

# **Bridge Over Troubled Waters: End-of-Life (EOL) Decisions, A Qualitative Case Study**

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*This case study investigated the psychological and emotional experiences of nine health care professionals who attended a Five Wishes seminar, designed to acquaint participants with thinking holistically about death. All the self-selected participants had experienced the death of a loved one and indicated they were able to discuss death issues. Data collection included interviews, observations, physical artifacts, and the Five Wishes documents. Content analysis was the central technique used to identify themes. Findings indicated participants attended the EOL seminar to share information with their colleagues and patients; the information also interested them personally. However, facing death and making EOL care decisions were difficult for the participants. The EOL seminars educated them regarding some of the mysteries and problems of EOL care and offered them some solutions and insights both professionally and personally. This study has implications for educators and health care professionals: 1) EOL decisions are facilitated by the social support of group settings. 2) Reluctance about facing death can be reduced by comprehensive, lifelong education beginning in the early childhood years and culminating with holistic advanced directives such as the Five Wishes.*

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**Key Words:** Advanced Directives, Living Wills, Death, Five Wishes, Holistic, End Of Life (EOL), Terminal Disease, Values, Social Support

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## **Introduction**

The purpose of this exploratory, qualitative collective case study was to discover the psychological and emotional experiences of self-selected seminar participants after attending a seminar about End-of-Life (EOL) care decisions and living wills.

## **Background**

For decades physicians rarely informed their patients of a terminal diagnosis, depriving them of the possibility of making informed decisions regarding management of

their treatment (Hill & Shirley, 1992). There were few curative therapies available for life-threatening illnesses (Golub, 1994). The nurse's role was to make the terminally ill patients comfortable as death approached. Prior to the early 1980's, physicians and the general public often felt that caring for patients meant withholding painful news of a terminal condition (Hill & Shirley, 1992). This stance was contrary to the position held by many nurses (Olson, 1997).

Remarkable developments in pharmacology and medical technology during the 1940's and 1950's brought many changes (Golub, 1994). The physician's role was to control symptoms of a dying patient, thereby becoming the "conqueror" of disease and death (Cassedy, 1991). Veath (1989) declared, "Death, as never before is looked upon as evil, and we are mobilizing technology in an all-out war against it. If not death itself at least certain types of death are beginning to be seen as conquerable" (p. 91). Dozer and Addison (1992), in their investigation of resident physicians' practices with dying patients, noted that biomedical technology provided a "credo of saving patients' lives at all costs" (p. 540).

Decision-making often was not an option because physicians routinely failed to share a terminal diagnosis with their cancer patients (Hill & Shirley, 1992). However, Annas (1989) indicated that during the 1960s and 1970s several court cases in which patients successfully sued their physicians for failure to disclose information about their conditions and treatment options reinforced the legal principle of informed consent. Since 1980, the rights of competent patients to refuse medical treatment became an option (Hill & Shirley, 1992).

Physician paternalism is less acceptable to patients and families today. Patients have opportunities to seek options and choices if they are aware of the situation. Society is attentive to reason-based decisions (Goldstein & Hogarth, 1997). However, Larson and Tobin (2000) reported that the structure of the medical care system discourages meaningful EOL discussions. They found these conversations are not a routine part of care. Further, it was not clear who should take responsibility for initiating such conversations when several physicians treat the patient. Insurance companies generally do not compensate for these discussions (Greene & Edelman, 1996). Tulskey, Fischer, Rose, and Arnold (1998) showed that advanced directive conversations averaged 5.6 minutes with physicians speaking for two thirds of the time.

According to Kübler-Ross (1969), the denial of death and dying in the medical community is pervasive. Physicians are formally taught that death is failure both directly and indirectly throughout their formal and informal medical education. Curricula focused on cures with a general absence of care of the dying (Schneiderman & Jecker, 1995). Dozer and Addison (1992) found that anxiety was also an important concept regarding how residents deal with dying patients noting, "Perhaps the most anxiety-provoking aspect of dealing with dying patients was residents' identification with them" (p. 540). There is a need for a greater focus on palliative care:

While modern medical science has provided physicians and nurses with effective treatments for promoting health and preventing disease in an increasingly older group of patients, it has at the same time distanced health care professionals from the traditional role of caring for their patients who are dying. Little research has focused on the process of

defining the shift from prevention to palliation and the necessary components of such care (Quill, 2000, p. 156)

Levin's (1998) study reported that oncologists' knowledge and attitudes about EOL care were close to ideal; however, their behaviors in caring for dying patients did not reflect this knowledge. Primary care physicians had even less knowledge, more negative attitudes, and less effective EOL care behaviors (Levin, 1998). Flaming (2000) suggested "silence" about death stems from health care professionals' view of death as a failure and not wanting patients to lose hope. Some believed that discussion of death would cause the patient to feel stigmatized. Kübler-Ross (1969) stated:

Death as viewed by physicians is no longer destiny like at the turn of the century, but failure of the doctors, written nowhere in God's plan. Death can be repelled, repulsed almost forever -- a disease that doctors should be able to cure. (p. 2)

Consumers have come to expect that by using scientific technology, physicians can indefinitely prolong life without the kind of suffering their ancestors often encountered (Golub, 1994).

Ironically, a generation of Americans that boasts of its openness and willingness to talk about anything does not talk about death, except in such Victorian euphemisms as "passed on" and "gone to heaven." A focus group study of 385 participants found that Americans would avoid the topic of death whenever possible (Lynn, 1997). These participants gave lengthy descriptions about why talking about death is so difficult.

Canine (1996) suggested that Americans have a distorted preoccupation with death that "mimics pornography in its danger of dehumanizing genuine human feelings and emotion" (p. 10). According to Gorer (1967), the word "pornographic" relates to that which is obscene or offensive such as sexual topics and nudity in a prudish society. When society says that sex is disgusting or immoral, then it is not to be talked about. Likewise, death, like sex in this instance, is treated the same: as obscene and offensive. As a consequence, American society seems insulated from and uncomfortable with the subject of death. "The modern age has created a veritable 'pornography of death'" (Bertman, 1991, p. 3).

