or accident, left loved ones a "goodbye" message.	16
221	Dying Environment References to aspects of the physical environment preferred and what happens there; home, hospice, with health care professionals present; issues of having control of medical decisions/life saving measures (dying with dignity); music, singing, or idyllic natural surroundings.	11
207	Religious Needs References to God, Jesus, Christian, and any organized religious practice such as last rites, "being saved," memorials, funerals or specific clergy present such as priest, rabbi, or minister.	10

Note: Participants (*n* = 256) who either did not respond or gave a response that did not answer the question were dropped from this analysis. Participants' responses could be coded in more than one theme.

Intercoder Reliability

Intercoder reliability calculations were conducted on a random sample of 20 pages of printed

data from the first response variable only. Therefore, some level of disagreement or missed

codes may be due to the intercoder not having complete responses to code. Response

comparisons were made on four different levels of agreement between coders on each

response: (a) complete agreement on each code listed for that response, (b) disagreement or

missing one code, (c) disagreement or missing two or three codes and (d) complete

disagreement on all codes. The findings on level of agreement are listed in Table 5 below.

Table 5.
Intercoder Reliability Percentages

Number of responses (N = 381)	Level of agreement	%
278	Complete agreement	73
64	Disagreed/missed one code	17
24	Disagreed/missed two or three codes	6
15	Complete disagreement	4

Note: Number of responses also includes responses determined unable to code by the investigator.
These responses (n = 27) were also categorized similarly by the external rater and were included in the
"Complete Agreement" level.

Overall, raters agreed on almost three quarters of the sample responses. Two specific issues

arose from post coding discussions. Some partial disagreements were the result of two issues.

The first was a determination by the outside rater about the word, "dignity" which appears in a

small number of responses. The original coding scheme called for that word and its perceived

connection to the dying person's control (or lack thereof) and medical-decision making at end-

of-life to be coded as Dying Environment. However, the external rater deemed it also to be a

part of Physical State. Additionally, while completing this analysis, a few responses coded as

Spiritual/Emotional Needs by the investigator were found to be coded by the external rater as

Relationship Needs. This may have been because of some lack of clarification between the two themes by the investigator during the initial instruction meeting. The discussion around the word "dignity" provided the investigator with new insight about the complexity of the word's meaning. However, no change in coding was made because the number of responses that included that word was small and not likely to alter the study's findings. Future studies, however, may reveal clearer differences in how the word, dignity, is used and defined.

Theme-Specific Response Data

Because the data are comprised of relatively brief answers, the six themes, although broadly defined, represent conceptually discrete needs. Most responses included references to several discrete needs and therefore had multiple codes. For example, a response written as "pain free and at peace" was coded as both a Physical State and a Spiritual/Emotional Need. Length of responses varied from a minimum of 1 to almost 150 words. Examples of theme-specific responses shown below demonstrate the prominent theme identified and point out the multiplicity of themes found within individual responses.

Point of view. Respondents approached their answers from two different points of view. Many responded from the point of view of the survey question, that is, the *prospective* death of a loved one whereas others responded *retrospectively* by reflecting on their actual experience of a loved one's death. In spite of this dual perspective, responses did not differ qualitatively insofar as they all included conceptually discrete needs similar to those identified in the data. Nonetheless, on their face, they differed in two ways. They differed in terms of temporal verb tense and more interestingly, in intensity by sharing compelling personal experiences of a loved one's death that was, at times, eloquently described.

Additionally, despite the fact that the survey question asked what would make for the good death of a loved one, some respondents answered from the point of view of their own eventual deaths.

> Ease their minds about the same things I am apprehensive about. What things
> are left behind, how everyone will take care of each other. Encourage talk
> about how the funeral should be. So that the person's wishes are carried out.

It could be argued that one's view of a good death for a loved one can be different from what one would want for one's own death. Individuals may know more about their own preferences rather than that of another. So too, some may communicate their needs more readily though others keep theirs hidden. Therefore, there may be differences between responses from these two perspectives. However, again, the data analyzed here were not qualitatively different in terms of discrete dimensions of a good death reported overall. Moreover, to test for such differences a comparison of responses about another's good death to responses to a similar question asked about one's own death is required, which is beyond the scope of this study.

Physical State

Just over 74% ($n = 1,513$) of the sample reported the importance of some aspect of a person's physical state as a component of a good death. Respondents wrote about a good death as one without pain or suffering, comfortable, dying quickly and preferably in their sleep, with no prolonged illness and no loss of mental capacities. Many responses addressed the issue of pain and several responded briefly and to the point: "As little pain and suffering as possible," "no pain," "painless," "Clean with no pain," "comfort," "Die without pain," and "Fast and no pain." Many responses also addressed multiple aspects of the physical state: "Sudden and painless—it's harder on those left behind but it is so much better for the one who dies." "Suddenly in their sleep." "As little suffering as possible, no extreme measures used to prolong life, just control pain." Some responded by describing a loved one's death such as, "…my mother was lucid, and not in obvious pain (emphesema) [sic]. It was a good death."

Many respondents viewed pain as the first link to other exacerbating issues, such as lingering and dependency, and wrote about their concern about a loved one in pain when there was little hope of recovery.

A "good death" in my opinion, means your loved one does NOT linger on in pain and suffering and that they are not dependent on another institution (Senior Citizen Home) other than home or hospital for their care.

Previous experience with a loved one coping with certain medical conditions provided a way for some respondents to define a good death. One person wrote, "My dad died of a massive heart attack on the phone to us, right after he said 'happy birthday' to my wife. That's a pretty 'good death'." Some responses often tied in the issues of not wanting a loved one to suffer, experience a lengthy illness or a prolonged death. Another shared, "Not suffering for a long period of time. My father died from a massive heart attack, it was a shock at the time, but helped to know he didn't suffer a prolonged death." For some, certain medical conditions such as cancer, defined an undesirable dying process; one person wrote, "One that doesn't involve pain and suffering. Death from cancer is awful!!! I would hate to think of anyone suffering so much."

Ultimately, some responses addressed the conflicting nature of death and its emotional unpredictability for the survivors, as one respondent remarked, "When they have been suffering for a long time then it's hard to let them go but it's good at the same time so we don't have to watch them suffer anymore and they become perfect again."

Spiritual/Emotional Needs

Twenty-six percent ($n = 526$) of respondents wrote about the spiritual/emotional needs of the dying and their families at end-of-life. These responses included the intangible elements of dying such as acceptance of or being reconciled with death, being at peace, resolving family/life issues, being grateful for the life lived, knowing they were loved, and having the time to overcome their fear of death.

Many respondents described a good death using physical and behavioral aspects of the dying experience that expressed emotion: "Peaceful-end of suffering," "peaceful slipping away without pain or fuss," or "Non-violent," and also, "Peaceful/no pain, holding the hand, smoothing the hair." Others wrote more specifically such as, "A person who doesn't have to

struggle in death." "Reassurance that they have been and are loved, respected and of value. Knowing mistakes are forgiven. Painless as possible. Feeling the world is a better place for their having lived." "Acceptance and peaceful anticipation."

Lastly, some respondents wrote about their hope to be of service to their dying loved one at or near the time of death. Most wrote about providing emotional care and support to help their loved ones complete their lives peacefully. One person noted, "Dying quickly, but still being able to tie up loose ends emotionally—goodbyes, speaking last important words." Another remarked, "With limited pain, person at peace with self and with GOD. Being able to make amends for any hurts or injuries."

