

The Relationship Between Parents' End-of-Life Planning and Adult Children's
End-of-Life Planning

A THESIS
SUBMITTED TO THE FACULTY OF
UNIVERSITY OF MINNESOTA
BY

Angela Lynn Woosley

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
MASTER OF ARTS

Sharon M. Danes, PhD

May 2014

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Acknowledgements

I would like to thank my adviser, Dr. Sharon Danes, for her patience and support, and for challenging me to produce my best work. Her uncanny ability to meet me in my learning process and simultaneously push it further made this work possible. I would also like to thank my committee members, Dr. Marlene Stum and Dr. Rob Warren, for their expertise, guidance, attention to detail, and flexibility. I am also deeply grateful to the faculty and staff in the Department of Family Social Science for their mentorship and assistance, especially Dr. Paul Rosenblatt and Cathy Schulz.

This work would not have been possible without the unflagging support of the faculty and staff in the Program of Mortuary Science, including Molly Diethelm, Jody LaCourt, Michael Mathews, Rev. Gloria Roach-Thomas, and especially our Program Director, Dr. Michael LuBrant. I also wish to acknowledge the support of my Family Social Science cohort; the value of our emotional bonds cannot be overstated. My brother, sister-in-law, and niece were also a constant source of support and inspiration.

Finally, I wish to acknowledge my two greatest sources of strength: my mother, Carol Woosley, and my partner, Bill Connell, both of whom always believed in me and supported me unconditionally at every turn.

This research uses data from the Wisconsin Longitudinal Study (WLS) of the University of Wisconsin-Madison. Since 1991, the WLS has been supported principally by the National Institute on Aging (AG-9775, AG-21079, AG-033285, and AG-041868), with additional support from the Vilas Estate Trust, the National Science Foundation, the Spencer Foundation, and the Graduate School of the University of Wisconsin-Madison.

Since 1992, data have been collected by the University of Wisconsin Survey Center. A public use file of data from the Wisconsin Longitudinal Study is available from the Wisconsin Longitudinal Study, University of Wisconsin-Madison, 1180 Observatory Drive, Madison, Wisconsin 53706 and at <http://www.ssc.wisc.edu/wlsresearch/data/>. The opinions expressed herein are those of the authors.

Dedication

This thesis is dedicated to the memory of my father, Jeffrey Lynn Woosley (1942-2011), who taught me, by example, the value of end-of-life planning.

Abstract

The increased incidence of chronic illness provides time for older adults to express their wishes for medical treatment at the end of their lives and their estate settlement after their deaths, a process called end-of-life (EOL) planning, but significant gaps in rates of EOL planning completion remain. Using public use data from the 2003 wave of the Wisconsin Longitudinal Study (WLS), this study explores bereaved adult children's ($n = 1,199$) EOL planning in the context of a deceased parent's EOL planning. This study uses Rettig's family decision-making theory foundation and the dependent variable incorporates both medical and financial EOL planning measures. Hierarchical regression results indicate that household net worth, parent's completion of a living will before death, and adult children's avoidance of death ideation explain the greatest proportion of variance in adult children's EOL planning, among variables included in the study. Practitioners can use this information to close accessibility gaps due to net worth differences, advocate for a more unified approach to EOL planning, and shift the focus of discussions of death from the death itself to a life well lived.

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Introduction

Advances in medicine have increased humans' life expectancy (Centers for Disease Control, 2003), but increased life expectancy comes with the increased incidence of chronic illness. Whereas the grandparents of today's older adults were most likely to die from infectious diseases such as influenza or pneumonia, their parents are more likely to die after a long-term, chronic illness such as heart disease and long-term respiratory disease (Carr, 2012a; Murphy, Xu, & Kochanek, 2013; Olshansky & Ault, 1986). This shift toward death from chronic illness, as opposed to acute infectious disease, provides individuals with more time to formulate and express their wishes for both their medical treatment at the end of their lives and the settlement of their estates after their deaths. Expressing one's wishes informally regarding medical treatment at the end of life and estate settlement after death and extending those wishes into formal legal documents may be referred to as end-of-life (EOL) planning.

EOL planning documents relating to medical treatment (medical EOL planning) include a living will and durable power of attorney for health care (DPAHC). A living will is a formal document that describes an individual's medical treatment preferences if he or she is unable to communicate his or her wishes (Miles, Koepp, & Weber, 1996). A DPAHC is a formal document that assigns a person to make medical treatment decisions on the individual's behalf if he or she is unable to communicate his or her wishes (Miles et al., 1996). EOL planning documents relating to estate settlement (financial EOL planning) include a will and revocable trust. A will is a formal document that describes how to distribute a person's assets after death (Ritchie, 1963). A revocable trust is an

estate-planning instrument that facilitates the transfer of assets after death, which Bloom (2008) refers to as “the functional equivalent of a will” (p. 768). Such “will substitutes” may be used increasingly in lieu of a will (Bloom, 2008; Foster, 2006; Langbein, 1984).

Medical EOL planning has been increasingly accessible to patients since the Patient Self-Determination Act (PSDA) was passed by Congress in 1990. The PSDA requires that all patients in hospitals, nursing homes, and care centers that receive federal funding are given the opportunity to complete a living will or DPAHC (McCloskey, 1991). Despite this accessibility, there remain significant gaps in Americans’ EOL planning completion rates. Studies suggest that between 15% and 59% of older adults have completed medical EOL planning (Bravo, Dubois, & Pâquet, 2003; Carr & Khodyakov, 2007a; Collins, Parks, & Winter, 2006; Hopp, 2000; Kahana, Dan, Kahana, & Kercher, 2004; Kelly, Masters, & DeViney, 2013; Miles et al., 1996; Silveira, Kim, & Langa, 2010; U.S. Dept. of Health and Human Services, 2008). A slightly higher percentage of older adults (56 to 70%) may have an executed will (AARP, 2000; Humphrey, Mills, Morrell, Douglas, & Woodward, 2010; James, 2009). Rates of EOL planning completion appear to increase with age (Humphrey et al., 2010; U.S. Dept. of Health and Human Services, 2008). Greater understanding of these and other factors positively associated with EOL planning may help guide public policy to inform and encourage more individuals to complete EOL planning.

Factors that are associated with greater levels of EOL planning, such as gender, health status, and net worth, have been explored on the individual level (Carr & Khodyakov, 2007a; Goetting & Martin, 2001; Ha & Pai, 2012; Kahana et al., 2004;

Moorman, 2011a; Su, 2008), but this research provides an incomplete picture of the context in which these decisions are made. An important contextual factor that may impact decision-making is the family (Rettig, 1993). Therefore, more research is needed at the intersection of the individual and family. While some studies acknowledge the family as a contextual factor in EOL planning, the majority of studies with a family focus explore the dynamics of spouses, but not the decision context of parents and their children (Carr & Khodyakov, 2007b; Chaya, 2011; Moorman, 2011a; Moorman & Carr, 2008; Moorman, Hauser, & Carr, 2009). It is apparent from research focusing on spouses that relationships are important to consider when studying the extent of EOL planning in which a person engages.

Exploring the parent-child relationship in particular is both relevant and timely. Due to the increased prevalence of chronic illness, aging adult children are more frequently caring for their ailing parents. In the process, they are confronted with many factors that appear to be associated with greater levels of EOL planning, such as experiencing the loss of a loved one (Carr, 2011; Carr & Khodyakov, 2007a, 2007b; Lambert et al., 2005; Leichtentritt & Rettig, 1999) or potentially experiencing a decline in their own health concurrent with their advancing age (Carr, 2012b, 2012c; Carr & Khodyakov, 2007b; Collins et al., 2006; Ha & Pai, 2012; Hopp, 2000; Lambert et al., 2005). Research has explored other dimensions of parents and their children across the life course (Mancini & Blieszner, 1989; Rossi & Rossi, 1990), such as in the context of the caregiving relationship (Barnes, Given, & Given, 1992; Ott, Sanders, & Kelber, 2007). However, the parent-child relationship and its association with EOL planning is a

unique component that has not been explored.

This study contributes to the literature in three ways. First, this study acknowledges the importance of the parent-child relationship by exploring bereaved adult children's EOL planning in the context of a deceased parent's EOL planning. Recent research suggests that those who have experienced the death of a close friend or family member who had engaged in EOL planning are more likely to engage in EOL planning themselves (Carr, 2012b). This finding reveals that there is an opportunity to focus research on deceased parents and their bereaved adult children and to explore the association between a parent's EOL planning and his or her adult child's EOL planning.

Second, this study explores factors affecting EOL planning through the theoretical lens of family decision-making theory (Rettig, 1993). Many studies exploring EOL planning are largely atheoretical (Carr, 2011, 2012b, 2012c; Carr & Khodyakov, 2007a; Chaya, 2011; Ha & Pai, 2012; Lambert et al., 2005; Moorman, 2011a, 2011b; Moorman & Carr, 2008) or only implicitly theoretical (Carr & Khodyakov, 2007b; Moorman et al., 2009; Sharp, Carr, & MacDonald, 2012; Su, 2008). However, firm theoretical grounding provides a structure that guides researchers and assists with conceptual clarity and precision. The present study addresses gaps in EOL planning research by approaching the topic both in the parent-child context and through the lens of family decision-making theory. This study examines the environmental factors, perceptions, and a parent's actions before death in relation to his or her adult child's actions to determine which factors are associated with greater levels of EOL planning.