Events such as mass murders, terrorist acts, and natural disasters influence people's level of fear. People recognize the timing and nature of death are unknown, so their death may follow an extended illness. According to Canine (1996), people tend to project and imagine the conflict between "dying with dignity" and "fighting for life" (p. 10). Kübler-Ross (1969) stated "Death is still a fearful, frightening happening and the fear of death is a universal fear even if we think we have mastered it on many levels" (p. 5). Nuland (1993) agreed, stating people are psychologically unable to cope with thoughts of their own deaths and view death as a looming terror. They seek ways to deny the power of death and its power over human thought.

Becker (1973) redirected Freudian psychoanalysis away from sexual and material drives toward an even more forceful drive, fear and anxiety about death. Wiedera-Wysoczanska's (1999) clinical investigation parallels Becker's beliefs concerning awareness of death. She found this awareness contributes to personal development and coping with fears of death enhanced patients' well being (1999).

Kübler-Ross (1969) and Kübler-Ross and Kessler (2001) asserted there are three primary categories of fear associated with the death and dying process. They include fear

of pain, loss of dignity, and being a burden to others. However, emotions, such as fear, are important in decision-making because they stir people to act (Jamieson & Campbell, 1992).

The EOL care decision-making process has as a central concern a mechanism to assure that once-competent patients rendered permanently incompetent by injury or illness can have holistic EOL care wishes adequately communicated and honored. White, Coyne, and Patel (2001) noted denial of death is reflected in national healthcare initiatives. Dickinson (1999) stated the Patient Bill of Rights produced by the Presidential Commission on Health Quality (1990) omitted mention of EOL care. Larson and Tobin (2000) addressed the need for EOL conversations that include content-based interventions attending to physical, psychological and spiritual needs.

The process of dying has changed over time for several reasons. One reason is the numerous biomedical advances available (Dozer & Addison, 1992; Golub, 1994; Veath, 1989). Furthermore, for both healthcare workers and the public in general, there is a pervasive cultural fear and denial of death (Becker, 1973; Kübler-Ross, 1969; Nuland, 1993; White, et al., 2001). These situations have created a culture of "silence" about death (Bertman, 1991; Flaming, 2000; Gorer, 1967). In recent years, some clinicians have moved toward holistic care for dying patients (Olson, 1997). Some have attempted to understand physicians' perceptions about EOL care such as Dozer and Addison's (1992) investigation of moving toward a "good death." However, much remains to be learned about how individuals perceive and cope with their own deaths. The purpose of this study was to investigate the lived experiences of participants who attended a *Five Wishes* seminar about holistic EOL care decisions. The hope was to record the perceptions of individuals who had taken this first step to address their own mortality--attending the seminar. Both the seminar and the living will document, developed by Callahan and Towey (1997), are entitled *Five Wishes*.

## Method

### Context: Self of the Researchers

Kate Callahan: My personal and professional experiences have prepared me for conducting this study, enabling me to manage my own issues of fear, denial, and self doubt about death and dying. The majority of Americans are part of a the death-denying society because they, unlike their ancestors who witnessed death often and who died quickly and at any age, are simply unfamiliar with death--at least the kind of death that most of us currently face--when we are old and from some chronic and debilitating disease. Unlike most Americans who will pass adulthood without personal contact with death, I have witnessed many deaths. I have learned that death is not a failure of the medical system, something to fear or deny, but rather a natural part of the life cycle. I have found a vision for caring for dying people, and am I committed to refining this vision. We are a nation that desperately needs stories about dying to provide some guides to appropriate roles and worthy behavior to end pain and suffering and denial at the end-of-life. I hope this study will serve as one.

Nancy Maldonado: I lived most of my life as one of the Americans who denied and feared death. I attended my husband's funeral at age 42; it was the first I had

attended. I was forced to see this death from cancer on an every day basis. It was very difficult. Afterwards, some time passed, and I became interested in the topic and read a number of books about the dying experience from both the clinical and the spiritual perspectives. It became clearer to me that death is a part of life. Time and the deaths of my parents and several close friends have provided additional experiences with dying. I still have my own fears and concerns, but faith and knowledge have both helped me to grow toward a greater acceptance. My participation in this study has helped me greatly to broaden my perspectives. I hope this study will, likewise, assist those who read it.

Joan Efinger: As a nurse for over 40 years, with clinical practice in a variety of areas, I have witnessed deaths of newborns and teenagers to centenarians. Deaths of family members and friends, with lack of dignity and comfort for them, prompted my paradigm shift to a holistic approach to care for the dying. My friendship with Dr. Patricia Nishimoto, an oncology clinical nurse specialist, contributed to my experiences of the "good death." I have shared experiences of my Nana (grandmother) and my mother-in-law having holistic, caring deaths. They died at home with dignity, comfort and family around them. I see death, as another phase of life to be experienced with loved ones. My spirituality contributes to not having denial and fear of death. My fears are that my death may not be according my wishes and needlessly painful. It is imperative that people have knowledge about their options, that family and healthcare providers have knowledge about people's wishes around their dying process, and that those wishes are honored. I believe that values clarification with my loved ones and healthcare surrogates reduces my fears and doubts about my own death. This research provided information that guides ways to improve education and care for people. Presenting the findings of this research is an integral part of my commitment to help people have a holistic death.

## **Design**

An exploratory, qualitative collective case study design was used to gain understanding of the participants' experiences (Yin, 1989). A narrative format, the telling of people's stories, was employed in the interviews. The narratives described thoughts, emotions, and interactions with others that occurred after the study's participants attended the *Five Wishes* seminar (Denzin & Lincoln, 1994). The researchers used taped, verbatim-transcribed interviews, observations, artifacts, and the participants' *Five Wishes* documents as data to provide a detailed picture (Creswell, 1998).

A constructivist approach most closely parallels the philosophical underpinnings of this study. This approach assumes an "emphasis on the world of experience as it is lived, felt, undergone by social actors....what we take to be objective knowledge and truth is the result of perspective..." (Schwandt, 1998, p. 236). What participants perceive as real is a construction of their minds. Individuals can have multiple, often conflicting constructions, and all have meaning for them (Denzin & Lincoln, 1998).