Relationship Needs

Twenty-four percent ($n = 485$) of respondents wrote about the importance of family, friends, and other loved ones as a component of a good death. Respondents offered several reasons for having loved ones near when close to death. Many shared that having family or loved ones there would prevent their dying alone, would be a source of emotional and physical comfort care and support, and would provide the chance to express love and affection directly and say "goodbye." For example,

> Being able to be with them and take care of them. Making sure any and all needs were being met, especially where pain control is concerned. Knowing they'd talked with and said all they needed to say to family and friends. Holding them when they "crossed over."

> Letting them know that they enriched your life, that you respected the way they lived their life, and letting them know that they will be missed and will be remembered.

Still, others expressed a need to be an integral part of their loved one's dying process. That is, to not only shepherd them in the process but also, not get in their way, evident in the following responses, "To be able to share with them in the 'letting go' process." and "Being surrounded by loved ones who LET you go." In some cases, respondents wrote of their own dying process, their wishes to leave a legacy and their concern about surviving family

members. For example, "Family around, getting to say goodbye. Leaving my children and/or grandchildren a special written message of my love and beliefs for them." Another wrote, "Dying prepared, with no regrets, and having affairs in order for survivors." "1. Time to visit and say goodbye. 2. Easy passage from life to death. 3. Organized aftermath of death. 4. Lack of contention among survivors." Respondents also wrote about relieving both the financial and emotional burden to the surviving family by hoping to have "things in order," including, for one person, "a 3-6 month follow up afterward for family."

Predeath Needs

Sixteen percent ($n = 319$) of respondents wrote about events hoped to have happened before death that would set the stage for a good death. Although these varied from the very practical (e.g., creating a will, advance directives, and financial plans) to the aspirations and wishes for a long life lived, underlying all of them is an apprehensive desire to have enough time before they die. One person wrote, "Time to put things in order as needed (mental, financial, spiritual, etc.) Support systems of family, medical professionals, spiritual mentors, etc. Financial abilities to remove those type worries." Many wrote about loftier ideals such as having achieved personal and professional goals and lifetime desires, the most prominent of which, to have had a "meaningful life."

> A person who has had a full life, one that has had a positive influence on others and can die with the satisfaction of knowing the world was a better place because they were there. A clear head that recognizes what is happening and accepts it.

Some of those writing about their needs before death wanted the time to make amends with those harmed or injured and reconcile before dying. These next two writers speak about their own deaths. The first speaks in the broadest of terms.

> For me, a "good death" would not be the act of dying, but knowing there is nothing else I wanted to do or say to anyone when the time came for me. If I were able to live each day to the fullest, when the time came, I think I would be ready.

Also related to this sense of predeath reconciliation is a concern of how these events affect the legacy they leave behind. For example, although many desired death only at an old age, most did not want their death preceded by a long, debilitating illness leaving their families struggling.

> I hadn't drained my family's financial or emotional resources—that they could remember me for my good heart and accomplishments and not an old, whiny, shriveled up sick person.

Dying Environment

Needs of the dying environment were expressed by 11% ($n = 221$) of the sample. The references to the preferred physical environment in which to die reflect how multiple themes influence each other, for this sample, as components of a good death. Because this theme focuses on the actual physical surroundings of the dying environment, it is necessarily concerned with more than the physical aspects of the space. It also concerns the actions that take place there and the people who are there—not the least of whom are those who direct those actions. The data also show the influence of the physical environment on other desired aspects of a good death such as pain management and palliative care, ability to cope with emotional issues of facing death, and the support of trusted family members and caring medical caregivers. Many reported a need for familiar surroundings such as dying at home, having family present, a peaceful atmosphere, and medical assistance in settings such as hospital, hospice, or home. One respondent shared, "Restful setting, service, music, kindness, home bed." And another reflected, "My grandmother had the passing she wanted. Hospice also helped." Some contributed fuller responses such as,

> Have a nurse there at all times to talk with the family. And your religion. If dying isn't done with support at home, I think it should be done at a facility. I hope to never experience it again. I will never forget it.

> Dying at home with family and knowing up until the end how much they're loved and have been appreciated. Not being burdened by severe pain or concerns about medical costs. To feel that the family members and health care providers genuinely care and want to help and are not cold and wish this person gone.

Many expressed a concern about their loved one's "dignity" while dying, and described it in different ways. Some associated it with the physical aspects of care. One respondent wrote, "Dignity!! Not being jump started to stay (alive) in a vegetative state." While another shared, "Dying with dignity (pain management, having my mental faculties intact, family, friends nearby)." Finally, one respondent put it quite simply, "Treating them with dignity and providing the best care possible."

Other respondents focused on the issues of autonomy, participation in medical decision making and financial preservation. Some of these responses were, "To die with dignity. To die the way they choose. For them to have control of what they can." "Their comfort, will to die or live taken seriously. That all money resources were not exhausted when death was inevitable. That doctors, clergy, or other family members yield to all wishes of dying person." Still others defined dignity in dying through the emotional components of a good death. One person wrote, "Death with dignity, family/friend support in telling you it is okay to die—their willingness to discuss and listen to your fears and help you laugh!"

Lastly, some described a need to have caring, compassionate medical caregivers present while their loved one was dying. "Health care workers who were there to help when needed, yet they wouldn't barge in their room. They would give us our private times."

Religious Needs

Religiosity was expressed in responses from just over 10% ($n = 207$) of the sample. Responses included references to symbols or practices of organized religions such as God, Jesus, the Lord, memorials, funerals, or "being saved." A striking commonality among most of these responses is their narrow focus. Most often, these responses included reflections of a good death from solely a religious perspective. Few included aspects of any of the other themes. Consequently, many responses were coded in only one theme and thus, do not reflect the pattern of a multiplicity of themes similar to the bulk of the data.

The preponderance of single-coded responses contained impassioned statements of faith that were less concerned with the actual dying process within a social context and more concerned about existential events that happen after the physical body dies. These responses were about salvation, accepting Jesus, living 'right,' and the belief of eternal life in heaven. Some examples are, "Knowing they had accepted Jesus' death on the cross for their sins." "Knowing they lived right and made the right choices so they could return to live with their Father in Heaven!" "Their acknowledgement of God and the gift of eternal life purchased by Jesus dying on the cross." "Them being a committed born again Christian." Here, some too wrote of their own death. "Them understanding that I have a hope to be resurrected, they very well may see me again. God can not [sic] lie."

Of those responses that were multiply coded the religious need described was often about having faith or a belief in God; gave some mention of a spiritual advisor such as clergy, priest, minister or rabbi; or made reference to some type of formal ceremony, such as a memorial service, wake, or cremation. Some response examples are, "No suffering, being there, faith in God," "Soft music, being with them, holding their hand and knowing that they are a child of God. Little or no pain." Other respondents blended religious needs with family needs. "Sacrament of penance and not to suffer with pain and having family at bed side." "Religious convictions fulfilled, family happy, and closeness assured that all has been tried."

Many respondents also testified to the importance of viewing death as a transition. For several respondents, the transition was to a 'better place.' "Faith that dying is just one 'phase' in a life to serve God." "Believing in Christ Jesus and knowing you are going to a better place. Giving Jesus your hand." While others viewed it as God's plan for them. "A good death would be to go as the Good Lord planned for you to go—Death is a part of His plan." "Biblical Salvation- knowing that they knew Jesus as their personal Savior and death will take them into heaven."

Themes of a Good Death: Frequency of Theme by Age Cohort

Cross tabulations were calculated to determine if theme frequency distributions varied across age cohorts. See Table 6 below.

Table 6.