Third, this study explores the association between environmental factors,

perceptions, and a parent's actions before death with a broader spectrum of EOL planning activities than those included in previous research. Su (2008) suggests that medical and financial types of EOL planning are often completed in tandem, yet very few studies include both medical and financial EOL planning (Carr, 2012d; Kelly et al., 2013; Su, 2008). This study measures the impact of a parent's medical EOL planning on both medical and financial EOL planning by his or her adult child, which is the first step toward further integration of these two complementary measures of EOL planning.

Conceptual Framework and Literature Review

Conceptual Framework: Family Decision Making Theory

Rettig's (1993) family decision-making theory (FDMT) uses a human ecology theory foundation (Bubolz & Sontag, 1993) to explore the environments, processes, and outcomes of families' decision-making. Using FDMT as the foundation of the present study provides a structure in which to organize and categorize variables conceptually, allowing theory to guide analysis. This study builds on the previous application of FDMT constructs to examine family level financing long-term care decision-making (Stum, 2005; Schaber & Stum, 2007). The theoretical constructs of FDMT are presented below, followed by their direct application to the present study. Because FDMT may be applied to a wide variety of family decisions, the word "family" is used here to describe the family as a decision-making unit. The word "individual" as used in the theory describes the adult child in the present study.

Figure 1 provides a visual representation of the constructs underpinning FDMT as they relate to the present study. At its foundation, FDMT explores concepts related to

problem-solving in families, which is the process of overcoming obstacles to reach a goal (Rettig, 1993, p. 191). Fundamentally, problem-solving processes must be seen as interdependent with the family environment, because the “family environment is an important influence on individual decisions, and the family unit, in turn, is affected by individual choices” (Rettig, 1993, p. 190).

Problem-solving activities include *decision-making* and *decision implementation*. *Decision-making* is the process of comparing alternative solutions to each other and choosing the best alternative to solve the problem at hand. *Decision implementation* is the process of actively carrying out the selected decision in order to overcome the obstacle. Decision-making and decision implementation are carried out by *decision makers*.

The decision-making process comprises the interdependent phases of *perceiving* and *deciding*. *Perceiving* is the phase in which individuals and families recognize that a change or decision is needed and *deciding* is the phase in which a proposed decision is settled upon. Individuals and families may move through these phases sequentially or via a series of feedback loops, meaning that those involved may move back and forth between these phases multiple times before arriving at a decision (Rettig, 1993, p. 193). Once the decision has been made, it is ultimately implemented with actions.

Theoretical Application of Family Decision Making Theory in the Present Study

Adult child’s environment. Figure 2 provides a visual representation of the variables used in the present study in the context of the theoretical constructs described above. A fundamental assumption of FDMT is that “most problems are identified at the interface between person and family or between family and environmental systems”

(Rettig, 1993, p. 191). Thus, it is vital that this model highlight the interface between family and environment. Human ecology theory, the foundation of Rettig's work, categorizes the environment into three interrelated components: the natural physical-biological, the human built, and the social-cultural (Bubolz & Sontag, 1993). The social-cultural environment includes other people, cultural constructs like norms and values, and social and economic institutions (Bubolz & Sontag, 1993, p. 432-433). While the environmental variables in the present study may be intertwined with more than one of these environmental components, they all may be broadly categorized as part of the social-cultural environment.

The first two elements of the environment are the adult child's gender and health status. Gender, a socially constructed concept, is often conflated with biological sex in health science research (Eliason, 2014), reducing its description to a dichotomous variable in EOL planning literature and thus, in the present study, as well. Within this dichotomy, studies suggest that women engage in greater levels of medical EOL planning than men (Bravo et al., 2003; Carr & Khodyakov, 2007a; Ha & Pai, 2012; Su, 2008). However, among studies that focus on completion of financial instruments alone, gender differences are not as clearly identifiable (AARP, 2000; Sussman, Cates, & Smith, 1970; Goetting & Martin, 2001). Health is affected by genetic markers as well as human behaviors (McGinnis, Williams-Russo, & Knickman, 2002). Studies imply that declining health is associated with greater levels of EOL planning (Carr, 2012c; Carr & Khodyakov, 2007b; Collins et al., 2006; Engler-Bowles & Kart, 1983; Ha & Pai, 2012; Hopp, 2000; Kelly et al., 2013; Lambert et al., 2005). The variables of gender and health

status share some qualities of the natural and social-cultural environments and studies suggest that they are both associated with the EOL planning process.

The next elements of the environment are the adult child's marital status and the number of children the adult child has. These two elements represent states of being that are the result of human behavior and, in turn, influence human behavior. Several studies provide some indication that those who are married are more likely to engage in EOL planning (Carr, 2012b; Carr & Khodyakov, 2007a; Clignet, 1992; Goetting & Martin, 2001; Ha & Pai, 2012; Humphrey et al., 2010; Su, 2008), while others suggest a negative association between marital status and EOL planning (Hopp, 2000; Kahana et al., 2004). Several studies suggest that there is a positive association between the number of children in a household and EOL planning (Carr, 2012b; Carr & Khodyakov, 2007a; Humphrey et al., 2010; Su, 2008), while there is some indication that there may be a negative association between the two (Hopp, 2000). Overall, these studies suggest that marital status and number of children play a role in EOL planning, and that there is more evidence of a positive association between these two factors and EOL planning than of a negative association.

The final elements of the environment are the adult child's education level, household income, and household net worth. These three elements represent the adult child's attainment of social-cultural goals within social and economic institutions, such as the education system and market economy. Studies suggest that there is a positive association between education level and EOL planning (AARP, 2000; Carr, 2012b, 2012c; Carr & Khodyakov, 2007b; Goetting & Martin, 2001; Ha & Pai, 2012; Hopp,

2000; Humphrey et al., 2010; Lee, 2000; Rosenfeld, 1992; Rossi & Rossi, 1990; Su, 2008) and a positive association between household income and EOL planning (AARP, 2000; Carr, 2012b, 2012c; Ha & Pai, 2012; Judge & Hrdy, 1992; Kelly et al., 2013; O'Connor, 1996; Rossi & Rossi, 1990; Simon, Fellows, & Rau, 1982; Su, 2008). Research also suggests that household net worth has a positive association with EOL planning (Carr, 2012d; Goetting & Martin, 2001; James, 2009; Lee, 2000; Rosenfeld, 1992; Rossi & Rossi, 1990; Simon et al., 1982; Su, 2008). Owning a home has a significant impact on net worth (Gottschalck, 2008; Kochhar, Taylor, & Fry, 2011), and studies also suggest that homeowners are more likely to engage in EOL planning (Carr, 2012b, 2012c). Overall, these studies provide some indication that education level, household income, and household net worth, as markers of social and economic success, are associated with the EOL planning process.

Decision-making process. The decision-making process comprises the interdependent phases of perceiving and deciding, and it also consists of the affective valuing and cognitive evaluations made by decision makers (Rettig, 1993, p. 195). These affective valuing and cognitive evaluations are dependent upon the decision makers' *perceiving styles*, which involve "how individuals sense and feel in regard to the decision situation" (Rettig, 1993, p. 198). The adult child's perceptions of the situation are therefore dependent on his or her personal values, psychological orientations, and past experiences (Rettig, 1993, p. 198).

First, personal values may influence the adult child's perception of the situation. Personal values, from human ecology theory, are "human conceptions of what is good,

right, and worthwhile” (Bubolz & Sontag, 1993, p. 435). One indicator of a person’s value orientation is his or her religiosity and spirituality; religion and spirituality often serve as the foundation of a person’s value orientation. Some research suggests that religiosity and spirituality have a negative association with EOL planning, with more strongly held religious convictions associated with lower levels of EOL planning (Allen et al., 2003; Balboni et al., 2007; Carr, 2011; Phelps et al., 2009). Other studies provide some indication that religiosity and spirituality are both important factors among those who engage in EOL planning (Carr & Khodyakov, 2007b; Kelly et al., 2013; Lambert et al., 2005; Leichtentritt & Rettig, 1999; Sharp et al., 2012; Steinhauser et al., 2000). Research suggests that religiosity and spirituality, as markers of personal values, are associated with adult children’s EOL planning.