## **Data Generation, Collection, and Processing**

**Participants.** A purposeful sample was chosen for their shared experience of attending a *Five Wishes* seminar. The self-selected sample of nine participants included one man and eight women. See the Appendix for a description of the participants. Many

people who attended the seminar were from various fields of work and could have participated in the study. However, all those who volunteered to participate were involved in health care. In addition, each of the nine had experienced the death of a loved one and felt able to talk about it. The study was explained to seminar attendees, and those participants who volunteered for the study were asked to answer the following questions: (1) Considering the sensitive nature of EOL care decisions, would you be able to participate in a study that asks questions about your feelings and experiences regarding attending this EOL seminar? And (2) Will you be able to communicate your EOL care decisions and your experiences of facing these decisions to the researchers? Those who indicated they would be able to participate were asked to contact the researchers to further discuss the nature of the study and arrange for the interviews.

**Observational data.** Context analysis included several types of observational data. The researchers noted and recorded physical responses of participants such as tone of voice, body language, and facial expressions. They also examined items such as family pictures, lifestyle posters (developed by each participant), and religious articles. It was the hope of the researchers that examining these symbols would assist in understanding patterns and cultural themes (Creswell, 1998).

**Document data.** Each participant's *Five Wishes* document was also part of the context analysis. Historically, advance directives (AD) only addressed the letter of the law as set out by the PSDA (1990). However, *Five Wishes* is an innovative AD document that goes beyond EOL care questions to deal with personal, emotional, and spiritual issues to help people who are caught in the dilemma between using advanced healthcare technology, which can prolong death and suffering, and using palliative or hospice care which can help people die with dignity. Further, it can assist people in decision making about how they want to be treated when they are in a terminal situation by addressing the "whole" person and not just the physical being (Silva, 1997).

Specifically, the *Five Wishes* (Callahan, 2000; Callahan & Towey, 1997) is a living will with Advanced Directives (AD) that asks the participants to think about the following: (1) The person I want to make care decisions for me when I can't (2) The kind of medical treatment I want or don't want (3) How comfortable I want to be (4) How I want people to treat me (5) What I want my loved ones to know.

**The interviews.** Examination of the literature regarding EOL care decision-making led to the development of the eight semi-structured interview questions regarding psychological and emotional concerns. The questions were: After the *Five Wishes* seminar, (1) What did you think about? (2) How did it feel thinking about these thoughts? (3) What emotions did these thoughts stir up? (4) Did you talk to anyone about these thoughts? (5) If you talked to someone about this experience, to whom did you speak? (6) What did you talk about? (7) How did it feel to talk about this to this person? (8) What emotions did this experience stir up? (Canine, 1996; Hill & Shirley, 1992; Nuland, 1993; Widera-Wysoczanska, 1999).

**Data collection and processing.** The interviews, conducted in the homes or offices of the participants, lasted from 60 to 90 minutes. The researchers ensured that all interviews were consistent by using the same interview questions and allowing the participants as much time as they wished to respond to each question. Tentative ideas regarding categories and relationships began from listening to the tapes and reading and re-reading the verbatim transcriptions and field notes (Maxwell, 1996).

Verbatim transcriptions of the audiotapes provided a copy of the interview for the purpose of analysis (Maxwell, 1996; Silverman, 2000) and an "audit trail" that would leave evidence so others could "reconstruct the process by which the investigators reached their conclusion" (Morse 1994, p. 230). At the end of the study, the tapes were erased.

### **Data Analysis**

Content and context analyses were employed. Content analysis was the central technique used to identify the concepts, categories, and themes that the interviewees revealed in their responses. The transcripts were read word for word while listening to the audiotapes to assure accuracy of the transcripts of the interviews. Each response to the interview questions was reviewed on a line-by-line basis. For each response to a given question, units of information: words, phrases, and concepts were identified. After units of information were identified, they were coded into subcategories and categories to determine themes (Berg, 1995; Maxwell, 1996). The subcategories were grouped into broader or core categories. Thematic connections and recurring patterns began to emerge from sorting the data into subcategories and categories (Denzin & Lincoln, 1994).

The researchers used the ATLAS.ti software for additional textual analysis of transcripts, following the general steps suggested when working with ATLAS/ti:

1. Transcribed all of the interviews and then created an "idea container" which was meant to enclose all the data and findings, codes, memos, and observations under a single name, calling this a "Hermeneutic Unit" (HU).
2. Associated the collective data files
3. Read and selected text passages that were of further interest, assigning code words ("coding") or memos.
4. Compared data segments equally coded and assigned more files from the different interviews to the project.
5. Organized the documents, codes, and memos using "Families."
6. Built semantic networks from the codes created in the first phase of the research. These networks, together with codes and memos were cornerstones of the emerging theories and themes.
7. Analysis resulted in a close correspondence regarding categories and subcategories already discovered by the researchers. The software analysis helped to identify relevant ideas and quotations from the participants to support the appropriate categories (Creswell, 1998).

### **Steps to Ensure Trustworthiness**

Reliability or trustworthiness refers to dependability over time and across researchers and methods (Creswell, 1998; Lincoln & Guba, 1985; Miles & Huberman, 1994). Data were collected until saturation occurred with redundancy of categories and themes across the nine interviews. Additional participants could have been included in the study, but it did appear saturation had been reached, as no new data appeared to be forthcoming. This study employed triangulation to enhance trustworthiness. Software was used to confirm the researchers' coded categories and themes.

Peer review provided feedback regarding methodology, coding procedures, and reliability procedures and verified that the subcategories, core categories, and themes accurately reflected the meanings of the participants' experiences. Transcripts of two randomly-selected cases were read and analyzed by two EOL care experts who checked for undisclosed researcher bias, accuracy, and to confirm emerging findings (Johnson, 1997; Krefting, 1991; Lincoln & Guba, 1985).

The EOL experts were chosen because together they had over 45 years of EOL care counseling experience. One of the researchers who had worked many years with these two experts believed they would be qualified to verify the outcomes of the research. Both are active members of ethics committees in a number of community settings, i.e., hospitals, nursing homes, hospice, and community committees. Their perspectives were also invaluable because of their professional backgrounds. One is a physician/minister and chair of an ethics committee at a major city hospital, and the other is a deacon in the Catholic Church who works as a spiritual counselor for a major hospice organization. The researchers believe that having this mix of medical, ethical, and clerical knowledge is salient and important to the validation of the study.