Frequency of Theme Response by Age Cohorts

years	< 25	25 - 34	35 - 44	45 - 54	55 - 64	65 - 74	≥ 75	Total	x^2 $df = 6$
n	58	302	552	496	286	206	124	2024	
	37	220	396	362	219	162	104	1500	
Physical State (%)	64	73	72	73	77	79	84	74	14.68*
	22	90	145	139	66	42	19	523	
Spiritual/Emotional Needs (%)	38	30	26	28	23	20	15	26	19.68*
	13	78	149	131	57	39	16	483	
Relationship Needs (%)	22	26	27	26	20	19	13	24	18.84*
	8	68	108	78	31	14	11	318	
Predeath Needs (%)	14	23	20	16	11	7	9	16	38.79**
	1	25	75	64	27	20	7	219	
Dying Environment (%)	2	8	14	13	9	10	6	11	17.87*
	8	31	49	42	38	28	9	205	
Religious Needs (%)	14	10	9	9	13	14	7	10	10.29

Note. $N = 2,024$. Fifteen respondents did not indicate age and were dropped from this analysis.
* $p < .05$. ** $p < .001$.

Pearson Chi Square tests for independence were calculated for each theme across cohorts to determine whether the differences between expected counts and observed counts were statistically significant. Significant differences were found among the age-related distributions of five of the six themes: Physical State, x^2 (6, $n = 1500$) = 14.68, $p < .02$, Spiritual/Emotional Needs, x^2 (6, $n = 523$) = 19.68, $p < .003$, Relationship Needs, x^2 (6, $n = 483$) = 18.85, $p < .004$, Predeath Needs, x^2 (6, $n = 318$) = 38.79, $p < .001$, and Dying

Environment, x^2 (6, n = 219, p <.007. Statistical significance indicates that the possibility of differences between counts occurring by chance is very small.

An alternative hypothesis for this finding could be that count differences occurred because of a variation of number of themes in age cohorts, for example, whether older age cohorts were coded more themes than younger cohorts. To rule out this rival hypothesis, the mean number of themes by age cohort was calculated. Mean number of themes across all cohorts ranged from 1.09, SD = .77 to 1.53, SD = .91. An analysis of variance (ANOVA) showed that there were significant differences in mean levels across age groups, with younger groups generally reporting more themes than older groups, F (6, 2271) = 7.00, p < .001. However, given that the means ranged from 1.09 themes to 1.53 themes, we conclude that although this is a significant difference, it is not a substantive difference.

Additionally, a further analysis could be conducted to determine whether age cohorts within themes are significantly different from each other, and therefore verify any possible cohort differences within themes. Individual Chi-Square calculations could be made to all pairs of cohorts but were beyond the scope of this study. Future research on possible cohort differences in views of a good death would be useful. Although a relationship of themes across age cohorts was neither hypothesized nor tested for, an informal discussion of the observed frequencies across cohorts and themes follows to explore apparent tendencies in the data in advance of possible future hypotheses generation. Figure 2 represents a graphic illustration of theme response frequencies across age cohorts.

Figure 2.
Theme Response Frequencies by Age Cohort
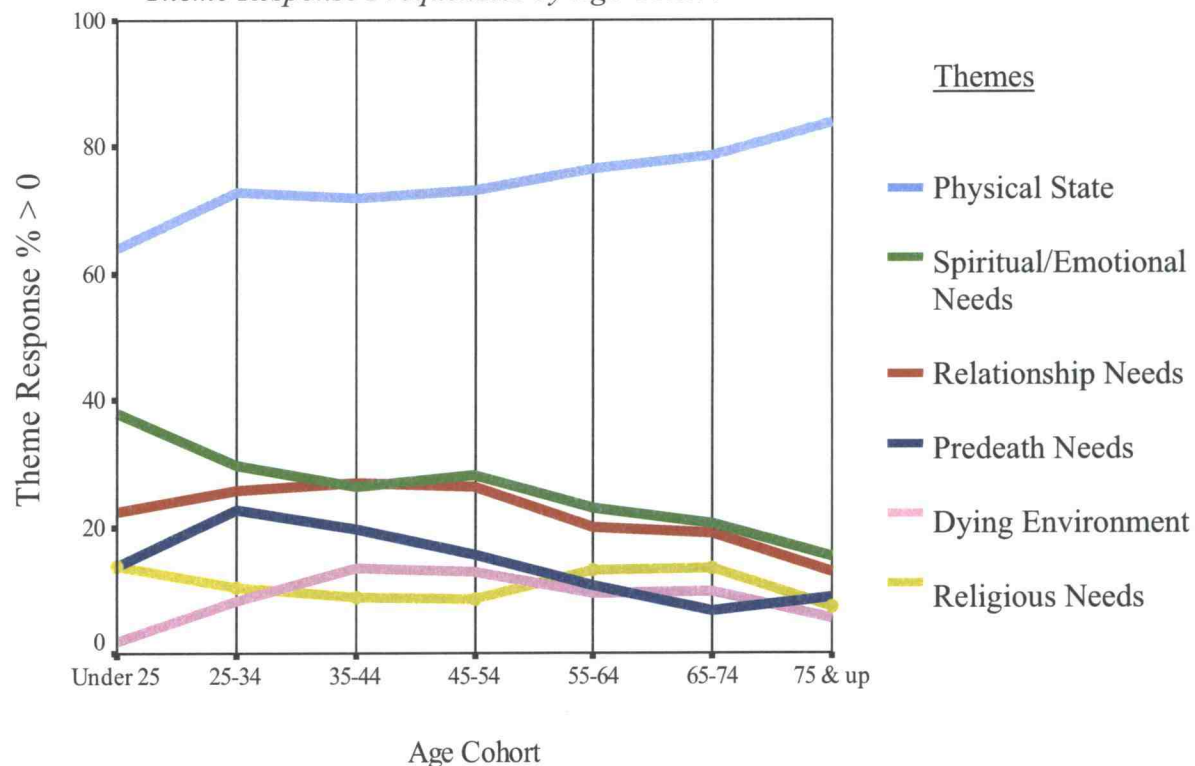
Physical State is the most prominent theme across all cohorts. It is the only theme frequency that remains higher than all other themes across all remaining cohorts. Frequency response of the 25-34 cohort is higher than the youngest cohort and remains so through the 35-44 and 45-54 cohorts. Frequencies then become higher through the 55-64 and 65-74 cohorts and are highest for the oldest cohort (75 & up). Spiritual/Emotional Needs were the next most frequent theme response, although, similar to the remaining themes, it appears to become lower from its highest frequency in the youngest cohort and lowers for the third cohort. This theme frequency is higher for the 45-54 age cohort, and then becomes progressively lower across the remaining cohorts. Relationship Needs appear lower for the youngest cohort and higher for the second, third and fourth cohorts and then appear to lower for the three remaining cohorts.

The response frequencies of Predeath Needs appears higher for the 25-34 cohort than the youngest cohort and is lower across all cohorts up to the 65-74 cohort, and is higher for the 75 & up cohort. The Dying Environment theme frequencies across cohorts appears similar in shape to that of Relationship Needs, yet represents much lower frequencies overall. It begins with a nearly zero frequency for the youngest cohort to higher frequencies for the 35-44 and 45-54 cohorts and gradually lowers for the remaining cohorts.

Chapter 4

Discussion and Conclusion

The relevant literature on dimensions of a good death is largely from individuals within the health care system, that is, patients, bereaved family members, and medical, spiritual, and family caregivers of the dying. Data on dimensions of a good death from a community-based sample are nonexistent. In this exploratory study, we analyzed existing qualitative data on dimensions of a good death from a large community sample to describe evidence from outside the healthcare system of common dimensions of a good death. Furthermore, we addressed the question of whether those dimensions varied by age.