Second, psychological orientations may influence the adult child’s perception of the situation. Psychological orientations are defined as the cognitive and motivational orientations that guide behavior (Rettig, 1993, p. 198). One of the greatest motivators, and a core value underlying human ecology theory, is that of survival (Bubolz & Sontag, 1993, p. 426). A person’s cognitive and motivational orientation may therefore be influenced by ideas of survival. With survival as a core value, researchers can consider what happens when a person thinks about death (death ideation). Some people may actively avoid thoughts of death in the interest of survival, while others may be more comfortable with ideas of mortality. Psychological orientations, by this logic, include death ideation avoidance and death ideation acceptance, since an adult child’s thoughts and beliefs about death are grounded cognitively and motivationally, and are rooted in

attitudes about survival. Greater death ideation avoidance appears to be associated with lower levels of EOL planning (Carr, 2012c; Carr & Khodyakov, 2007a, 2007b; Moorman, 2011b; Roth, 1987; Zimmerman, 2007), while greater death ideation acceptance may be associated with greater levels of EOL planning (Carr, 2011; Lambert et al., 2005). Research suggests that death ideation avoidance and death ideation acceptance, as markers of one's psychological orientation, are associated with adult children's EOL planning.

Finally, past experiences may influence the adult child's perception of the situation. Because the interface between person and family is critical in the perception of the decision to be made, past experiences adult children have had with their parents may affect how adult children perceive the situation. The association between a parent's death and children's perceptions of the death has not been fully explored in the context of EOL planning. However, some studies suggest that greater levels of EOL planning are associated with those who have experienced the recent death of a relative, friend, or significant other (Carr, 2011; Carr & Khodyakov, 2007a, 2007b; Lambert et al., 2005). Other research qualitatively suggests that previous experiences with loved ones' deaths are connected with EOL planning (Leichtentritt & Rettig, 1999). In the present study, all participants in the sample have experienced the loss of a parent.

Because all participants in the present study have experienced the loss of a parent, the present study explores adult children's perceptions of their experience with their parent's death. The adult children's perceptions of this experience inform their understanding of the experience of dying. Aspects of this experience that may affect the

adult children's perceptions include their parent's ability to decide in the last week of life and pain level in the last week of life. Research by Carr (2012b) suggests that those whose loved one experienced a greater ability to decide are more likely to engage in EOL planning. Further, Carr's (2012b) research suggests that those whose loved one experienced higher levels of pain are less likely to engage in EOL planning, whereas other studies provide some indication that they are more likely to engage in EOL planning (Carr & Khodyakov, 2007a, 2007b). These studies suggest that a parent's ability to decide and a parent's pain level before death may play a role in EOL planning, and that there is more evidence of a positive association between a parent's pain level and EOL planning than of a negative association.

The present study has no direct measure of the deciding phase, though its inclusion in the analytical model is necessary to demonstrate a clear link between the perceiving phase of the decision-making process and the decision implementation process. The deciding phase, as described theoretically, may involve numerous feedback loops and takes place ultimately and essentially in the mind. Because it occurs intangibly, it is difficult, if not impossible, to determine exactly when or how the adult child has decided to engage in EOL planning. Measurement of the deciding phase would require multiple waves of longitudinal data or retrospective data, which are beyond the scope of the present study. The present study can, however, measure the products of this phase by observation of the decision implementation process. Therefore, if an individual has engaged in EOL planning, it serves as confirmation of the decision implementation process and is evidence of completion of the deciding phase.

Decision implementation process. Decision implementation in the present study may be viewed from two different perspectives. First, the parent's decision implementation before death may have a connection with the adult child's decisions, reaffirming Rettig's assumption that "the family unit, in turn, is affected by individual choices" (1993, p. 190). As previously stated, there is some indication that among those who experienced the death of a close friend or relative, individuals were more likely to engage in EOL planning if their deceased close friend or relative had completed a living will or a DPAHC (Carr, 2012b). This finding is crucial to the foundation of the present study, as it indicates that the context of relationships may help researchers understand factors that affect EOL planning. The present study focuses on parents and their children, rather than the broader category of close friends and relatives. Parent's decision implementation is evidenced by the adult child's awareness of a parent's completion of a living will or a DPAHC.

Second, the adult child's decision implementation may be measured in the context of the environment, his or her perceptions, and his or her parent's decision implementation. In the present study, decision implementation is measured by the number of EOL planning activities in which the adult child has knowingly engaged. While the specific definition of EOL planning varies across studies, it often involves some aspects of informal and formal planning related to either medical aspects or financial aspects at the end of life and after death. Some studies include only formal medical EOL planning, such as the completion of living will or DPAHC (Carr, 2011; Carr, 2012b; Carr & Khodyakov, 2007b; Chaya, 2011; Lambert et al., 2005), and several

more include informal EOL planning in the form of discussions about medical treatment plans (Allen et al., 2003; Bravo et al., 2003; Carr, 2012c; Carr & Khodyakov, 2007a; Ha & Pai, 2012; Hopp, 2000; Kahana et al., 2004; Moorman, 2011a; Moorman & Carr, 2008; Moorman et al., 2009). Several studies explore only formal financial EOL planning, such as a will or revocable trust (Humphrey et al., 2010; James, 2009; Judge & Hrdy, 1992; Rosenfeld, 1992). However, very few include both medical and financial measures of EOL planning (Carr, 2012d; Kelly et al., 2013; Su, 2008).

The inclusion of formal financial EOL planning in the measure of EOL planning is important, and has been neglected in the study of EOL planning. Research by Su (2008) suggests that medical EOL planning is highly correlated with financial EOL planning and that these plans tend to be completed in tandem. Several other studies also point toward the inclusion of financial and medical EOL planning. First, several studies suggest that EOL medical decisions often have economic implications at the end of life and after death (Chambers, Diamond, Perkel, & Lasch, 1994; Fan & Zick, 2004). Second, Steinhauer et al. (2000) found that there is indication that those with advanced chronic illness and recently bereaved family members both agree that “naming a decision maker” (implying a DPAHC) and “having financial affairs in order” (implying a will or revocable trust) are very important tasks to complete before death. Finally, Parnaby (2011) connects medical and financial EOL planning with the common thread of risk. Since both health and financial planning rely on estimates of an unwritten future, Parnaby argues, they should be studied together. Thus, as Su (2008) notes, “EOL health planning can be viewed as a legitimate component of estate planning” (p. 655).

Due to the complementary nature of medical and financial EOL planning, both types should be included in measures of EOL planning to provide the richest possible picture of the adult child's decision implementation. Therefore, the present study measures EOL planning with both informal and formal measures, as well as both medical and financial measures of EOL planning. The present study measures EOL planning with the adult child's awareness of informal plans regarding EOL planning and medical treatment toward the end of one's life, formal medical plans in the form of a completed living will and completed DPAHC, and formal financial plans in the form of a will and revocable trust.

It should be noted that because FDMT stresses the importance of decision makers' perceptions of their world, the present study aims to measure the adult child's *perceptions* and the associations with their EOL planning. If the adult child is unsure of his or her parent's EOL planning actions, this lack of cognizance informs his or her perceptions, perhaps more so than "objective" reality. Similarly, if the adult child is unsure of his or her own EOL planning actions, that perception informs his or her decision-making process.

Advantages of the Analytical Model of the Present Study

The framework of the present study highlights the context of parents and their children in two ways, while previous studies focused on individuals or spouses. First, this study incorporates adult children's perceptions of aspects of their parent's death experience. Second, this study incorporates adult children's awareness of their parent's EOL planning. Adult children's perceptions of their parent's death experience and their

parent's EOL planning may be connected with the extent of their own EOL planning.

Further, this framework highlights the advantages of a theoretically integrated approach to the study of EOL planning. Variables of interest, rather than being broadly characterized as merely demographic, may be seen as part of a complex set of influences that shape the decision-making process of the adult child. Influences may be categorized as environmental or perceptual, or the result of the parent's own decision-making. This theoretical integration guides statistical analysis in a meaningful and logical manner.

Finally, this framework integrates medical and financial EOL planning in its measurement of the adult child's EOL planning. EOL planning, rather than being restrictively defined with formal medical EOL planning measures, is more inclusively defined with the addition of informal medical and formal financial EOL planning measures. Because these measures may be completed in tandem (Su, 2008), this inclusion allows the researcher to capture a richer picture of the extent of EOL planning in which the adult child has engaged.

Research Questions

Based on the analytical model described above and presented in Figure 2, the following research questions and hypotheses were developed.

RQ1. How does the adult child's environment explain the extent of EOL planning among adult children whose parent has died?

H1.1. Gender (with female participants coded as zero) and health self-rating will have a negative relationship with the degree of the adult child's EOL planning.

H1.2. Marital status, number of children, education, household income and

household net worth will have a positive relationship with the degree of the adult child's EOL planning.

H1.3. The adult child's environment variables will significantly explain the variance in the adult child's EOL planning.

RQ2. How do the adult child's decision-making perceptions explain the extent of EOL planning among adult children whose parent has died?

H2.1. Religiosity and spirituality, death ideation acceptance, and parent's pain level in the last week of life will have a positive relationship with the degree of the adult child's EOL planning.

H2.2. Death ideation avoidance and parent's ability to make decisions in the last week of life will have a negative relationship with the degree of the adult child's EOL planning.