Member checks were used to verify the researchers' interpretations. (Creswell, 1998; Merriam, 1988; Miles & Huberman, 1984). Credibility, paralleling internal validity, addressed the issue of assurances of congruence between participants' views and expressed values and the reconstruction and representation of their views and experiences. Member checking was conducted in the following manner:

Each participant was notified that they would be receiving a copy of the transcript, an audio tape, and a copy of notes consisting of observations and impressions of the researchers. Participants were asked to listen to the audiotape and to read the information submitted to them. They were notified that in one week they would be called and asked the following questions:

1. Upon reflection, did they believe the transcript was accurate?
2. Did the information clearly convey their message?
3. Were there any changes, additions, or deletions?
4. Did they have any suggestions to make their story more clear?

Multiple data sources were combined to create the themes in the Findings section. The interview transcripts were the primary source of data because of their length and coverage of the questions. Researcher field notes of observations provided data regarding the artifacts in the participants' homes or offices and some of their responses such as laughing and body language. The participants' *Five Wishes* documents--those that were completed--were added to a construct a detailed picture (Creswell, 1998).

## Findings

Some of the results of this study are in agreement with previous research in the areas of death and dying (Annas, 1989; Becker, 1973; Kübler-Ross, 1969; Kübler-Ross & Kessler, 2001) and theories about the psychological aspects of death and dying (Canine, 1996; Flaming, 2000; Nuland, 1993; Widera-Wysoczanska, 1999). However, several apparently new understandings emerged. For example, although participants were solicited from various fields, only healthcare workers volunteered for the study.



Furthermore, these participants indicated they did not speak about health issues to colleagues or patients in terms of themselves. These participants indicated that education, experience, and professional occupation had no major influence on their abilities to make EOL care decisions and to select health care surrogates. Participants' denial and delay were surprising, and provide areas for recommendations and further research.

It appears that the group setting facilitated completing the *Five Wishes* document for five of the nine participants. The concept of the paradox of burden versus treasure appeared to be a new finding. Often the caregivers viewed providing end of life care for a loved one as a blessing rather than a burden or obligation.

Participants stated the primary reason they attended EOL care seminars was to share information with colleagues and patients/clients. They also suggested that the seminar content and their lived experiences became important personally as well as professionally. All participants had volunteered to discuss their experiences of facing EOL care decision making; however, participants implied that discussions about facing death and making EOL care decisions with their family members were still difficult for them. At the conclusion of the data collection process, five participants completed the AD document while four did not.

Six themes emerged from the data. They could be described as a voyage leading to using the metaphor of a journey over troubled waters and completing the *Five Wishes* document became the Bridge Over Troubled Waters. No other metaphors came to mind. Perhaps being young women in the 70's, listening to the music of that era with meaningful lyrics, provided a familiar and true representation of the findings. The data fit the essence of the song's lyrics and told the story of what the *Five Wishes* could represent, namely, A Bridge Over Troubled Waters.

The journey leading to the Bridge Over Troubled Waters is primarily a literary metaphor in that it describes the "unpalatable" end of life decisions about dying in a way that allows the reader to hear the story and the meaning of the experience. But the language of metaphor is often a private language only understood by the erudite (Hesse, 1996). The metaphor we selected is understandable by most people, providing intersubjectivity. That commonly understood theoretical language moves it to a scientific metaphor, which is a deductive account of the empirical data gleaned from the inductive analysis. As a scientific metaphor, the Bridge Over Troubles Waters (BOTW) communicates the real meaning of the journey and the experiences of choosing or not choosing the BOTW. This metaphor eases the reader into seeing the meaning with both poetic and scientific clarity.

Hesse (1996) supports the notion that a literary metaphor has cognitive implications and provides another way to communicate the findings. In this research, the BOTW metaphor has an added power of adding "choice" as to whether people use the bridge, the *Five Wishes*, or gives up the choice to use the bridge to ease their mind. Dozer and Addison (1992) guided readers toward examining the concept of a "good death" by use of metaphor. This discussion of physicians' oscillating experience between moving toward and away from the good death was alluded to as a "nautical journey," sometimes stormy and sometimes peaceful (p. 542).

Dr. Efinger suggested the literary metaphor during the writing process. After being immersed in the data, the inspiration of using a metaphor came during reflections, that the *Five Wishes*, which included advanced directives and the selection of a health

care surrogate, were the basic structures of the bridge to "ease of mind." The metaphor of a BOTW seemed to convey the picture, meaning, and essence of having one's wishes respected as one approaches the last phase of the journey of life. As death approaches, "weariness" is experienced by the dying person and the loved ones as well. There are "tears...times get rough," and "evening falls so hard." Having one's wishes honored will "comfort you," and someone will "take your part when pain is all around." Death and the hope of heaven is "Your time has come to shine. All your dreams are on their way; see how they shine." The journey to the merging streams leads to the BOTW, but the findings reveal that the choice to use the bridge is not for many people, even when they know about it. Some participants appeared unable to merge their professional knowledge and their own personal lives.

As we sought to understand our metaphor more thoroughly, we found the "nautical journey" was touched on by Dozor and Addison (1992) in their grounded, interpretive study of 28 family practice residents and their practices with dying patients. This confirms our view that the BOTW is a both a literary and scientific metaphor, because it is commonly understood and describes the process and actual empirical data reported in this study. Other researchers (Ely, Vinz, Downing & Anzul, 1997, pp. 110-122; Munhall, 1994, pp. 176-183, 190-193) have used "the river" and "uncharted waters" as metaphors to reduce the abstract to the understandable and describe the fully human experience.

The dying journey begins on an ocean of denial fed by rivers of fear with many streams of conflicting feelings. The journey ultimately leads to waves of decisions, but even after riding these waves leading to their shore destination, the lone traveler experiences destination doubts. Travelers found that sharing the lifeboat with others was helpful, comforting and healing. Data revealed a paradox for dying persons and their family caregivers. Participants feared their own dying process would be a burden for their families. Yet, participants in the caregiver role for their loved ones often perceived the experience as an opportunity to provide loving care not a burden. Some felt the time special and a blessing to care for a dying loved one. It could be described as a buried, shared and treasured experience. The end of the dying journey is made more comfortable by the *Five Wishes* document, which is a Bridge Over Troubled Waters.

