ABSTRACT

AN EXAMINATION OF END-OF-LIFE DECISIONS IN YOUNGER AND MIDDLE-AGED ADULTS

By Eric W. Beck

Previous research has found that choices about end-of-life decisions are typically not made prior to terminal diagnosis (Bomba & Sabatino, 2009). Although research has examined end-of-life decision making after receiving a terminal diagnosis, few studies have investigated proactive end-of-life decision making. Similarly, few studies have focused on those who may be making such proactive decisions (i.e., young and middle-aged adults) with the majority of research focused on older adults. This study examined proactive end-of-life decision making by comparing younger adults and their selected middle-aged adults in choosing whether to select life-sustaining treatment after imagining fictional diagnoses of terminal illness with one month to live (with or without loss of cognitive functioning). In addition, the influence of religiosity, self-control, and other factors that have been demonstrated to contribute to reactive end-of-life decision making were assessed (Cicerelli, MacLean & Cox, 2000; Mishra & Lalumiere, 2010; Winter, Dennis & Parker, 2009).

One-hundred-sixty-one younger and middle-aged adults (82% women) were surveyed in person, through mail or via email. Participants imagined being diagnosed and then decided whether they would select life-sustaining treatment, rated the influence of factors contributing to their decision and completed a religiosity and self-control survey. Findings from this study indicated that, regardless of age, less than 50% of participants had communicated about end-of-life decisions with friends and loved ones and even fewer had communicated with medical care providers. Consistent with research, surrogates were more likely to select treatment for others who are faced with a terminal illness than when faced with their own terminal illness. In addition, having hope that the disease will improve was a significant predictor of selecting life-sustaining treatment while making peace and being ready to move on was predictive of not selecting life-sustaining treatment. Unlike the older adult reactive research (Carr & Moorman, 2009), this study found no relationship between proactive treatment decisions and religiosity, religious affiliation, or self-control. This suggests that treatment decisions may differ when they are not fictitious or may differ by age group. Future research should continue to compare treatment decisions by age group. Further, research should continue to investigate what factors influence treatment decisions among all age groups. If confirmed, these findings will allow researchers, medical staff and clinicians to better understand influences on proactive end-of-life treatment decisions and may assist in guiding the treatment process.