H2.3. The adult child's decision-making perception variables will explain greater variance in the adult child's EOL planning than that was explained by the adult child's environment variables alone.

RQ3. How do parent's EOL planning actions before death explain the extent of their adult children's EOL planning actions?

H3.1. Parent's completion of a living will and parent's completion of a DPAHC will have a positive relationship with the degree of the adult child's EOL planning.

H3.2. Parents' EOL planning action variables will explain greater variance in the adult child's EOL planning than that was explained by the adult child's environment and decision making perception variables alone.

Method

Participants

Data source. Participants were drawn from the 2003 wave of the public use data set of the Wisconsin Longitudinal Study (WLS) (1957-2005) (Hauser & Sewell, 2003). This study has followed a cohort of men and women, along with their spouses and selected siblings, who graduated from Wisconsin high schools in 1957. It is representative of White, non-Hispanic Americans with at least a high school education. Data were gathered using a combination of telephone and mail surveys. See Table 1 for a summary of environment variables of participants used in this analysis. Age of participants was not included in the final analysis, as it was essentially constant, because participants were drawn from the same high school cohort. However, age distribution is included in Table 1 for descriptive purposes. Further information about the WLS may be found at the WLS website (Wisconsin Longitudinal Study, 2006).

Sampling procedure. In the 2003 wave of the public use data set, a total of 7,265 participants were surveyed. In an effort to reduce survey burden, 70% ($n = 5,106$) of these participants were randomly selected as respondents for a series of questions relating to their EOL planning. Of the participants who were randomly selected as respondents for a series of questions relating to their EOL planning ($n = 5,106$), 3.3% ($n = 167$) had invalid responses to one or more of the questions. Of those with invalid responses, 135 participants were labeled as having a “Partial Interview.” The remaining responses were labeled either “Inappropriate” or “Refused.” Only those participants with valid responses to all six EOL planning questions ($n = 4,939$) were kept in the sample. Finally, of the

remaining participants with valid responses to the EOL planning questions, 24% ($n = 1,199$) were also asked a series of questions about a parent's death. Participants were asked this series of questions if one or more of their parents died less than ten years, but more than six months, prior to data collection, without a concurrent spouse loss. Participants with a concurrent spouse loss in this time frame were asked a series of questions about their spouse's death instead of questions about their parent's death, and thus were not included in this analysis. See Figure 3 for a visual representation of the n used for this analysis.

Sample description. More than half of the participants included in the present study's sample were 64 years old at the time of data collection (57.1%). Participants included slightly more women than men (52.7%), who were generally self-described as in good-to-excellent health (91.2%), currently married (83.7%), with most participants having two or three children (54.8%). Because the WLS follows members of a high school graduating class, all participants have a high school education, and almost half of the participants completed at least one year of college (48.2%). The participants' median income at the time of data collection in 2003 was \$49,128, above the 2003 national average of \$43,318 (DeNavas-Walt, Proctor, & Mills, 2004). Over 50% of the participants have completed the individual measures of EOL planning, with the exception of the completion of a revocable trust, which only 29.9% have completed.

Dependent Variable

Adult child's end-of-life planning. For this study, the adult child's EOL planning is defined as informal and formal plans regarding medical treatment toward the

end of one's life, as well as formal financial plans related to one's estate settlement. A six-item index was developed from the dichotomous EOL questions related in Table 2 to measure the extent of end-of-life planning in which participants had engaged. ($\alpha = .81$) For participants who responded "I don't know" to an individual EOL planning question, these responses were recoded to "No," as this indicated a lack of cognizant EOL planning. Factor analysis, as reported in Table 3, confirmed that the six EOL planning questions constitute one factor. Responses to the six items were counted to produce an index score on a scale of zero to six. An index score of zero indicates the participant answered "No" to all six EOL planning questions, while an index score of six indicates the participant answered "Yes" to all six EOL planning questions. Higher adult child's EOL index scores indicate greater amounts of EOL planning on the part of the participant. This index has a mean score of 3.63, and 46% of respondents have a score of five or six on the index, indicating higher levels of EOL planning among the participants. Table 4 summarizes the adult child's EOL planning index scores and distribution.

Independent Variables

Adult child's environment. Gender was dummy coded with women serving as the reference group (coded as zero). Marital status was assessed with the dichotomous question "Are you currently married?" Number of children, household income and household net worth were recoded into groups for the purpose of descriptive analysis as reported in Table 1, though the continuous variables were used in the regression analysis. Health self-rating and education level were recoded into groups, as indicated in Table 1.

Decision making perception variables.

Religiosity and spirituality. A five-item index was developed to measure participants' identification as religious or spiritual. ($\alpha = .92$) Factor analysis, as reported in Table 6, confirmed these five items comprise one factor. The items were scored on a five-point scale (1 = *not at all* to 5 = *extremely*). Items are, "How religious are you?;" "How spiritual are you?;" "How important is religion in your life?;" "How important is spirituality in your life?;" and "When you have important decisions to make in your life, how much do you rely on your religious or spiritual beliefs?" Responses to the five items were summed and averaged to produce an index score on a scale of one to five. Higher religiosity and spirituality index scores indicate more identification as religious or spiritual. The index has a mean score of 3.46, a median score of 3.52, a mode of 4.00, and a standard deviation of 0.83, indicating religiosity and spirituality generally above the midpoint of this index.

Death ideation. Participants were asked a series of questions relating to their attitudes toward death. Factor analysis, as reported in Table 5, revealed these items measure two factors instead of one. Thus, two indexes were prepared from this series of questions.

Death ideation avoidance. A two-item index was developed to measure participants' active avoidance of thoughts of death. ($\alpha = .72$) These questions relate to participants' conscious actions to avoid or deny mortality. The items were scored on a six-point scale (1 = *disagree strongly* to 6 = *agree strongly*). Items are, "I avoid thinking about death altogether" and "Whenever the thought of death enters my mind, I try to push it away." Responses to the two items were summed and averaged to produce an index

score on a scale of one to six. Higher death avoidance index scores indicate greater amounts of death ideation avoidance or mortality denial. The index has a mean score of 3.09, a median score of 3.02, a mode of 4.00, and a standard deviation of 1.16, indicating death ideation avoidance around the midpoint of this index.

Death ideation acceptance. A three-item index was developed to measure respondents' passive acceptance of death as a life event. ($\alpha = .72$) These questions relate to participants' beliefs that thoughts of death are not something fearful, and therefore, may not be worth the energy to actively avoid, as indicated by the previous index. The items were scored on a six-point scale (1 = *disagree strongly* to 6 = *agree strongly*). Items are, "Death is simply a part of life;" "I would neither fear death nor welcome it;" and "Death should be viewed as a natural, undeniable, and unavoidable event." Responses to the three items were summed and averaged to produce an index score on a scale of one to six. Higher death ideation acceptance index scores indicate greater amounts of death ideation acceptance. The index has a mean score of 5.16, a median score of 5.22, a mode of 6.00, and a standard deviation of 0.76, indicating generally higher levels of death ideation acceptance.

Past experience with parent's death. Participants were asked two questions about a parent's death if one or more of their parents died less than ten years, but more than six months, prior to data collection, without a concurrent spouse loss. Participants with a concurrent spouse loss in this time frame were asked a series of questions about their spouse's death instead of questions about their parent's death, and thus were not included in this analysis. If participants experienced the death of both parents in this time frame,

they were asked this series of questions about a randomly selected parent's death. The question "During the last week of your deceased parent's life, how much pain did s/he experience?" was scored on a four-point scale (0 = *no pain* to 3 = *severe pain*). This variable has a mean score of 1.10, a median score of 1.00, a mode of 0.00, and a standard deviation of 1.03, indicating lower levels of pain. The question "Was your deceased parent able to make decisions during the last week of his/her life?" was dichotomous. For participants who responded "I don't know" to this question, these responses were recoded to "No," as this indicated a lack of cognizance about the deceased parent's death experience. Distribution of this question is summarized in Table 7.

Parent EOL planning action variables. Participants were asked two questions about a parent's EOL planning if one or more of their parents died between six months and ten years prior to data collection, without a concurrent spouse loss. Participants with a concurrent spouse loss in this time frame were asked a series of questions about their spouse's death instead of questions about their parent's death, and thus were not included in this analysis. If participants experienced the death of both parents in this time frame, they were asked this series of questions about a randomly selected parent's death. The question "Did your deceased parent have a signed Living Will, giving directions for the kind of medical treatment s/he wanted?" was dichotomous. The question "Did your deceased parent have a signed Durable Power of Attorney for Health Care, naming someone who could make decisions about his/her medical treatment?" was dichotomous. For participants who responded "I don't know" to these two questions, these responses were recoded to "No," as this indicated a lack of cognizance about the deceased parent's

EOL planning activities. Distributions of these two questions are summarized in Table 7.