## Oceans of Denial

All participants expressed a vast, deep ocean of denial. It appeared that facing death, dying, and communicating effective EOL care decisions are quite difficult. It might also be inferred that the defense mechanism of denial protected participants or their family members from facing deaths or deaths of loved ones. Also, body language, voices, and demeanor often seemed to indicate discomfort experienced during interviews regarding the subject of death. Nervous laughing and fidgeting also appeared to indicate denial of death.

Signs of denial appeared to include certain behaviors: (a) use of euphemistic language such as "passed on" or "expired" rather than "died" (b) discussing sending family members to nursing homes or hospitals to die, and (c) avoiding conversation about death for fear of becoming upset or upsetting their own family members.

As an example, Bea demonstrated her uneasiness concerning death as she commented about her daughter's discomfort. Her daughter preferred not to read Bea's AD:

My daughter said, "Do we have to talk about this?" (The AD) [Laughing]  
And I said yes, I just want to . . . And she said, "All right, all right, all right, all right. I'll read it. I'll read it. I'll do whatever you say."

Bea and her daughter seemed to have difficulty discussing Bea's death. Bea's EOL care wishes were not resolved. Bea [laughing] described the conversation with her daughter:

I told my daughter to make sure that she knew what I wanted in case her father couldn't do it she would know. She said, "I'm not sure if I can do it."  
I said then let me know because if not I don't want you . . . But she knows very well, so I'm sure . . .

Bea [laughing] disclosed her husband's inability to "dig out of the trenches of denial" to complete his own document. He made no decisions for himself, leaving his EOL care decisions to Bea:

My husband . . . I had to fill out my husband's. So he said, "Well, whatever you put down in yours, put the same thing down on mine."  
Yeah, he read it and signed it. Because I asked him. I said you better tell me if this is what you want. Yeah, that's . . . Is that what you want me to put down? You put down whatever you want [laughing].

Lisa suggested death and dying are not complicated subjects in the US as she stated:

It's a part of life. And, the way you die . . . I mean, let's face it; living that's what's hard.

Marie discussed her son's use of humor to deny her death:

You know, whenever we talk about this, he goes . . . My son's very funny. He's very . . . I mean, he has a wonderful sense of humor, and he always talks about spilling my ashes . . . He always makes very light of it. . .

Some participants appeared to deny their emotions, and apparently had difficulty expressing emotions concerning thoughts of one's own or a loved one's death. Some declared, "they did not fear death." As an example, Ivan stated:

We weren't real emotional about it [laughing]. It was taken in stride is the way I would put it. . . . I know what you're after, but it's hard to do but you got my ideas about how I feel about . . . It doesn't matter what anyone says or decides, it's going to happen.

Bea explained perceived difficulties arising with her spouse if faced with discussing EOL issues:

No, but then this was not the kind of conversation that my husband indulges in . . ." [laughing]. And, when asked if her daughter could have a discussion with her or her husband she responded: "No because she knows her father" [Laughing].

Bea believed she did not experience any emotions when facing EOL decisions:

Emotionally, um, no you know, I don't know how to explain it. It's something you know that's going to happen, and I guess I'm practical enough to know, you know, that that's just the way it is and nothing is

going to change that. I just want it to be as easy on my family as possible....

When Lisa started to discuss her fears, she appeared to be blocking her emotions by saying that facing EOL care decisions was no reason to get emotional:

After a seminar, a little fear. And thank goodness you've heard about this information. And it removed some of the emotions from the decision. These are good decisions that you have to make.

When Carla discussed which emotions the experience of facing EOL care caused among family members, she replied:

Nothing. Just, you know, just very open communication. I mean, it wasn't . . . there was no sadness or anything involved in it. I think it was just a very intimate conversation, if you would, of sharing your feelings and concerns...

A common method participants initially used seemed to be transference; this surfaced as denial when questioned regarding thoughts of their own death. They did not respond in reference to personal experiences, but rather answered in reference to their professional selves, a relative, or another person. As an example, Marie said:

Well, I have been . . . A very good friend of mine had a ten-year long battle with cancer. So, I always thought of it (death) in terms of Patti and the end of her life, not the end of mine, of course, but the end of hers [laughing]. I also thought of it in terms of my own parents, well, particularly my mother because my father died very suddenly.

### **River of Fear**

In addition to indications of denial, participants discussed a number of feelings flowing from a river of fear--streams of confidence, confusion, frustration, and sadness. It appeared when fear of death was mentioned; it was often connected to fear of pain, suffering or loss. Some expressed fear of the actual dying process. Palliative care options for EOL care needed clarifying for others. Still others expressed that they feared being the one left behind; they feared the death of a loved one more than their own death. Elsie said it succinctly:

No, I was terrified of death. I was terrified of losing my husband more than I was terrified of dying. I was scared so much. I didn't want to talk about it. Once I had a friend that wanted me to do some volunteer work for hospice, work with AIDS. No, no, no, no, no, I don't do that. So, no. The experiences I went through made me very uncomfortable with death for myself, for anybody. . . [crying].

Jan talked about fears of losing mental and/or physical capabilities more than her fear of dying. She explained:

I think, at that point, it was fear . . . it was fear that I would not be able . . . more so when I was having my blood pressure problems and I was having lots of these flashes where I was . . . I went from here to here (she indicated two points on a spectrum-- point A being physically well and point B becoming ill very quickly --The thing that really, I think for me, in

this huge gap is not the dying, it's the disability that precedes it and how do you cope with varying levels of it.

Another participant admitted [laughing] she feared one of her children acting too swiftly in carrying out her EOL care decisions thereby using poor judgment. She indicated that she feared her son would select to end her life to prevent suffering:

Well, first of all, Juan doesn't, you know . . . I know that he agrees (with me) and he wouldn't . . . and he doesn't want it for himself, but I get very nervous of his decisions anyway [Laughing]. A little Kevorkian.

Despite feelings of fear, some participants implied they were confident that decisions they made or would make for a loved one would be honored even if an AD were not legally completed. However, some participants felt confusion regarding ADs and EOL care decisions. For example, Jan explained a conscientious person designated to make EOL care decisions could experience confusion when the patient is transferred from one facility to another. Bea, her mother's surrogate, talked about her confusion regarding lack of understanding the medical system enough to assist in carrying out her mother's wishes. That seemed surprising because Bea is an EOL instructor. The example suggests that professional roles and expertise are not necessarily carried over into the professional's personal, intimate relationships and decision-making abilities.