AN EXAMINATION OF END-OF-LIFE DECISIONS IN YOUNGER- AND MIDDLE-AGED ADULTS

by

Eric W. Beck

A Thesis Submitted
In Partial Fulfillment of the Requirements
For the Degree of

Master of Science-Psychology

Experimental Psychology

at

The University of Wisconsin Oshkosh
Oshkosh, WI 54901-8621

May 2012

COMMITTEE APPROVAL

Advisor

5-22-12 Date Approved

Member

5-22-12 Date Approved

Member

5/22/12 Date Approved

PROVOST AND VICE CHANCELLOR

5/30/12 Date Approved

FORMAT APPROVAL

4/25/12 Date Approved

TABLE OF CONTENTS

Page

LIST OF TABLES ……..... …..……. 4

INTRODUCTION ……..... ...…… 5

RELIGIOUS AFFILIATION AND RELIGIOSITY…. …..…….…….... 15

SELF-CONTROL ……..… ……...……..... 20

HYPOTHESES ……..… ……...……..... 22

METHOD ……..…….. ……..... 28

DATA ANALYSIS ……..... ……..... 38

RESULTS ……..…….. …..……...……..... 39

DISCUSSION …….. …..…...……..... 46

APPENDIXES …… ..……..... 57

Appendix A …….. ...……..... 57

Appendix B …….. .....……..... 59

Appendix C ……... ……..……...……..... 61

Appendix D ……..…… ……..... 69

Appendix E ……..… ……..... 75

Appendix F …….. ……..... 77

Appendix G ……...……..... ……...…….…….... 79

Appendix H ……..… ……..... 81

REFERENCES …..…….. ……..... 83

LIST OF TABLES

Page

Table 1. Ethnicity and Religious Affiliation by Age Group ...….....29

Table 2. Religious Affiliation Categories …..…….....37

Table 3. Factors Contributing to Treatment Selection Decisions 42

Introduction

Decisions about our lives are made every day. We decide when we need to go to the grocery store, we plan for holidays and vacations, and we plan for our future and our children's futures. Despite the attention given to these future-oriented decisions, one decision that many people fail to make proactively is deciding how they want to die if faced with a terminal illness or an unforeseen catastrophic event. Most treatment decisions are made reactively (after a diagnosis or accident). Whether failure to make proactive end-of-life decisions about dying is due to negligence, death anxiety (Fritsche, Jonas, & Fankhanel, 2008), or other reasons, this failure forces such decisions upon loved ones. Limerick (2007) and Wilson (2011) found that the end-of-life decision-making process is complicated, involves many influencing factors, and may cause emotional stress for surrogates when treatment decisions are made after a diagnosis rather than proactively. The current study investigates whether life-sustaining treatment is pursued proactively for oneself or for another when presented with a fictional terminal diagnosis. This study also examines factors that may influence proactive end-of-life decisions as well as the role of religiosity and self-control in predicting such decisions.

The importance of discussing end-of-life decisions and having familial congruence about these decisions has never been more pressing. According to the United States Census Bureau, the projected population increase from 2010 to 2030 will be 17.7 percent (United States Census Bureau [USCB], 2004). Adults over the age of 65 in 2030 will total 71.5 million. Comparatively, the 2010 projection for adults over the age of 65

was only 40.2 million. This is an increase of 44 percent in 20 years (USCB, 2004). This tremendous increase in the aging population is particularly important when considering end-of-life decisions because as the population ages, end-of-life decisions will be made more frequently.

Until recently, most states have used advance directives (e.g. designating a person to make decisions for patients) for end-of-life care. However, these directives do not provide specific instructions for family members or medical personnel to proceed with patients' end-of-life wishes when the persons are unable to clearly communicate their preferences (Bomba & Sabatino, 2009). Recognition of this problem has resulted in changes within the medical community in an attempt to ensure that patient end-of-life preferences are well known. Specifically, a communication approach to patient care has been instituted whereby doctor/nurse recommendations are clearly communicated with patients, decisions about treatment are made jointly between medical staff and their patients, and end-of-life care decisions are encouraged prior to a patient being unable to communicate their preferences to loved ones (Sabatino, 2010).

As a result of this shift to a communication approach, new end-of-life programs have emerged to assist with end-of-life decision-making. The Physicians Orders for Life Sustaining Treatment (POLST) is a national program that is designed to permit patients to proactively decide their end-of-life decisions prior to physicians utilizing life-sustaining treatments (Physicians Orders for Life Sustaining Treatment [POLST], 2011). This program is based on determining a patient's end-of-life choices prior to possible future diagnoses, documenting these choices in the event of a future emergency, and

obtaining signed consent by health care professionals to adhere to these wishes. Patient-centered care is based on the belief that communication between the patient or legally designated decision-maker and health care professionals ensures decisions are sound and based on patients' understanding their medical condition, their prognosis, the benefits and burdens of the life-sustaining treatment, and their personal goals for care (POLST, 2011, p. 1)

POLST forms are distributed to patients during a doctor's visit and cover a variety of life-sustaining treatment options. For example, in California, the POLST form includes cardiopulmonary resuscitation, medical interventions, and artificially administered nutrition (POLST, 2011). In New York, the program includes life-sustaining options of antibiotics and future hospitalization/transfers as well as those items listed on the California document (POLST, 2011). Patients and doctors complete this form together and both sign the document. POLST is currently endorsed in eleven states and is expanding into many others.

Research has found that the POLST program provides patients with more planning options (Hickman et al., 2010), allows older patients to communicate their treatment preferences more clearly (Hickman, Tolle, Brummel-Smith, & Carley, 2004), and is generally viewed as helpful by medical personnel (Hickman et al., 2009). Hickman et al. (2010) examined nursing facilities in three states for the use of POLST forms versus traditional practices (such as documented resuscitation choices and advance directives) and found that the facilities using POLST were more likely to have documented treatment plans. Further, Hickman et al. (2004) found that patients who completed

POLST forms were more likely to have documented life-sustaining treatment plans and when utilizing POLST forms, older adult patients were more likely to abstain from life-sustaining treatment as their age increased. In addition, Hickman et al. (2009) found POLST was viewed as useful by hospice personnel. These findings suggest that POLST is an effective tool for conveying patient preferences.