Despite previous researchers' best efforts with small sample sizes, many, if not most, have been unable to sort out consistent, overarching themes that organize the dimensions of a good death (Steinhauser et al., 2000; Vig et al., 2002). This study's findings indicate that six broadly themed domains of process-oriented elements of a good death exist. The evidence here also suggests that individual differences may coexist with the themed domains. Therefore, these data support the prevailing view in the literature of recognizing specific individual needs for a good death. Additionally, they suggest that broad domains of dimensions of a good death might inform how individuals prioritize their needs as reflected in their view of a good death.

Themes of a Good Death

The themed domains of Physical State, Spiritual/Emotional Needs, Relationship Needs, and Dying Environment in this study concur with those dimensions of a good death established in the literature (Hanson et al., 1997; Kim & Lee, 2003; Mak & Clinton, 1999; Masson, 2002; Pierce, 1999; Steinhauser et al., 2000; Ternestedt et al., 2002; Vig et al., 2002; Wilson, 2000). Further, this study identified a new domain, Predeath Needs.

Some investigators argue that any commonality of views of a good death is swept away by large individual differences (Steinhauser et al., 2000; Vig et al., 2002). We argue that the theme-related data from this study suggest that the commonalities of views of a good death can exist while preserving inherent individual differences. Furthermore, by categorizing these conceptually discrete needs, variation within themes and individuals' prioritization of themes, can occur without invalidating one or the other.

To understand the reasons behind this it is useful to structure the discussion within the underlying theoretical framework of Bronfenbrenner's (1977) ecological systems theory. Ecological theory provides a framework in which to study dying individuals and their related settings or environments together as a whole. Therefore, it is possible to examine, theoretically, how those settings influence individuals' definition of a good death, and how those findings support the overriding commonalities found in those definitions.

The predominant theme of Physical State offers good footing to launch such an examination. As noted earlier, the issue of pain management and symptom control as an aspect of care and a characteristic of death and dying in the U.S. is a priority concern. It has been widely addressed in clinical studies on the chronically ill (SUPPORT Principal Investigators, 1995), bereavement studies of families of the deceased (Hanson et al., 1997), and, broadly in the fields of medicine, law, human services, healthcare policy and programs, and spirituality and religion.

Ecological theory allows us to view the commonalities of a good death found among large individual differences because of the influence of settings within a *microsystem* that have common systems, structures, and processes that impinge equally on all individuals' views of a good death. For example, hospitals and other care centers, whether large or small, abide by the same medical imperative of curative care that Kauffman (2000) argues also drives philosophy and prescription of care for those terminally ill and/or dying. In doing so, individuals who come to know the system through their own experience of care or that of a loved one's or even

more distantly through friends or coworkers' experience, learn about similar deficits in care based on their exchanges (*mesosystem*) with those common systems, structures, and processes. Therefore, part of what they think would make for a good death is influenced by what they experience in that setting. The data from this study offer support for this claim by respondents' sharing their emotionally painful participation in the dying process of a loved one. Few respondents in this large sample reported actually witnessing what they considered a good death.

This framework is evident in other *microsystem* settings that also influence views of a good death. The theme of Relationship Needs in particular reveals the strong influence of relationships not only in the dying process and aspects of a good death, but in the residual effects after death occurs. During the dying process, it appears that relationships act to ensure certain aspects of a good death for some such as not dying alone and the ability to be of service to their loved one. Moreover, individuals' reflection on witnessing a dying experience, whether positive or negative, appears to sway strongly one's view of one's own eventual death.

Exosystem influences emphasize the role of community data, which is consistent with the commonalities in the literature gathered solely by those within the healthcare system. Community data includes evidence of influence from the healthcare setting that may be overwhelming to the participants within that system. One can speculate that respondents who reported the frustration of feeling powerless to effect any change in their loved one's dying process might also see the healthcare system as an overbearing and unavoidable influence on the dying process. It is also possible that community data simultaneously confirms this overriding influence to represent a growing common experience of death and dying in the U.S. Respondents' main concern and fear of painful dying reflects a part of this experience. For some, reporting on the horrors of watching a loved one die painfully or linger on unnecessarily was the only way they could answer the study question.

Alternatively, it may be that this repulsion and fear of pain at end-of-life has stimulated the growth of community-based allied health systems and structures in the U.S. such as hospice and home health care, and substantiates their existence in other countries in the developed world. Many respondents reported positive experiences with hospice care for their loved one and viewed it as both a helpful alternative and a way to avoid the mainstream healthcare setting in their community. Therefore, with the addition of community data to the current dialogue of care, it is reasonable to expect continued growth of end-of-life palliative care settings.

Finally, underlying *macrosystem* influences on individual's views of a good death, although reported less frequently in the data (one or two respondents referred to "assisted suicide" or "euthanasia"), can be said to appear indirectly and yet, pervasively in the data. The influence of legislative issues on care for the dying and the ethics involved is palpable in the retelling of respondent's tearful and agonizing experiences with death and dying. One might imagine how different these responses might be if the medical model of forcefully curative care and ethic of "doing no harm" relied instead on the use of palliative care in the dying process. Ecological theory tells us that these macrosystem influences create ripple effects in other settings. Certainly, the efforts of revised federal regulations on dispensing pain medication, the availability of complimentary palliative medications, and a focus on palliative care in both medical education and the practices of formal care settings may help generate a wave of change to improve the dying process in the U.S.

Views of a Good Death by Age Cohort

Although common themes of a good death for a loved one can be derived from the data, how those themes are prioritized might vary among age cohorts. Physical State, Spiritual/Emotional Needs, Relationship Needs, Predeath Needs, and Dying Environment showed significant differences by age. However, because the reporting of Religious Needs did not significantly differ by age, that theme is not included in this discussion.

To understand the implications of these findings, it is helpful to place these views in context. Age cohorts provide a useful mechanism within which to observe frequency trends in the themes of a good death. Moreover, by capturing perspectives of a good death at one point in time, over multiple cohorts, the practical implementation of these data within a healthcare setting becomes more relevant. Age is not the only predictor of death. People of all ages become terminally ill or the victims of accidents and other events from which they may die before they become old. Therefore, examining frequency trends of themes of a good death may act to inform medical caregivers of the range of possible differences as a function of age cohort in how individuals prioritize needs for a good death.

Observed Frequency Trends

In addition to the prominent finding of Physical State needs in the data, interesting patterns appear in the remaining themes across cohorts. Overall, the theme trend in the data seems to be more clearly defined for the youngest cohort as opposed to the oldest. For the youngest, frequency of themes are more dispersed where for the oldest group they appear to cluster around a narrow range. One possible interpretation may be that younger people have priorities that are more distinct early in life, in general, than older people are. It is possible that older adults perceive they have fewer options that are less distinct. Therefore, they may focus on fewer and more generalized priorities.

Theoretically, socioemotional selectivity theory provides support for this likelihood. As age increases, people perceive time as more limited, which leads them to reorganize goal priorities. Moreover, socioemotional selectivity theory tells us that goal priority reorganization is more related to deriving emotional meanings from life and is more important than goals that make the most of long-term goals when the future is questionable (Löckenhoff & Carstensen, 2004). However, the change is not driven by age, but how time is perceived. Again, these data might appear very different if the sample was not community-based young people but was

drawn from a terminally ill population of young people who might perceive time similar to an older person.