Data Analysis Plan

Steps in data analysis. Initially, variables were selected for analysis and frequencies and descriptive statistics for the selected variables were examined. Variables measured on Likert scales were recoded as necessary so that the direction of the numeric values corresponded to the direction of the conceptual values for each question. The continuous variables of number of children, household income, and household net worth were recoded into groups that reflected the overall distribution of the variables for the purpose of descriptive analysis. In the hierarchical regression, the ungrouped, continuous variables were used.

Next, potential index items were examined with factor analysis, correlations, and reliability. Factor analysis for the adult child's EOL planning variables, as related in Table 3, confirmed the adult child's EOL planning index items represented a single construct. Factor analysis for the death ideation variables, as related in Table 5, confirmed death ideation variables represented two constructs, and thus two indexes were built. Factor analysis for the religiosity and spirituality variables, as related in Table 6, confirmed the religiosity and spirituality index items represented a single construct. Inter-item correlations for all indexes were confirmed to be greater than 0.30 at a minimum and Cronbach's α values were confirmed to be greater than 0.70 but generally less than 0.90, to ensure the index items measured the same construct but were not redundant. The only exception in the present study was the religiosity and spirituality index, which has a Cronbach's α of 0.92. This was considered acceptable for the purposes of the present

study, due to the fact that both religiosity and spirituality were being combined conceptually under one index construct.

Missing data analysis. After those with invalid responses to the EOL planning questions were removed from the sample, as described in the sampling procedure section above, missing values for the remaining variables ($n = 1,199$) were addressed. Most variables had zero cases missing. All items on the death ideation indexes and religiosity and spirituality indexes had 138 cases (11.5%) listed as “System Missing.” Missing value analysis (MVA) was conducted in SPSS 22.0.0 to impute values for missing cases using maximum likelihood estimation, an accepted best practice (Acock, 2005; Garson, 2012). MVA imputes values for all continuous variables by estimating the most likely response for a participant based on observed values and parameter estimates (SPSS, 2007). All categorical variables measured on a scale were treated as continuous variables in order to qualify for MVA imputation. Little’s Chi-Square test result was not significant, indicating the data were missing at random.

Hierarchical regression. This statistical analysis procedure required compliance with several assumptions, which this sample met. First, it was verified that error was uncorrelated with predictors and that the variables did not have multicollinearity by examining correlation and crosstabulation tables. No variables included in the final analysis had a correlation higher than 0.50 with any other variable in the analysis. Next, a linear relationship between the dependent variable and each independent variable was verified. Linearity was assessed with curve-fit analysis and by reviewing scatterplot matrices. Finally, the assumption that the residuals were normal was verified with the

regression output. No assumptions were violated, and thus the analysis could proceed.

A priori power analysis was also conducted. With 14 predictor variables, a desired power of .80, and a significance threshold of $\alpha = .05$, a sample size of $n = 135$ would be needed in order to detect a medium effect size ($f^2 = .15$) with a multiple regression analysis (Cohen, 1992). Given the present study's sample size ($n = 1,199$), there was sufficient power for the hierarchical regression to detect significant results.

The hierarchical regression proceeded in the order suggested by the analytical model presented in Figure 2. The adult child environment variables of gender, health self-rating, marital status, number of children, education, household income, and household net worth were entered into the first step of the hierarchical regression model. In the second step of the regression model, the decision making perception variables of religiosity and spirituality, death ideation avoidance, death ideation acceptance, parent's pain level, and parent's ability to decide were entered. Finally, the parent's EOL planning action variables of parent's completion of a living will and DPAHC were entered into the model. Performing such an analysis, it is possible to evaluate the contribution of variables in each progressive step to the explanation of variance of the adult child's EOL planning over and above the previously entered variables. The statistical analysis was performed using IBM SPSS Statistics software version 22.0.0.

Results

RQ1. Household Environment and EOL Planning

The first research question was: How does the adult child's environment explain the extent of EOL planning among adult children whose parent has died? The hypotheses

were: Gender (with female participants coded as zero) and health self-rating will have a negative relationship with the degree of the adult child's EOL planning (H1.1). Marital status, number of children, education, household income and household net worth will have a positive relationship with the degree of the adult child's EOL planning (H1.2). The adult child's environment variables will significantly explain the variance in the adult child's EOL planning (H1.3).

The joint effects of the adult child's environment variables (gender, health self-rating, marital status, number of children, education, household income, and household net worth) in the first step of the regression model (see Table 8) accounted for a statistically significant amount of variance in the adult child's EOL planning, $F(7, 1191) = 12.01, p < .001$, adjusted $R^2 = .06$, with six percent of the variance in the adult child's EOL planning accounted for by these variables, supporting H1.3. The adjusted R^2 indicates a small-to-medium effect size ($f^2 = .06$) (Cohen, 1992). Results indicate that women engaged in greater amounts of EOL planning than men, supporting H1.1. Further, those who were currently married, those with higher education, and those with higher household net worth engaged in greater amounts of EOL planning than those who were not currently married, and those with lower education and lower household net worth, supporting H1.2. Household net worth explained the greatest proportion of variance in the adult child's EOL planning, followed by marital status, and gender explained the third greatest proportion of variance in the adult child's EOL planning. However, the individual effect of health self-rating was not significant, as hypothesized in H1.1, and the individual effects of number of children and household income were not significant,

as hypothesized in H1.2.

RQ2. Decision Making Perception Variables and EOL Planning

The second research question was: How do the adult child's decision-making perceptions explain the extent of EOL planning among adult children whose parent has died? The hypotheses were: Religiosity and spirituality, death ideation acceptance, and parent's pain level in the last week of life will have a positive relationship with the degree of the adult child's EOL planning (H2.1). Death ideation avoidance and parent's ability to make decisions in the last week of life will have a negative relationship with the degree of the adult child's EOL planning (H2.2). The adult child's decision-making perception variables will explain greater variance in the adult child's EOL planning than that was explained by the adult child's environment variables alone (H2.3).

In the second step of the regression model, the combined effects of the adult child's environment and decision making perception variables continued to account for a statistically significant amount of variance in the adult child's EOL planning, $F(12, 1186) = 9.44, p < .001$, adjusted $R^2 = .08$, with eight percent of the variance in the adult child's EOL planning accounted for by these variables. The adjusted R^2 indicates a small-to-medium effect size ($f^2 = .09$) (Cohen, 1992). The results from the second step of the analysis indicated that these decision making perception variables jointly accounted for an additional two percent of variance in the adult child's EOL planning, over and above the variance accounted for by the adult child's environment variables alone, $F(12, 1186) = 5.52, p < .001, \Delta R^2 = .02$, supporting H2.3.

Results indicated that adult children with higher levels of death ideation

acceptance engaged in greater amounts of EOL planning than those with lower levels of death ideation acceptance, supporting H2.1. Further, results indicated that those with lower levels of death ideation avoidance and those whose parents were unable to make decisions in their last week of life engaged in greater amounts of EOL planning than those with higher levels of death ideation avoidance and those whose parents were able to make decisions in their last week of life, supporting H2.2. Of the variables added in this step of the model, death ideation avoidance explained the greatest amount of variance in the adult child's EOL planning, followed by death ideation acceptance and parent's ability to decide. Overall, household net worth continued to explain the greatest proportion of variance in the adult child's EOL planning, followed by death ideation avoidance, and marital status explained the third greatest proportion of variance in the adult child's EOL planning. However, the individual effects of religiosity and spirituality and parent's pain were not significant, as hypothesized in H2.1. The individual effects of gender, marital status, education, and household net worth remained statistically significant when the decision making perception variables were added to the model.

RQ3. Parents' EOL Planning Actions and Children's EOL Planning Actions

The third research question was: How do parents' EOL planning actions before death explain the extent of their adult children's EOL planning actions? The hypotheses were: Parent's completion of a living will and parent's completion of a DPAHC will have a positive relationship with the degree of the adult child's EOL planning (H3.1). Parents' EOL planning actions will explain greater variance in the adult child's EOL planning than that was explained by the adult child's environment and decision making perception

variables alone (H3.2).

In the final step of the regression model, the combined effects of the adult child's environment, the decision making perception variables, and the parent's EOL planning actions continued to account for a statistically significant amount of variance in the adult child's EOL planning, $F(14, 1184) = 10.01, p < .001, R^2 = .10$, with 10 percent of the variance in the adult child's EOL planning accounted for by these variables. The adjusted R^2 indicates a small-to-medium effect size ($f^2 = .11$) (Cohen, 1992). The results from the final step of the analysis indicated that parent's completion of a living will and DPAHC jointly account for an additional two percent of variance in the adult child's EOL planning, over and above the variance accounted for by the adult child's environment and decision making perception variables alone, $F(14, 1184) = 12.32, p < .001, \Delta R^2 = .02$, supporting H3.2.