Some participants experienced frustration when interacting with family members regarding EOL care for themselves or a loved one. For example, Marie explained the frustration she experienced with her son's lack of cooperation while she was with her dying friend, Patti:

That he didn't want to hear it? I guess what I . . . I guess what I wanted to, I wanted to force him to hear it, but he wasn't ready to hear it. So, I didn't push it. How did I feel? I felt like he should be listening....What I'm saying to you is important because you may have to do this for me some day, and I want you to be ready.

Dale, an attorney, discussed her frustration with the EOL care laws in the US:

I think a frustration with seeing people languish and die a slow, agonizing, painful death that can be facilitated and ought to be facilitated in my opinion because we allow this courtesy to our pets... So, the emotion that that issue triggers is frustration that we can't do for our two-legged loved ones what we do for our four-legged loved ones.

Sadness was a common feeling described by the participants as they faced EOL care decisions for themselves and others. Elsie's tears and feelings of sadness emerged while discussing EOL decision making for her father and the medical community:

I have . . . oh, this is where I might get teary. I had to make a decision with my dad against the doctor's wishes to not start tube feeding when my father was dying.... I wanted him to go with dignity and just not, you know . . . so I decide on hospice.... And the doctor gave me a real hard time. It was very emotional.

Alicia appeared sad when visualizing her own premature death. She expressed empathy toward her caretakers if she became terminally ill with a long-term illness and for loved ones remaining after her death.

## Waves of Decisions

Themes that emerged were EOL care decisions such as those described in the *Five Wishes* seminar. It should be noted that the information needed to make effective EOL care decisions was offered at the seminar. However, the participants sometimes seemed to lack appropriate knowledge or insight about EOL care issues. This appears to have prevented some from making appropriate judgments, specifically decisions regarding the kinds of care they wished to receive.

In addition to feelings of fear, some participants felt confidence that the decisions they made or would make for a loved one would be honored even if an AD were not legally completed. However, some participants expressed confusion regarding ADs and EOL care decisions. Additionally, some of the participants who did make seemingly appropriate decisions failed to effectively communicate their wishes for care to the people responsible for honoring their wishes.

Another apparent decision-making problem was some participants' inability to identify proper health care surrogates or lifeguards. Probably some of the concepts and aspects of EOL care that were discussed during the *Five Wishes* seminar were misunderstood; therefore, it seems appropriate to infer that information from the seminar alone was not adequate for effective EOL care decision making. This lack of knowledge about making decisions together with denial and fear of death appeared to prevent some participants from effectively understanding, making, and sharing EOL care decisions. Perhaps their emotions prevented them from effectively hearing and processing the information.

Most participants talked about what decisions needed to be made, but not how to make them. The decision-making theme emerged--procrastination or floating around EOL care decisions. This apparently occurred after the participants had transferred thoughts about decision making back towards them. Marie made this point as she stated: "Yes, [pause] I think that I thought about my own EOL decisions...I just kind of like, well it's what I'll do tomorrow, but not to take action today about it." Lisa's response was very similar to Marie's. Neither of them completed the ADs:

Yes. Typically, you leave the seminar feeling like you need to go take care of your own paperwork . . . but, always, after hearing that, you leave with the good intentions and...then other things get in the way and you just forget about doing it.

## Destination Doubts/Assurances

Self-doubt and assurance were themes that emerged in the process of attempting to make or carry out EOL care decisions for loved ones. In the process of decision-making, most participants agreed they had made the right decisions for their loved ones and were assured they wanted the same for themselves. Most participants agreed no artificial means of life-prolonging therapies and required pain management.

Bea's statement was a good example of how self-doubt moved toward assurance:

You know, the longer I was involved in this work, the clearer I could see how different it was going to be with her as opposed to my father who did not have a Living Will...it was difficult because there were five siblings

and everybody had a different opinion...With my mother, I knew pretty much what I would do...she made a comment in passing to me that she didn't want machines.

Bea also discussed how the process of helping her family make EOL care decision during her mother's death reinforced her own EOL care wishes. Another participant, Elsie, talked about how difficult it was for her to carry out her father's EOL care decisions while being challenged and not supported by the medical community. She explained that she believed this experience led first to self-doubt but eventually that experience reinforced her own decision-making. This experience emphasized for Elsie the importance of being educated about what might happen during the dying process in order to be better able to make decisions and face death.

### **Sharing the Lifeboat**

All the participants were willing to share their feelings with the researchers and others. They not only discussed with whom they shared their decisions but what emotions were stirred by sharing these experiences. Many of them disclosed their emotions or some unresolved issues with family members during this sharing process. The themes that were discovered through the sharing were: control, loss, shared values and experiences, and life's meanings.

For example, Elsie implied she had a new sense of control over her own destiny as she described her feelings while sharing her experiences of facing EOL care decision making with her husband. Another participant, Lisa, shared the *Five Wishes* document with her sister:

Also my sister...I was sharing the *Five Wishes* with her, and she liked that document better than the one that the service had provided, so I sent her a copy.

Sometimes losses remind people of other losses and how they become cumulative. For example, Elsie shared issues of loss with her sister regarding their parents' deaths; she discussed shared values and then shared information with the researchers about a ritual she and her sister used that helped them both cope with their parent's death. It appeared to be a resource for coping with their losses. When asked if she shared her EOL care decisions with anyone else Elsie said:

Oh, my doctor, because see my doctor is my friend." Elsie revealed that she, her husband and her physician have shared values.

Dale had shared values with her physician: "Yes, yes. My general physician, my GP, is aware. She has a copy of my living will. My HMO also has a copy." And Bea shared her beliefs with her friend who is not her surrogate, saying, "As friends, we promised we'd unplug each other if the family didn't do it" [Laughing].

Elsie talked about how she would soon be sharing information with a friend, and how she often shared statements about life's meaning. She had witnessed her parents' deaths that were filled with suffering, and facing EOL decisions have apparently helped Elsie focus on what is truly of value in her life.

### **Paradox of Burden Verses Treasure**

Data revealed a paradox for dying persons and family caregivers. Participants feared their dying process would be a burden for their families. Yet, participants in the caregiver role for loved ones often perceived the experience as an opportunity to provide loving care. Two participants expressed feelings of gratitude that they could "be there" for their dying loved ones. They viewed the care-giving role as an important part of their life, not a burden. For example, one participant said:

I felt . . . I really felt privileged. I felt privileged to be with Patti at the end of her life period....I felt like it was a privilege to be able to go through that with her. I don't know that she knew that, but my feeling was that it really is an honor for someone to love you -- to love you enough to bring you into this whole process...