Socioemotional selectivity theory also states that when time is limited, younger and older people both "pay more attention to the emotional aspects of situations, prioritize emotion-focused over problem-focused coping strategies, and prefer emotionally gratifying social contacts over contacts with novel social partners" (Löckenhoff & Carstensen, 2004 p.1396). This would seem counterintuitive to the trend apparent in Spiritual/Emotional Needs that appears to be more important to the youngest cohort and less important to the oldest. However, Carstensen's revised theory (2004) would argue that the influence of a limited time perspective on health-related goal priorities, make relevant those goals with most emotional meaning. Therefore, older adults or the terminally ill, may expend more time fulfilling goals focused on alleviating negative symptoms (as in Physical State needs) to make available resources for emotionally meaningful interactions such as with loved ones. This clearly supports the cohort specific observation for the older cohorts' higher response frequency for Physical State leaving fewer resources (lower response frequency) for Spiritual/Emotional needs and similarly, Relationship needs. Overall, older adults had lower response frequencies than the youngest cohort on every theme except for Dying Environment and Physical State. Dying Environment findings, which were the lowest reported for the oldest group, may be for the reason of being chronologically close to death and are consistent with time perceptions according to socioemotional selectivity theory. However, it is the least important for them overall. In contrast, an even smaller portion of the youngest cohort even mentioned this aspect, if at all. It is possible that young adults simply have never experienced a dying environment of a loved one nor even have had the awareness of its relevance at the end of life.

Lastly, a new theme, Predeath Needs, consists of the wished-for thoughts of those who will some day die. In this theme, we would expect to find age to be a relevant influence. For example, we would expect that younger people would find this need more important than

older people who are closer to death—and we do. However, again the frequencies in the two tails of the cohort span appear different. Though the higher frequency for the younger cohorts is not surprising, the lower frequency for the oldest cohort is surprising and intriguing. Why would the oldest cohort think and even respond about this theme? They are chronologically closest to death, they perceive time as limited, and they may have little time left to make life changes. Yet, these responses provide evidence that there may be little difference between asking someone about the good death of a loved one or that of their own. A closer inspection of the data reveal that respondents in this cohort more often reported wanting their loved one to have had a "good life." It is possible that this oldest cohort answered from their own experience of a good life and realizing its' importance wished it for their loved one.

<div align="center">Limitations of the Study</div>

Low response rates are one of the major limitations of this study. Survey researchers note that to avoid possible sample bias, a 75% or higher response rate is needed (Mangione, 1998). High nonresponse error can introduce a high level of sample bias. The lower the response rate, the higher the chance that nonrespondents differ from responders (Mangione, 1998). For example, in the missing values analysis for this study we found a significant difference in age of nonresponders and responders. It is likely that there may be other differences between responders and nonresponders to the survey in general that may be limiting this analysis. Although this study is a secondary analysis on existing data, and information on actual number of surveys sent was incomplete, because of the low response rates we must conclude that the sample is biased on some level. However, we do not know on what level and in what way it is biased. Based on this limited knowledge, one possible reason response rates are low may be because follow up efforts among the different coalitions were not as consistent or rigorous as those in the Montana distribution.

An additional limitation is the study's unclear sampling frame. Because we do not know how the sample was selected from the commercial mailing list, coverage error is a

concern. Coverage error, a form of sample selection bias, may be evident if the mailing list

obtained was out of date or incomplete (Singleton & Straits, 2005). Other limitations of this

study include its geographic coverage area and its lack of broad-based diversity in ethnicity

and cultural representation in the sample. In spite of the large sample size, respondents were

geographically located predominantly in the midwestern part of the U.S. Therefore, the

findings' generalizability would be limited to that region of the U.S. population. Additionally,

the majority of respondents identified as White. Although the overall ethnicity distribution of

the sample was proportionally equal to those of each state's population, there are important

reasons to oversample ethnic minority populations in end-of-life research. Disparities in end-

of-life care among minority populations have been reported in the literature and continue to be

studied (The Robert Wood Johnson Foundation, 2003). Some of these issues include

differences in "access to services, disparities in health care delivery systems, cross-cultural

communication, cultural competencies, spirituality, religion, beliefs, rituals, community

caregiving, economics, and family dynamics" (p. 1). Moreover, cultural differences may be

apparent in how people from cultures outside the U.S. might answer the question about the

good death of a loved one. Future studies should make a concerted effort to have a broad

cultural representation of participants.

Examining responses to only one question of a 73-item survey also limits the analysis.

Even though the intent of this study was to examine the self-reported dimensions of a good

death, which this question specifically asked, a more in-depth understanding of these

dimensions could be gained by including other relevant questions from the survey. Doing so

would build a broader analysis that would allow for additional comparisons. The study is also

limited by the nature of a self-administered questionnaire versus the benefit of face-to-face

interviews. Responding to open-ended questions on a self-administered questionnaire restricts

the respondent to the space available to develop their thoughts fully. Furthermore, a lengthy

questionnaire such as the one used here, may limit the amount of time an individual may take

to respond fully to many questions. Lastly, participants' point of view in responding about the good death of a loved one or that of oneself may present difficulties in interpreting results such as making comparisons and drawing conclusions.

Directions for Future Research

There is much room for continued research on aspects of a good death and whether those aspects can help to define dimensions of what people want at the end-of-life. Data indicate that the issue of pain management and symptom control is a high priority for those facing death. Based on the overpowering evidence of this devastating aspect of dying in the U.S., even slight improvements in how our society addresses pain within a clinical setting could potentially make a difference in reducing the number of painful deaths. Most likely, the broadest stroke of change would effectively be at the macro level of society that is, public policy on pain medication regulations. This is an integral part of creating more specific, systematic change in how pain medication is dispensed. It may also bring about changes in the medical community's perception of pain medication to palliate rather than to cause addiction in patients or even hasten death.

We must know more about individuals' perception of pain and examine any difference by culture, gender, age, and disease etiology for death to become less painful. Patient provider communication could act as a platform to address these issues, however informally, patient by patient. The outcome may be two-fold; it may improve not only patient care around pain, but may also motivate the provider's willingness to become an integral part of the patient's dying process. Furthermore, physicians may then see that the palliative care model does not strip them of their imperative to cure, thus rendering them hopeless to help the dying, but introduces medical comfort care as the ultimate pain relieving mechanism that only medicine can offer. Additionally, the findings in this study could be used to strengthen patient provider communication with the help of developing interview tools that address theme content areas found here to be pertinent to many.

Settings in which dying occurs should also continue to be studied with a focus on current medical practices. Hospice, in particular, may provide some of the most helpful models in which to adapt current practices for end-of-life care. Excellent overseas models of hospice are far ahead of those in the U.S., and are studying substantive modifications to their model based on operationally-defined dimensions of a good death (Ternestedt et al., 2002). Finally, cross-cultural studies are needed to understand vital differences among cultural definitions and norms about death and dying. As the U.S. continues to grow to be a society of many cultures, all of its institutions, and importantly those in healthcare, must be informed about the culturally specific, humanistic end-of-life needs and desires of people from all over the world.

References

Berg, B. L. (2004). *Qualitative research methods for the social sciences* (5th ed.). Boston: Pearson Education.

Braun, K. L., & Zir, A. (2001). Roles of the church in improving end of life care: Perceptions of Christian clergy and laity. *Death Studies, 25*, 685-704.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32*, 513-531.

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology, 22*, 723-742.

Buntin, M. B., & Huskamp, H. S. (2002). What is known about the economics of end-of-life care for Medicare beneficiaries? *The Gerontologist, 42*(Special Issue III), 49-53.

Byock, I., Norris, K., Curtis, R., & Patrick, D. L. (2001). Improving End-of-Life Experience and Care in the Community: A Conceptual Framework. *Journal of Pain and Symptom Management, 22*, 759-772.