Results indicated that adult children whose parents completed a living will before death engaged in greater amounts of EOL planning than those whose parents did not complete a living will before death, supporting H3.1. However, the individual effect of a parent's completion of a DPAHC before death was not significant, as hypothesized in H3.1. Further, the individual effects of gender, household net worth, death ideation avoidance, death ideation acceptance, education, marital status, and parent's ability to decide remained statistically significant when the parent's EOL planning actions variables were added to the model. Overall, the β weights and significance values presented in Table 8 indicate that household net worth explained the greatest proportion of variance in the adult child's EOL planning, followed by parent's completion of a

living will, death ideation avoidance, marital status, death ideation acceptance, education, gender, and parent's ability to decide.

Discussion

Overview of Findings

The present study explored factors that were associated with EOL planning, both at the adult child's level and at the interface between parent and child. The variables used in this study described the adult child's environment, decision making perceptions, and parent's EOL planning actions which affect the adult child's engagement in the decision-making process, and were selected in an effort to identify which of these factors might have the greatest association with adult children's engagement in EOL planning. Some variables, such as gender and household net worth, were indicators of the adult child's environment in which the decision-making process took place. Other variables, such as death ideation avoidance and parent's pain level in the last week of life, comprised the decision making perceptions which the adult child used in the decision-making process. Finally, still other variables, such as the completion of a living will by a parent before his or her death, were a part of the parent's EOL planning actions.

Results from the hierarchical regression indicated that a parent's living will was positively associated with his or her child's EOL planning, controlling for gender, household net worth, education, and marital status. However, results from the analysis failed to identify a similar association between a parent's DPAHC and his or her adult child's EOL planning, controlling for these same factors. Overall, results suggest associations between the adult child's EOL planning and his or her environment,

perceptions, and parent's planning actions.

Three factors emerged as the strongest predictors of EOL planning: household net worth, a parent's completion of a living will, and death ideation avoidance. First, because previous studies suggested that greater economic resources are associated with greater levels of EOL planning (AARP, 2000; Carr, 2012b, 2012c; Ha & Pai, 2012; Judge & Hrdy, 1992; Kelly et al., 2013; O'Connor, 1996; Rossi & Rossi, 1990; Simon et al., 1982; Su, 2008), it was anticipated that household net worth would be positively associated with EOL planning.

Second, previous research suggested that the family context is connected with EOL planning (Carr, 2012b; Carr & Khodyakov, 2007b; Chaya, 2011; Moorman, 2011a; Moorman & Carr, 2008; Moorman et al., 2009). Based on the present study's theoretical foundation and acknowledging that EOL planning decisions take place at the interface of the individual and the family, it was anticipated that parent's completion of a living will would be positively associated with the adult child's EOL planning.

Finally, because previous research suggested that higher levels of death ideation avoidance are associated with lower levels of EOL planning (Carr, 2012c; Carr & Khodyakov, 2007a, 2007b; Moorman, 2011b; Roth, 1987; Zimmerman, 2007), it was anticipated that death ideation avoidance would be negatively associated with EOL planning. Other significant findings of this study, such as women engaging in more EOL planning, positive relationships between death ideation acceptance, marital status, and education and EOL planning, and a negative association between parent's ability to decide and EOL planning, were also consistent with past research findings (AARP, 2000;

Bravo et al., 2003; Carr, 2012b; Carr & Khodyakov, 2007a; Clignet, 1992; Goetting & Martin, 2001; Ha & Pai, 2012; Hopp, 2000; Humphrey et al., 2010; Lee, 2000; Rosenfeld, 1992; Rossi & Rossi, 1990; Su, 2008).

Theoretical Foundation of Findings

Results from this study point to links among the adult child's environment, the decision making process, and the decision implementation process. With EOL planning as the tangible evidence of the deciding phase, the adult child's environment, decision making perceptions, and parent's EOL planning actions account for a significant amount of variance in the adult child's own EOL planning. As part of the adult child's environment, household net worth, marital status, education, and gender are associated with EOL planning. As for the decision making perceptions, the adult child's death ideation avoidance and death ideation acceptance, as well as parent's ability to decide in the last week of life, account for a significant amount of variance in the adult child's EOL planning. Finally, parent's EOL planning actions account for a significant amount of variance in the adult child's EOL planning.

The analytical model used in the present study provided utility and clarity. Organizing variables into the conceptual categories of the adult child's environment, perceptions, and the parent's EOL planning actions provided a clear guide for analysis. Future research could use the foundation of this model and extend it by including alternate variables or multiple family members, such as both parents, family of origin, and a spouse or partner. As stated previously, future research could include multiple waves of longitudinal data in an attempt to quantify the deciding phase that was elusive

in the present study. This analytical model and family decision making theory provide flexible guidelines for future use.

Practical Implications of the Present Study

While the present study offered some methodological and theoretical utility, it also has practical utility. First, because household net worth accounted for the greatest amount of variance in the adult child's EOL planning, this may point toward other ways, beyond EOL planning, that those with higher household net worth differed from those with lower household net worth. If those with lower household net worth have less access to professionals who can advocate for the completion of EOL planning, such as financial planners, lawyers, or informed medical professionals, this indicates a gap that can be addressed by practitioners. Lee (2000) noted that those who have a financial advisor are more likely to have a will, highlighting the association between practitioners' work and EOL planning actions.

Second, practitioners could advocate for a more unified approach to EOL planning. As previously noted, there is some indication that medical and financial EOL planning may be completed in tandem (Su, 2008). However, if those with lower household net worth have less access to professionals, they may be doubly disadvantaged if they are less likely to complete both medical and financial EOL planning (Carr, 2012d). Some EOL planning documents, especially medical documents, may be completed without legal assistance, while others, such as a trust, require legal assistance. Determining which documents can or should be completed without professional assistance, and how to access trustworthy documents and planning tools may be difficult,

especially due to differences in state laws. If practitioners across disciplines presented a more unified approach to EOL planning, perhaps more people would engage in EOL planning. For example, financial advisers, who are accustomed to discussing financial EOL planning with clients, may also discuss medical EOL planning. Similarly, hospital social workers, who are accustomed to discussing medical EOL planning with patients and their families, could discuss financial EOL planning, as well. This integrated approach is one alternative to large-scale initiatives that may not have successfully increased the completion rates of EOL planning (Teno et al., 1997). For example, the integrated model has been explored at least on a cursory level; one cancer institute incorporated “medical-legal partnerships” between hospital social workers and a legal referral service to increase access to and completion rates of both medical and financial EOL planning, as part of a comprehensive palliative care program (Rodabaugh, Hammond, Myszka, & Sandel, 2010).

Third, because death ideation avoidance accounted for a significant amount of variance in the adult child’s EOL planning, this may indicate that a relationship exists between a person’s psychological orientations and his or her EOL planning actions. Practitioners could advocate for greater understanding and acceptance of human mortality. In spite of Americans being branded in popular culture as a “death denying” and “death defying” society (Fulton, 1964), the veracity of this label is debatable (Kellehear, 1984). Regardless of whether American society actively avoids discussions of death, it is proposed that those with higher levels of death ideation avoidance might benefit from a continued public discussion of EOL planning (Field & Cassel, 1997;

Zimmerman, 2007). As Zimmerman (2007) notes, “There is in contemporary Western society a public interest in the control of the dying process . . . and this control may be achieved by bringing death into discourse, by increased talk about death and dying” (p. 310).

The discourse itself may change as funeral rituals change. A shift in consumer attitudes has sparked a rise in so-called “celebrations of life,” in lieu of traditional, somber funeral rituals. Rather than gathering in a dimly-lit funeral parlor and listening to tearful eulogies and organ music, bereaved families today are increasingly opting for highly personalized, joyful celebrations that shift focus away from the death experienced and onto the life lived (Dillman, 2011; Joachim, 2012; Stansbury, 2013; Thomas, 2012). Perhaps death ideation avoidance may be ameliorated by shifting the focus from the death to the experience of a life well lived. If discussions of death can be reframed in this way, people may engage in greater levels of EOL planning.

Limitations and Recommendations for Future Research

While the present study has theoretical and methodological strengths, limitations and areas for future research should be examined as well. Some limitations presented by this study were the result of the data source. First, the results of any study utilizing data from the public use data set of the WLS are only representative of White, non-Hispanic Americans with at least a high school education and thus may only be generalizable to this population. Second, data used in this study were collected in 2003, more than 10 years prior to this analysis. Results from this study may no longer be currently generalizable to its participants or to the greater population of which it is generally

representative. Third, questions asked of participants were not written by the author of the present study and may have been asked with different intentions for their usage in research. Primary researchers' intentions for, as well as participants' interpretations of, these questions may have affected the results of the present study. For example, while living wills and wills were at least somewhat defined for participants, revocable trusts were not. This might have accounted for the lower response rate to this measure, relative to the other individual measures of EOL planning included in the analysis. Fourth, this study was unable to isolate parent's financial EOL planning, and as a result, this study was unable to compare parent's financial and medical EOL planning with the adult child's financial and medical EOL planning. Finally, while results using the public use data set are representative of White, non-Hispanic Americans with at least a high school education, participants included in the sample of the present study all experienced the death of a parent. This may make them different from the general population, narrowing the scope of the present study's generalizability.