Another participant revealed she helped her father die at home as he had requested:

I went home and we made arrangements and took dad home with hospice care... he really wanted to go home. But, you know, he was home for eight days and it was really good.

### **Discussion**

All the participants were self-selected health care professionals. Most worked primarily with the elderly or in EOL care issues. It might be inferred that such a group would be more comfortable discussing and sharing information about EOL than non-health care professionals. However, in the workplace, the participants indicated they did not speak about health issues to their colleagues or patients in terms of themselves or their loved ones. Neither did they address or explore EOL care in regard to their emotional, psychological, and spiritual selves. These professionals may have thought that this topic would be easier. They, along with the researchers, apparently discovered when people confront their own experiences of facing EOL care; it is not easy to look into the mirror of mortality.

Issues that emerged included procrastination, self doubt, confidence that decisions would be honored without formal ADs, confusion, frustration regarding their loved one's inability to handle participants' EOL care decisions and experiences, fear of pain and suffering, and the inability to discuss their emotions about their EOL care. Participants appeared to use transference to face EOL decisions. They later allowed themselves to share insights about facing EOL decisions including psychological, emotional, and spiritual aspects of their own experience. They told long and often elaborate stories of sharing and giving birth to their goals and values with the assistance of others. These experiences were uplifting, reflective, liberating and offered peace of mind to some of the participants.

Although the themes of denial and fear did emerge, all of the participants did take some type of action after attending an EOL care seminar. Nearly all of the participants shared the information that they gleaned from the EOL care seminar with colleagues and family members. Other actions taken by some or all of the participants after attending the



EOL seminar included: (a) completing the document, (b) encouraging others to fill out ADs, (c) lecturing to students about EOL issues, (d) talking to their parents' physicians as advocates for their parents, (e) helping others fill out the document, and (f) assisting loved ones during their deaths.

The results of this study are in agreement with previous research in the areas of death and dying (Annas, 1989; Becker, 1973; Kübler-Ross, 1969; Kübler-Ross & Kessler, 2001) and theories about the psychological aspects of death and dying (Canine, 1996; Flaming, 2000; Nuland, 1993; Widera-Wysoczanska, 1999). For example, Canine (1996) reported that society's lack of intimacy with death has led to widespread denial of death. This denial is demonstrated by simply ignoring death, using euphemistic language to hide or couch the painful reality, or by adopting prudish notions of death and seeing it as offensive and unfit for conversation. Furthermore, Nuland (1993) described how people are not psychologically able to cope with thoughts of their own deaths and view death as a looming terror. They, therefore, seek ways to deny the power of death and the hold it has over human thought. These descriptions are similar to the experiences of the participants in this study.

Several apparently new understandings emerged as well. For example, although participants were solicited from various fields, only healthcare workers volunteered for the study. Furthermore, these participants indicated they did not speak about health issues to colleagues or patients in terms of themselves or their loved ones. In other words, it appeared that the participants' indications were such that they did not employ a therapeutic use of the self. It seems entirely possible if the study had required more participants, people from other fields would have volunteered. It also appears that the group setting facilitated completing the *Five Wishes* document for five of the nine participants. This setting and the discussions may have allowed those who were initially hesitant to complete the document. The concept of the paradox of burden versus treasure appeared to be a new finding. Participants feared their own dying process would be a burden for their families; however, participants in the caregiver role often perceived the experience as a treasured opportunity, being able to "be there" for their dying loved ones.

Although this study examined the perceptions of only nine participants, some conclusions may be drawn from this study: (1) EOL care discussions and decision-making are difficult and emotional experiences for some healthcare professionals. They seem to be more comfortable with the subject when it is discussed in relation to their patients instead of themselves or their loved ones. (2) Denial of death and dying is prevalent. The participants, to prevent them from thinking about their own mortality, appeared to use the defense mechanism of denial. This denial seemed to be manifested through body language and responses. (3) People continued to think about the information they learned from EOL care and AD seminars after the seminars were over. Apparently, the thoughts that continued to resurface are related to their need to make EOL care decisions for themselves and a need to help their loved ones to make EOL care decisions. People did share the information they learned at EOL care seminars with at least one other person, and five participants completed an AD. (4) There is uncertainty as to what EOL care decisions should be made and written into an AD document. One might deduce that it is difficult for a healthy person to imagine the EOL care that might be needed in the future even though the best time to complete an AD is when one is healthy and not under the stress of illness. (5) Finding an appropriate health care surrogate seems

to be difficult. The Hemlock Society provides a Surrogate Volunteer Program in many areas of the country. (6) Confusion about what happens after EOL care decisions are made and a formal AD is completed apparently can occur even after attending a comprehensive seminar that addresses ADs and EOL care. (7) People seem to want to die with dignity, without pain. Apparently, they want to stay independent and not be a burden to others. People suggested they want closure in their lives, and they want to do this with their loved ones.

There are several strengths as well as limitations to this study. Certainly, this study is not generalizable in the usual quantitative sense; however, concepts discussed by the interviewees may have transferability or fittingness to certain other settings (Lincoln & Guba, 1985). The somewhat homogeneous nature of the participants may be considered a limitation, as well as the small number. However, the participants' willingness and openness to discuss an apparently difficult topic may be considered strength.