Carstensen, L. L., Isaacowitz, D. M., & Charles, S. T. (1999). Taking time seriously: A theory of socioemotional selectivity. *American Psychologist, 54*, 165-181.

Cicirelli, G. (2002). *Older adults views on death.* New York: Springer.

Ehman, J. W., Ott, B. B., Short, T. H., Ciampa, R. C., & Hansen-Flaschern, J. (1999). Do patients want physicians to inquire about their spiritual or religious beliefs if they become gravely ill? *Archives of Internal Medicine, 159*, 1803-1806.

Emanuel, E. J., & Emanuel, L. L. (1998). The promise of a good death. *Lancet, 351*(Supplement Cancer 9114), 21-29.

Field, M. J., & Cassell, C. K. (1997). *Institute of Medicine Committee on Care at the End of Life. Approaching death: Improving care at the end of life.* Washington, DC: National Academy Press.

Hanson, L. C., Danis, M. D., & Garrett, J. (1997). What is wrong with end-of-life care? Opinions of bereaved family members. *Journal of the American Geriatrics Society, 45*, 1339-1344.

Kaufman, S. R. (2000). Senescence, decline and the quest for a good death: Contemporary dilemmas and historical antecedents. *Journal of Aging Studies, 14*(1), 1-23.

Kaufman, S. R. (2002). A commentary: Hospital experience and meaning at the end of life. *The Gerontologist, 42*(Special Issue III), 34-39.

Kayser-Jones, J. (2002). The experience of dying: An ethnographic nursing home study. *The Gerontologist, 42*(Special Issue III), 11-19.

Kim, S., & Lee, Y. (2003). Korean nurses' attitudes to good and bad death, life-sustaining treatment and advance directives. *Nursing Ethics, 10*, 624-637.

Knebel, A., & Buckwalter, K. C. (2002). End-of-life research: Focus on older populations, Preface. *The Gerontologist, 42*(Special Issue III), 4-10.

Koenig, H. G. (2002). A commentary: The role of religion and spirituality at the end of life. *The Gerontologist, 42*(Special Issue III), 20-23.

Life's End Institute: Missoula Demonstration Project, I. (2003, April 22, 2003). *Our story*. Retrieved May 9, 2004, from www.lifes-end.org/our_story.phtml

Löckenhoff, C. E., & Carstensen, L. L. (2004). Socioemotional selectivity theory, aging, and health: The increasingly delicate balance between regulating emotions and making tough choices. *Journal of Personality, 72*, 1395 - 1424.

Lynn, J. (2002). A commentary: Where to live while dying. *The Gerontologist, 42*(Special Issue III), 81-85.

Lynn, J., Teno, J. M., Phillips, R. S., Wu, A. W., Desbiens, N., Harrold, J., et al. (1997). Perceptions by family members of the dying experience of older and seriously ill patients. *Annals of Internal Medicine, 126*, 97-106.

Mak, J. M. H., & Clinton, M. (1999). Promoting a good death: An agenda for outcomes research- a review of the literature. *Nursing Ethics, 6*, 97-106.

Mangione, T. W. (1998). Mail surveys. In L. Bickman & D. L. Rog (Eds.), *Handbook of Applied Social Research Methods* (pp. 399-427). Thousand Oaks: SAGE.

Masson, J. D. (2002). Non-professional perceptions of 'good death': a study of views of hospice care patients and relatives of deceased hospice care patients. *Mortality, 7*, 191-209.

Mezey, M., Neveloff Dubler, N., Mitty, E., & Brody, A. A. (2002). What impact do setting and transitions have on the quality of life at the end of life and the quality of the dying process? *The Gerontologist, 42*(Special Issue III), 54-67.

Morrison, R. S., & Siu, A. L. (2000). The hard task of improving the quality of care at the end of life. *Archives of Internal Medicine, 160*, 743-747.

Pierce, S. F. (1999). Improving end-of-life care: Gathering suggestions from family members. *Nursing Forum, 34*(2), 5-14.

Singleton, R. A., & Straits, B. C. (2005). *Approaches to Social Research* (4th ed.). New York: Oxford University.

Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine, 132,* 825-832.

Stolick, M. (2003). Dying to meet you: Facing mortality and enabling patient styles. *American Journal of Hospice & Palliative Care, 20,* 269-273.

Sulmasy, D. (2002). A biopsychosocial-spiritual model for the care of patients at the end of life. *The Gerontologist, 42*(Special Issue III), 24-33.

SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments. *Journal of the American Medical Association, 274,* 1591-1598.

Ternestedt, B. M., Andershed, B., Eriksson, M., & Johansson, I. (2002). A good death: Development of a nursing model of care. *Journal of Hospice and Palliative Nursing, 4,* 153-160.

The Robert Wood Johnson Foundation. (2003). *Disparities at the end of life.* Retrieved August 18, 2004, from www.rwjf.org/news/special/endDisparities_2.html

Tilden, V. P., Tolle, S. W., Drach, L., & Hickman, S. (2002). Measurement of quality of care and quality of life at the end of life. *The Gerontologist, 42*(Special Issue III), 71-80.

Tolle, S. W., Rosenfeld, A. G., Tilden, V. P., & Park, Y. (1999). Oregon's low in-hospital death rates. What determines where people die and satisfaction with decisions on place of death? *Annals of Internal Medicine, 130,* 681-685.

U. S. Census Bureau. (2004, July 9, 2004). *Census 2000.* Retrieved August 27, 2004, from www.quickfacts.census.gov/qfd/states

Vig, E. K., Davenport, N. A., & Pearlman, R. A. (2002). Good deaths, bad deaths, and preferences for the end of life: A qualitative study of geriatric outpatients. *Journal of the American Geriatrics Society, 50,* 1541-1548.

Walter, T. (2003). Historical and cultural variants on the good death. *British Medical Journal, 327,* 218-220.

Weinman, B. P. (2003). Freedom from pain: Establishing a constitutional right to pain relief. *Journal of Legal Medicine, 24,* 495-539.

Wilson, D. M. (2000). End-of-life care preferences of Canadian senior citizens with caregiving experience. *Journal of Advanced Nursing, 31*, 1416-1422.

Appendix

Missoula Demonstration Project, Inc.

The Quality of Life's End: Community Survey

Missoula Demonstration Project_{INC}

The Quality of Life's End

COMMUNITY SURVEY

The *Quality of Life's End* is a community project designed to meet the needs of people who are dying and their families. We want to help our loved ones meet end of life experiences in a positive and meaningful way. Please help us achieve this goal by answering the following questions:

1. **Are you?** *(SEX)*

    ☐ Female
    ☐ Male

2. **Are you?** *(ETHNIC)*

    ☐ American Indian/Native American
    ☐ Asian/Hmong
    ☐ Black/African American
    ☐ Hispanic/Latino
    ☐ White/Caucasian
    ☐ Other (___(ETH_OTH)_____)

3. **Current Marital Status (check <u>one</u>): (MARITAL)**

    ☐ Married/Committed Relationship
    ☐ Separated
    ☐ Never married
    ☐ Divorced
    ☐ Widowed

4a. **How many persons live in your household <u>including yourself</u>? (PERSONS)**

    _____ # persons in household, <u>including</u> you

4b. **Who are they?**

    _____ # Spouse/Partner *(SPOUSE)*
    _____ # Children *(CHLDREN)*
    _____ # Other Family Members
             (OTHER_FA)
    _____ # Persons not related to you
             (PER_NO_R)