Further limitations presented by this study were the result of the variables selected for analysis. While the results of the regression analysis were statistically significant, they only accounted for ten percent of the total variance in the adult child's EOL planning. Some links between the decision-making process and the decision implementation process were confirmed by the present study; however, other links between these processes were not supported. It is possible that other important variables may have been overlooked. Or, rather than overlooking important variables, some of these links may not have been supported due to the potential presence of a mediating or moderating

relationship among the variables explored in this study.

Many more variables, especially those relating to the quality of the parent-child relationship, could be included in future research to present a clearer picture of the factors associated with greater EOL planning among adult children. More than simply focusing on the decision context of parents and children, future research could focus more specifically on dimensions of the parent-child relationship or dimensions of parents' deaths. For example, the quality of the parent-child relationship or the perceived closeness between parents and children could have an association with EOL planning. Further, other dimensions of parents' deaths, such as the perceived suddenness of the death, or the perceived efficacy of planning tools completed by parents, may have some association with adult children's EOL planning activities. The impact of the parent-child context might also be more clearly identified by comparing children who have lost a parent with those whose parents are still living. Future research could explore these topics with different combinations of independent variables to clarify the links that were indicated or contraindicated by the results of this study. Alternatively, future research could approach EOL planning in different ways, separating the planning tools individually to tease apart their individual influences and effects.

The present study contributes to the literature by exploring parents' EOL planning as a contextual factor in adult children's EOL planning, by thoroughly integrating analysis with a theoretical foundation, and by broadening the scope of EOL planning activities measured. In this study, the three factors that showed the strongest associations with adult children's EOL planning were household net worth, parent's completion of a

living will, and the adult child's death ideation avoidance. These findings set the stage for future research to explore adult children's EOL planning more thoroughly from the parent-child perspective. Practitioners may encourage adult children to complete EOL planning activities by working to close gaps between those with higher and lower net worth, by acknowledging that EOL planning decisions occur at the interface of families and the environment, and by continuing a public discourse about death and dying that reframes our experience of death as a celebration of a life lived.

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Table 1

Distribution of Adult Child's Environment Variables (n = 1,199)

Characteristic	<i>n</i>	%	M	Median	Mode	SD
Age at interview (years)			64.32	64.00	64.00	0.68
63	90	7.5				
64	685	57.1				
65	377	31.4				
66	44	3.7				
67	3	0.3				
Gender						
Female (0)	632	52.7				
Male (1)	567	47.3				
Health self rating						
Good to Excellent	1,094	91.2				
Fair to Poor	105	8.8				
Marital status at interview						
Currently married	1,003	83.7				
Not currently married	196	16.3				
Number of children			1.67	2.00	2.00	0.82
Zero	79	6.6				
One to two	425	35.4				
Three to four	507	42.3				
Five or more	188	15.7				
Post-secondary education						
Less than 1 year of college	621	51.8				
1 year of college or more	578	48.2				
Household income (\$)			71,348.05	49,128.00	0	90,970.60
0 to 18,000	218	18.2				
18,004 to 36,000	224	18.7				
36,020 to 56,400	243	20.3				
56,436 to 89,384	247	20.6				
89,400 to 7,834,600	267	22.3				
Household net worth (\$)			735,789.22	350,000.00	0	1,390,936.35
-1,672,500 to -600	9	0.8				
0 to 115,000	221	18.4				
115,000 to 244,000	228	19.0				
245,000 to 437,000	231	19.3				
437,500 to 848,000	254	21.2				
850,000 to 113,500,000	256	21.4				

Table 2

Distribution of Individual Questions Comprising the Adult Child's End-of-Life Planning Index (n = 1,199)

Question	n	%
"Have you made any preparations for the end of life?"		
No	195	16.3
Yes	1004	83.7
"Have you made plans about the types of medical treatment you want if you become seriously ill in the future?"		
No	446	37.2
Yes	753	62.8
"Have you made any legal arrangements for someone to make decisions about your medical care if you become unable to make those decisions yourself? This is sometimes called a Durable Power of Attorney for Health Care."		
No	549	45.8
Yes	650	54.2
"Do you have a living will or an advance directive, which is written instructions about the type of medical treatment you would want to receive if you were unconscious or somehow unable to communicate?"		
No	517	43.1
Yes	682	56.9
"Do you have a signed and witnessed will?"		
No	287	23.9
Yes	912	76.1
"Do you have a revocable trust?"		
No	840	70.1
Yes	359	29.9

Table 3

Adult Child's End-of-Life Planning Index Factor Analysis

Item	Factor End-of-Life Planning
1. Do you have a living will?	.86
2. Do you have a durable power of attorney for health care?	.80
3. Have you made any plans for medical treatment if you become seriously ill?	.67
4. Have you made any preparations for the end of life?	.64
5. Do you have a signed and witnessed will?	.49
6. Do you have a revocable trust?	.42

Table 4

Distribution of Adult Child's End-of-Life Planning Index

Response	<i>n</i>	%	M	Median	Mode	SD
	1,199	100.0	3.63	4.00	5.00	1.97
0 No progress	106	8.8				
1 Very little progress	122	10.2				
2	148	12.3				
3 Some progress	144	12.0				
4	128	10.7				
5	308	25.7				
6 Substantial progress	243	20.3				

Table 5

Death Ideation Index Factor Analysis

Item	Factor	
	Death Ideation Acceptance	Death Ideation Avoidance
1. Death should be viewed as a natural, unavoidable event.	.75	.33
2. Death is simply a part of life.	.65	
3. I would neither fear death nor welcome it.	.54	
4. I avoid thinking about death altogether.	-.36	.66
5. Whenever the thought of death enters my mind, I try to push it away.	-.44	.62

Table 6

Religiosity and Spirituality Index Factor Analysis

Item	Factor Religiosity and Spirituality
1. When you have important decisions to make, how much do you rely on your religious or spiritual beliefs?	.86
2. How important is spirituality in your life?	.86
3. How important is religion in your life?	.85
4. How religious are you?	.81
5. How spiritual are you?	.79

Table 7

Distribution of Dichotomous Past Experience with Parent's Death Variable and Parent's End-of-Life Planning Action Variables

Question	<i>n</i>	%
“Was your deceased parent able to make decisions during the last week of his/her life?”		
No	627	52.3
Yes	572	47.7
“Did your deceased parent have a signed Durable Power of Attorney for Health Care, naming someone who could make decisions about his/her medical treatment?”		
No	346	28.9
Yes	853	71.1
“Did your deceased parent have a signed Living Will, giving directions for the kind of medical treatment s/he wanted?”		
No	506	42.2
Yes	693	57.8

Table 8

Hierarchical Regression Analysis for Variables Associated with Adult Child's EOL Planning (n = 1,199)

Predictor	Model 1			Model 2			Model 3		
	<i>B</i>	<i>SEB</i>	β	<i>B</i>	<i>SEB</i>	β	<i>B</i>	<i>SEB</i>	β
Gender (Female = 0)	-.34	.11	-.09**	-.28	.12	-.07*	-.25	.11	-.06*
Health self-rating	-.22	.20	-.03	-.24	.20	-.03	-.18	.19	-.03
Marital status	.46	.16	.09**	.48	.15	.09**	.45	.15	.09**
Number of children	.02	.03	.02	.01	.03	.01	.02	.03	.02
Education	.32	.12	.08**	.25	.12	.06*	.25	.12	.06*
Household income	.00	.00	.06	.00	.00	.05	.00	.00	.05
Household net worth	.00	.00	.16***	.00	.00	.17***	.00	.00	.17***
Religiosity and spirituality				.03	.07	.01	.03	.07	.01
Death ideation avoidance				-.18	.05	-.11***	-.17	.05	-.10***
Death ideation acceptance				.16	.07	.06*	.18	.07	.07*
Parent's pain level				.04	.05	.02	.03	.05	.02
Parent's ability to decide				-.22	.11	-.06*	-.23	.11	-.06*
Parent's living will							.62	.13	.16***
Parent's DPAHC							-.25	.14	-.06
Total R^2		.06***			.08***			.10***	
ΔR^2					.02***			.02***	

* $p < .05$. ** $p < .01$. *** $p < .001$.