Given these limitations and strengths, the following are recommendations developed from the findings of this study:

1. In the US, death is considered a failure and unnatural and is hidden from everyday reality; therefore, a reframing of death would appear to be beneficial--death once again would become a natural occurrence of life. Children have little or no opportunity to witness death in the US. They need to have opportunities to experience death as a natural part of life, so when they become adults, they will expect and not deny death. If every classroom had a goldfish or another animal with a natural, short life expectancy, and teachers were instructed on bereavement care, this could be a start in reframing the attitudes of American children about death and dying. Attitudes change with education. Education produces knowledge. Knowledge changes behavior.
2. Participants appeared to have a very difficult time focusing on their own deaths and began sharing only when talking about others' experiences. Therefore, it seems it would be beneficial to offer EOL care seminars for couples and families. Participants, as couples, or in small groups would question others about their EOL care preferences. Each participant could fill out the AD with the other(s). This might help to clarify wishes and, at the same time, "divorce" the participant from the document. This might have the effect of increasing the number of people who actually complete EOL care documents.
3. Participants seemed confused about who should be designated as healthcare surrogate. Shared values are imperative for a surrogate to effectively carry out or make decisions for another. People may want to consider completing a values history form before facing EOL care decisions. A values history form may be more beneficial if it is completed with the person who is being considered to be healthcare surrogate.
4. Physicians are usually not paid to have EOL care discussions with their patients; perhaps they should receive incentives to have these discussions, and EOL care advocates might develop public policy legislation that would serve this purpose.
5. A comprehensive educational program for both consumers and health care professionals about technology, judgment, and EOL care choices developed on a web site is recommended. People could learn about EOL care and have the opportunity to take active steps toward making EOL decisions and completing ADs. California mandated that physicians attend classes on ways to comfort and relieve the pain of the dying as part of the requirements for license renewal (AARP, January, 2002, pp.7-10).

6. The nursing and medical professions need to provide more comprehensive EOL care education in their textbooks and curricula, including palliative and hospice care. Articles such as "Educating for Mission, Meaning and Compassion" by Rachel Naomi Remen, M.D., (1996) found in the book *Kitchen Table Wisdom* may be a starting point for this education. Until there is a paradigm shift in medical education, even though people may request these types of EOL care, there will remain a dearth of practitioners who understand the holistic needs of their patients.

7. Death-care professionals should consciously make an investment of emotions as well as time and skill. This requires regularly confronting their own mortality. When bonds are formed between caregiver and client, deaths may provoke a grief response that must be acknowledged and processed. It may be prudent for death-care professionals to address factors that place them at risk for profound sadness, stress and burnout. Canine's model illustrating management of burnout identifies five major arenas of life that death care professionals should attend to in order to minimize potential for burnout. This model is a holistic approach that helps manage burnout by taking into account spiritual, mental, emotional, physical, and social requirements for a harmonious, well-balanced life.

8. Media education might provide society with knowledge and supportive recourses such as organizations and web sites that could facilitate EOL care decisions and AD information. People might also be able to record their EOL wishes and ADs on a secure website so that in the event that people are unable to communicate in a healthcare emergency, their wishes are accessible to the health system's providers through the Internet.

After examination of the findings of this study, there are several recommendations for future research:

1. A study might be conducted with participants who are not health care professionals but who have had the experience of attending EOL care seminars. Experiences and viewpoints could then be compared regarding the two studies. This would provide a more comprehensive understanding of the experiences of facing EOL care decision-making.
2. Future research might include those from groups not equally represented in the current study. This might include more men and a more representative sample of a multi-cultural community.
3. Participants of the current study found it easier to "transfer" their thoughts about EOL care decision-making and found it more comfortable expressing their emotions by sharing their experiences with others. A new study could investigate the use of these tactics as successful strategies for helping people face EOL care decision-making.
4. Internet resources that may assist nurses, families and educators to help a dying patient or to help in planning their own living wills are listed following the references.

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### Web Resources

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*The Hemlock Society USA*. (2002). Retrieved January 4, 2002, from <http://www.hemlock.org>

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*The Last Acts Campaign*. (2002). Retrieved January 4, 2002, from <http://www.lastacts.org>

*National Family Caregivers Association*. (2002). Retrieved January 4, 2002, from <http://www.nfcacares.org/>

*National Hospice and Palliative Care Organization*. (2002). Retrieved January 4, 2002, from <http://www.palliativecarenursing.net>

*Partnership for Caring: America's Voices for the Dying*. (2002). Retrieved January 4, 2002, from <http://www.partnershipforcaring.org>

### Appendix

Description of Participants

Participant	Age	Sex	Cultural Identification	Religious Affiliation	Occupation	Completed Advanced Directives
Bea	63	F	Cuban-American	Catholic	EOL Care Instructor	Yes
Alicia	37	F	Cuban-American	Catholic	Consultant, oversees nursing home placements	Yes
Elsie	55	F	Caucasian	Orthodox	V.P. Sales and	Yes

			American	Jewish	Marketing for a large nursing home in Miami-Dade County	
Marie	61	F	Caucasian American	Unitarian	Data Processor, Consultant to RNJ for an EOL Care Project	No
Ivan	74	M	Caucasian American	Jewish Non-practicing Agnostic	Volunteer Ombudsman, oversees State of Florida nursing homes	Yes
Dale	48	F	Caucasian American	Spiritual with no affiliation	Lawyer, expert in guardianship and EOL care issues	Yes
Jan	55	F	Caucasian American	Christian	Researcher on aging issues at a major Florida university	No
Lisa	38	F	Caucasian American	Christian	Healthcare worker	No
Carla	51	F	Cuban-American	Catholic	Professor of Nursing	No

### Author Note

As a nurse for 30 years, *Kate Callahan* has served as Physician Assistant and for many years as a nurse in intensive care units. Her business experiences include sales representative and product manager for American Hospital Supply Corporation. Kate has the unusual experience of working in both the public and private sectors of the health care arena. Presently Kate is a partner with The Huntington Consulting Group where she manages projects geared toward assisting non-profit and community organizations to

respond to the rapidly changing health care arena. Included in this work are four organizations that help people in Florida learn about health care and aging in America--The Pepper Institute on Aging and Public Policy, The Commission on Aging with Dignity, Nova Southeastern University (NSU), and Barry University. Her work with The Commission on Aging with Dignity, includes her co-authoring the national FIVE WISHES advance directive document. She is presently assisting with the writing of a curriculum about EOL care for the Medical School at NSU where she is also serving as assistant professor teaching third year medical students Geriatrics and EOL care.

She holds many positions that benefit her community. Presently Kate serves on the Boards of the Public Health Trust of Jackson Memorial Hospital of Miami-Dade County, The Community Relations Board of Miami-Dade County, The Camillus House, Miami-Dade County's Alliance for Aging (AAA), and The Community Voices Oversight Board. Last year Kate was the recipient of the Women's Business Journal's Women of Power Award, and she was featured as one of The 100 Women Leaders to watch in Florida in the "Miami Metro" Magazine.

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