5. **What is your age?** *(AGE)*

    _____

6. **Highest grade in school completed? (for example if you completed high school, mark 12. Mark 13 for one year of college or technical school, 14 for two years, & so on) (HIGHEST)**

    _____ highest grade completed

7. **How long have you lived in this community:**

    ☐ Less than 1 year *(UNDER_1)*
    _____ # Years (if 1 year or longer)
             (YEARS_LI)

8. **What type of work do you do?** *(TYP_WORK)*

☐ professional
☐ technical
☐ service / sales / clerical
☐ agricultural
☐ other: ___ **(TYPWKOTH)**_____ ____

☐ None
☐ 1% to 25%
☐ 26% to 50%
☐ 51% to 75%
☐ 76% to 100%
☐ Don't Know

9. *Regarding work, do you currently?*

    ☐ Work for pay: **(WORK_PAY)**
       _____ # hours per week
           (HOURS_WO)
    ☐ Volunteer: **(VOLUNTER)**
       _____ # hours per month
           (HOURS_VO)
    ☐ Other:___ **(OTHER_WO)** _____

15. *How many times in the past year have you received services at the emergency room?* **(TIME_IN)**

    _____

16. *How many overnight stays have you had in a hospital over the past year? (OVERNIGH)*

    _____ # overnight stays

10. *Do you identify yourself with an organized religion or have a spiritual orientation?* **(IDENTIFY)**

    ☐ No
    ☐ Yes *(please describe below):*
      ___**(RELIGION)**_____

17. *Do you have a signed Living Will or Durable Power of Attorney (DPOA) for Health Care?* **(LIVE_WIL)**

    ☐ Yes, Living Will
    ☐ Yes, Durable POA for Health Care
    ☐ Yes, Both
    ☐ No
    ☐ Don't know

11. *How often do you attend religious services?* **(REL_OFTN)**

    ☐ Never
    ☐ Rarely
    ☐ Occasionally
    ☐ Regularly

12. *Yearly Household Gross Income (before taxes):* **(INCOME)**

    ☐ less than $15,000 yearly
    ☐ $15,001 - $30,000 yearly
    ☐ $30,001 - $45,000 yearly
    ☐ $45,001 - $60,000 yearly
    ☐ $60,001 - $75,000 yearly
    ☐ more than $75,000 yearly

13. *What kind of health insurance do you have? check ALL that apply*

    ☐ none **(Q13A)**
    ☐ through current employer **(Q13B)**
    ☐ self pay **(Q13C)**
    ☐ Medicare **(Q13D)**
    ☐ Medicaid **(Q13E)**
    ☐ HMO/PPO **(Q13F)**
    ☐ other government/military subsidy
      (Q13H)
        other___**(Q13G_OTH)**_____

14. *About how much of your health care expenses are currently paid by your health insurance?* **(INSR_PER)**

18. While you were growing up, how often were death & dying talked about in your family? *(TALK_DEA)*

- ☐ Never
- ☐ Rarely
- ☐ Occasionally
- ☐ Fairly often

19. **Please list persons who have died whose death had a significant impact on you.**
EXAMPLES: spouse/partner; lover; child; grandparent; sister or brother; close friend.

Relationship to You?	How long ago? Please circle yrs or months
	circle yrs or mnths
__(TYPE1)_____	(TIME1) yrs OR mnths
__(TYPE2)_____	(TIME2) yrs OR mnths
__(TYPE3)_____	(TIME3) yrs OR mnths
__(TYPE4)_____	(TIME4) yrs OR mnths
__(TYPE5)_____	(TIME5) yrs OR mnths
__(TYPE6)_____	(TIME6) yrs OR mnths
__(TYPE7)_____	(TIME7) yrs OR mnths

20. How familiar are you with hospice services? (check only ONE) (HOSPICE)

- ☐ I have never heard of hospice services
- ☐ I have heard a little bit about hospice
- ☐ I have a good understanding of hospice services, but no direct experience
- ☐ I know someone who has used hospice
- ☐ I am/have been a hospice volunteer
- ☐ I have direct experience with hospice services provided to my family or a close friend

How uncomfortable would you be to:

Circle your level of discomfort
comfortable & & & & UNcomfortable

21. talk about death? (Q21) — 1 2 3 4 5 6 7
22. see a dead body (e.g., at a funeral or wake)? (Q22) — 1 2 3 4 5 6 7
23. write your own will if you thought your death would occur soon? (Q23) — 1 2 3 4 5 6 7
24. think about life after death? (Q24) — 1 2 3 4 5 6 7

How afraid are you of:

Circle your level of worry or fear
none at all & & & & & extreme

25. dying painfully? (Q25) — 1 2 3 4 5 6 7
26. getting cancer? (Q26) — 1 2 3 4 5 6 7
27. having a heart attack? (Q27) — 1 2 3 4 5 6 7
28. time passing so quickly? (Q28) — 1 2 3 4 5 6 7
29. the subject of death? (Q29) — 1 2 3 4 5 6 7

How likely are you to:

Circle how likely you would be to
not at all & & & & & extremely likely

30. avoid attending funerals or memorial services? **(Q30)**   1   2   3   4   5   6   7

31. read books that deal with the subject of death and dying? **(Q31)**   1   2   3   4   5   6   7

32. watch television programs or movies that deal with the subject of death and dying? **(Q32)**   1   2   3   4   5   6   7

33. avoid medical checkups because you are afraid the doctor will find "something serious?" 1   2   3   4   5   6   7
(Q33)

34. speak freely to loved ones about death and dying? **(Q34)**   1   2   3   4   5   6   7

35. visit or telephone a friend or relative who has recently lost a loved one in order to see how 1   2   3   4   5   6   7
they are doing? **(Q35)**

36. preplan your own funeral? **(Q36)**   1   2   3   4   5   6   7

How strongly do you agree or disagree with the following statements? Circle a number on the right.   *Circle how strongly you agree*

strongly disagree & & & strongly agree

37. Old people should get out of the way to make room for young people. **(Q37)**
  1   2   3   4   5   6   7

38. I want to live in a world without death. **(Q38)**   1   2   3   4   5   6   7

39. There is a special value in getting old. **(Q39)**   1   2   3   4   5   6   7

40. Dying is an important stage of life. **(Q40)**   1   2   3   4   5   6   7

41. If someone had the power to tell me when my death would be, I would want to know. **(Q41)** 1   2   3   4   5   6   7

42. Caring for people who are dying is good for those giving care. **(Q42)**   1   2   3   4   5   6   7

43. I don't know where people get the courage to face death. **(Q43)**   1   2   3   4   5   6   7

44. I often wonder why people have to die. **(Q44)**   1   2   3   4   5   6   7

Circle your level of worry or fear

none at all & & & & & extreme

45. In thinking about dying, are you worried that your money won't last? **(Q45)**   1   2   3   4   5   6   7

46. In thinking about dying, are you worried that your family's money will be used up? **(Q46)**   1   2   3   4   5   6   7

47. In thinking about dying, are you worried about being a burden to your family or friends? 1   2   3   4   5   6   7
(Q47)

48. If you were terminally ill, do you think you might want assistance with suicide? **(Q48)**   1   2   3   4   5   6   7

49. If you were terminally ill, where do you think you would want to die? *(choose only ONE)* **(Q49)**

☐   at home

☐　　　　in a hospital

☐　　in a nursing home

☐　　in a residential hospice

☐　　other (please describe): _____(Q49OTH)_____

Why? _____(Q49WHY1)'_____(Q49WHY2)_____

_____

50.　If you were dying, do you think you would want hospice support? *(choose only ONE)* **(Q50)**

☐　　Yes

☐　　No, because: _____(Q50NO)_____

☐　　Not sure

☐　　Don't know what hospice is

51.　If you could choose the way in which you die (e.g., sudden death, suicide, lengthy illness), what would your choice be?