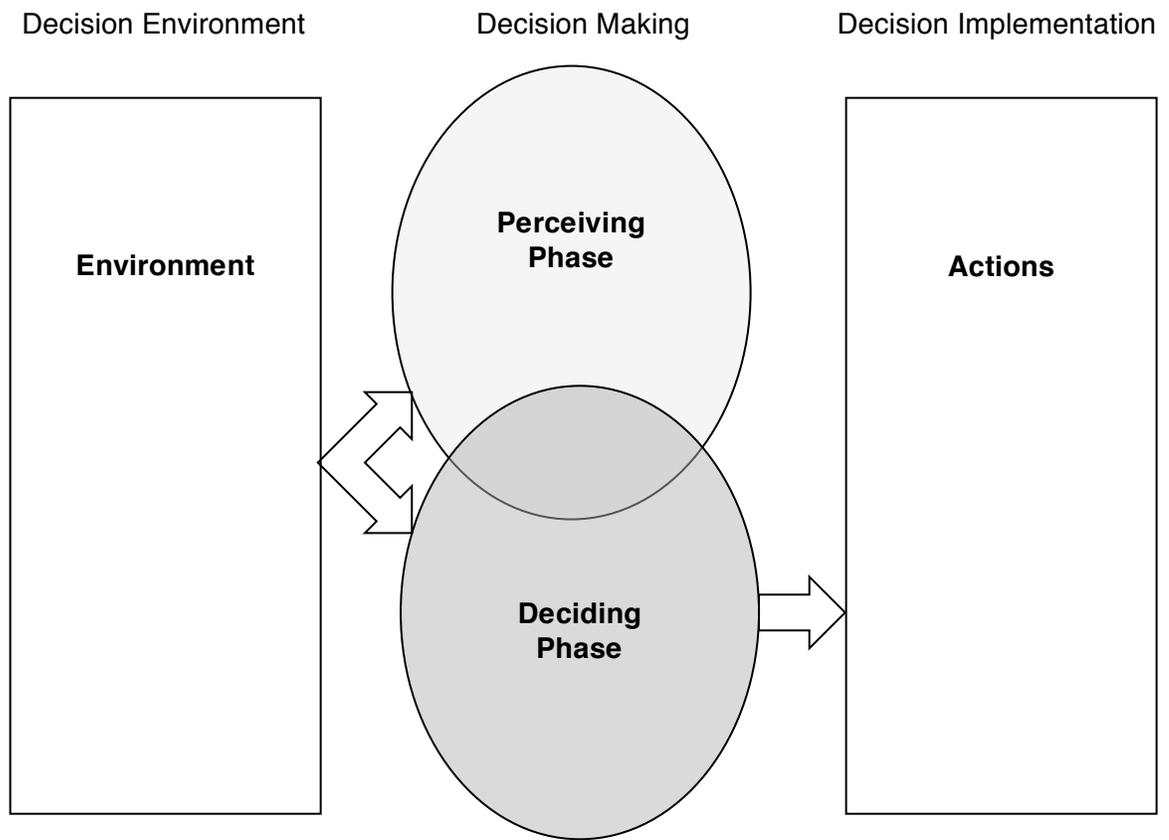


Figure 1. Conceptual model of family decision making theory theoretical constructs as interpreted for the present study.

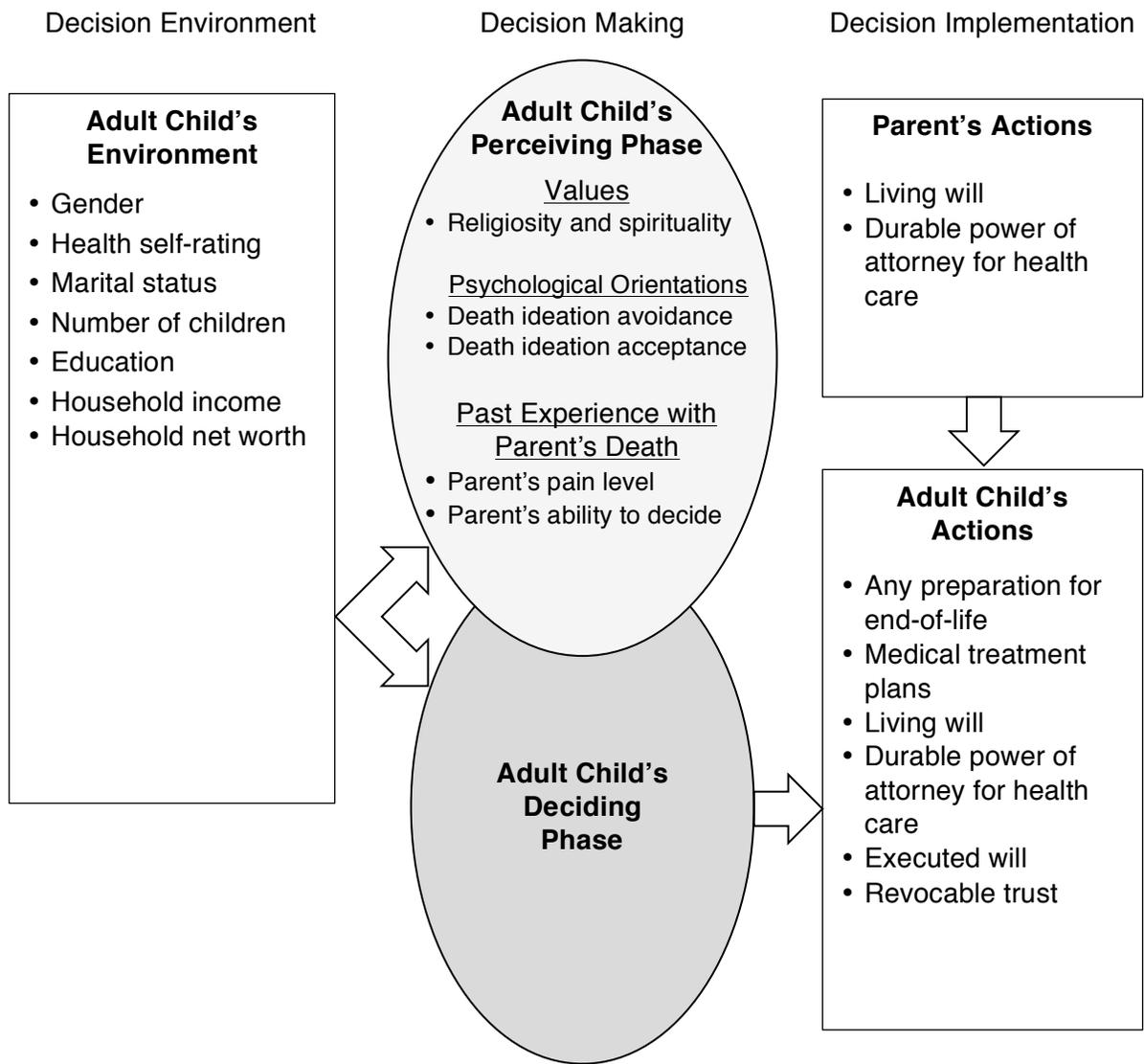


Figure 2. Analytical model of variables of the present study in the context of family decision making theory theoretical constructs.

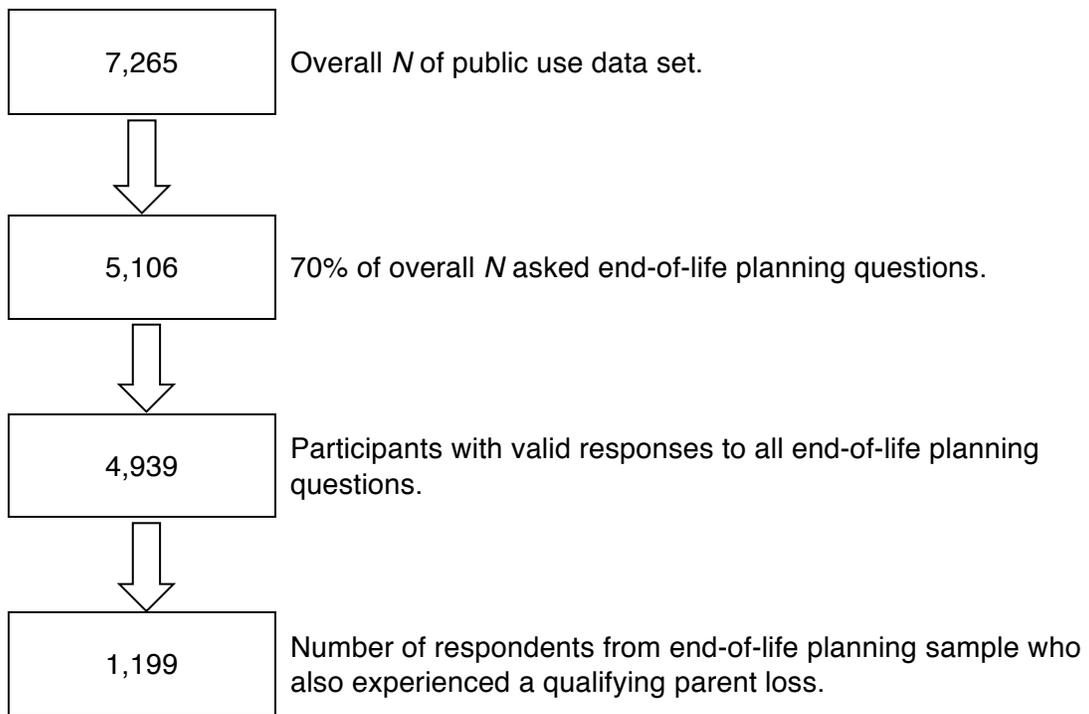


Figure 3. Flowchart representing n used in analysis of the present study.