_____(Q51HOW1)　(Q51HOW2)_____

52.　When you imagine yourself dying, are there any customs, activities, or forms of spiritual support that you think might help you deal with your own dying process?

(Q52CUS1)_____

(Q52CUS2)_____

(Q52CUS3)_____

53.　How <u>important</u> would each of these be in helping you deal with your own dying?

	<u>not</u> important	&	&	&	&	&	<u>very</u> important
(Q53A) a) Family members visiting you	1	2	3	4	5	6	7
(Q53B) b) Being able to stay in your home	1	2	3	4	5	6	7
(Q53C) c) Honest answers from your doctor	1	2	3	4	5	6	7
(Q53D) d) Religious/spiritual persons visiting you	1	2	3	4	5	6	7
(Q53E) e) Attending services at your place of worship	1	2	3	4	5	6	7
(Q53F) f) Knowing medicine was available to you	1	2	3	4	5	6	7
(Q53G) g) Planning your own funeral	1	2	3	4	5	6	7
(Q53H) h) Being able to complete your will	1	2	3	4	5	6	7
(Q53I) i) Fulfilling personal goal(s)/pleasure(s)	1	2	3	4	5	6	7
(Q53J) j) Reviewing your life history with your family	1	2	3	4	5	6	7
(Q53K) k) Having health care professionals visit you at your home	1	2	3	4	5	6	7
(Q53L) l) Participating in an Indian sweat lodge ceremony	1	2	3	4	5	6	7
(Q53M) m) Getting your finances in order	1	2	3	4	5	6	7
(Q53N) n) Outside help so your family won't have to work too hard	1	2	3	4	5	6	7
o) other: _ **(Q53OTH1)**____ **(Q53OTH1S -- score)**____	1	2	3	4	5	6	7
p) other: _ **(Q53OTH2)**____ **(Q53OTH2S -- score)**____	1	2	3	4	5	6	7
_ **(Q53OTH3)**____ **(Q53OTH3S -- score)**____							

54.　If you have experienced the death of a loved one, were there any customs, activities, or spiritual support that seemed to help you with their dying process or death? *Please describe.*

_____(Q54A)_____

_____(Q54B)_____

_____(Q54C)_____

_____

55. When you think of a loved one dying, what would make for a "good death"?

_____(Q55A)_____

_____(Q55B)_____

_____(Q55C)_____

_____

56. In the dying process, what do you think is important:

	not important & & & & & _very important_

	1	2	3	4	5	6	7
(Q56A) a) Physical comfort	1	2	3	4	5	6	7
(Q56B) b) Freedom from pain	1	2	3	4	5	6	7
(Q56C) c) Having things settled with the family	1	2	3	4	5	6	7
(Q56D) d) Spiritual well-being	1	2	3	4	5	6	7
(Q56E) e) Not being a burden to loved ones	1	2	3	4	5	6	7
(Q56F) f) Knowing how to say goodbye	1	2	3	4	5	6	7
(Q56G) g) Sense of my own worth	1	2	3	4	5	6	7
h) other: ___**(Q56OTH1)**___**(Q56OTH1S - score)**_____	1	2	3	4	5	6	7

57. When you are nearing life's end, you will need support from people in your life. Place a checkmark / in the boxes below to indicate the people you expect to support you.

Type of Support	spouse / partner	children	family / relatives	neighbors	friends	work associate	health providers	faith community
a) Will listen when I just want to talk.	(Q57A1)	(Q57A2)	(Q57A3)	(Q57A4)	(Q57A5)	(Q57A6)	(Q57A7)	(Q57A8)
b) Provide transportation.	(Q57B1)	(Q57B2)	(Q57B3)	(Q57B4)	(Q57B5)	(Q57B6)	(Q57B7)	(Q57B8)
c) Help with chores.	(Q57C1)	(Q57C2)	(Q57C3)	(Q57C4)	(Q57C5)	(Q57C6)	(Q57C7)	(Q57C8)
d) Do fun things with me.	(Q57D1)	(Q57D2)	(Q57D3)	(Q57D4)	(Q57D5)	(Q57D6)	(Q57D7)	(Q57D8)
e) Work with agencies to provide my needs.	(Q57E1)	(Q57E2)	(Q57E3)	(Q57E4)	(Q57E5)	(Q57E6)	(Q57E7)	(Q57E8)
f) Know about my illness.	(Q57F1)	(Q57F2)	(Q57F3)	(Q57F4)	(Q57F5)	(Q57F6)	(Q57F7)	(Q57F8)
g) Know what I want when I die.	(Q57G1)	(Q57G2)	(Q57G3)	(Q57G4)	(Q57G5)	(Q57G6)	(Q57G7)	(Q57G8)
h) Help care for other family members.	(Q57H1)	(Q57H2)	(Q57H3)	(Q57H4)	(Q57H5)	(Q57H6)	(Q57H7)	(Q57H8)
i) Encourage me when I'm down.	(Q57I1)	(Q57I2)	(Q57I3)	(Q57I4)	(Q57I5)	(Q57I6)	(Q57I7)	(Q57I8)
j) Understand what I'm going through.	(Q57J1)	(Q57J2)	(Q57J3)	(Q57J4)	(Q57J5)	(Q57J6)	(Q57J7)	(Q57J8)

64

The *Missoula Demonstration Project* will also be conducting a companion study on issues related to pain. Completing the questions on this page will assist us in formulating a research strategy for the follow-up study.

Please circle how strongly you agree with each of the following statements (by circling the appropriate number on the right).

Circle *how strongly you agree*

strongly disagree & & strongly agree

58. I am afraid my doctor may not believe or treat my pain. **(Q58)** — 1 2 3 4 5 6 7

59. I feel that appearing ill is embarrassing. **(Q59)** — 1 2 3 4 5 6 7

60. Cancer pain can be effectively relieved. **(Q60)** — 1 2 3 4 5 6 7

61. Pain medicines should only be taken when pain is severe. **(Q61)** — 1 2 3 4 5 6 7

62. Most people taking pain medicines will become addicted to the medicines over time. **(Q62)** — 1 2 3 4 5 6 7

63. It is important to take the lowest amount of medicine possible to save larger doses for later when the pain is worse. **(Q63)** — 1 2 3 4 5 6 7

64. There are other effective remedies for pain besides medicine (such as massage, heat, relaxation). **(Q64)** — 1 2 3 4 5 6 7

65. People are often given too much pain medicine. **(Q65)** — 1 2 3 4 5 6 7

66. Pain medicine cannot really control pain. **(Q66)** — 1 2 3 4 5 6 7

67. People get addicted to pain medicine easily. **(Q67)** — 1 2 3 4 5 6 7

68. Good patients avoid talking about pain. **(Q68)** — 1 2 3 4 5 6 7

69. It is easier to put up with pain than with the side effects that come from pain medicine. **(Q69)** — 1 2 3 4 5 6 7

70. Complaints of pain could distract a physician from treating my underlying illness. **(Q70)**

1 2 3 4 5 6 7

71. Pain medicine should be "saved" in case the pain gets worse. **(Q71)**

1 2 3 4 5 6 7

72. The experience of pain is a sign that the illness has gotten worse. **(Q72)**

1 2 3 4 5 6 7

73. If you are living in daily pain, what have you found to be helpful? _____

_____ **(Q73A)**_____ **(Q73B)**_____ **(Q73C)**_____ **(Q73D)**_____