Similar to POLST, another end-of-life program used in the United States and other countries is Five Wishes (Aging with Dignity, 2011). Five Wishes was created by Aging with Dignity, "a national non-profit organization with a mission to affirm and safeguard the human dignity of individuals as they age and to promote better care for those near the end-of-life" (Aging with Dignity, 2011). The Five Wishes form asks patients to engage proactively in decision-making about end-of-life care. Specifically, this form asks patients to decide whether or not they want life-sustaining treatment if they were close to death (i.e., in a coma and not expected to recover or having sustained permanent and severe brain damage and not expected to recover). The form also allows for the patient to articulate treatment for any other perceived future conditions. The Five Wishes form is currently distributed in 40 states (Aging with Dignity, 2011).

Research on the effectiveness of the Five Wishes form has yet to be completed. However, with its similarities to the POLST form, it can be inferred that the form is beneficial in encouraging people to think about end-of-life decision-making. Interestingly, although both programs are available to medical facilities, some facilities do not make use of the programs. Resnick, Foster and Hickman (2009) found that in 2004, less than one in five nursing homes in the United States participated in end-of-life

programs. Currently, no research has examined why some doctors do not provide POLST or Five Wishes forms to their patients and no data were available on how many doctors participate in these programs in states where the forms are available.

Although research suggests that end-of-life decision forms are helpful in determining patients' end-of-life wishes when at the end of life (Hickman et al., 2009), little is known about the process of making such a proactive end-of-life care decision and the factors influencing treatment choice. In research on surrogates' reactive treatment decisions (decisions after diagnoses), factors that influenced treatment choice were knowing the patients' end-of-life wishes, having communication with healthcare providers, accepting/acknowledging futility of the situation, strengthening relationships with loved ones, and having adequate pain and symptom management (Wilson, 2011). Other factors that may contribute to surrogates' end-of-life decision-making process include the life experiences of the surrogate and evaluation of the patient's past and present condition (Limerick, 2007). Limerick (2007) interviewed surrogate decision-makers after the loss of a family member. Most reported that decisions were influenced by personal beliefs/evaluation of the patient's condition, the hospital environment, and acceptance of the treatment suggestions by other family members. Utilization of these factors when making an end-of-life decision was helpful to all surrogates.

In patient populations, factors that have been found to influence patients' well-being and reactive treatment decisions include hope that the disease will improve, making peace/being ready to move on, physician recommendations, beliefs of friends/family, fear about quality of life, control of medical decisions over one's life, and medication

acceptance (Herve, Mullet and Sorum, 2003; Johnson, 2007; Matsui, 2007; Radley & Payne, 2009; Rousseau, 2000; Rotham, Van Ness, O'Leary & Fried, 2007; Sharf, Stellies, & Gordon, 2005; Wilson, 2011). Rousseau (2000) and Johnson (2007) reviewed how hope influences the experience of terminal illness after diagnoses were given to patients and found that hope plays a pivotal role in controlling symptoms, allowing for positive coping and improving the quality of the patient's life (Johnson, 2007; Rousseau, 2000). Research has also suggested that accepting the futility of the situation (i.e., understanding that death is inevitable) leads to patients (Sharf, Stellies, & Gordon, 2005) and surrogates (Wilson, 2011) acknowledging that they are ready to move on and increases the chances of a person not selecting life-sustaining treatments.

Physician recommendations also influence patient treatment choices after diagnosis (reactively). In research on end-of-life care, Heyland et al. (2006) found patients' and family members' "need to trust in the physician" was one of the most important elements related to quality end-of-life care. However, physician recommendations may not match patient preferences. For example, Radley and Payne (2009) reviewed current research on refusal of treatment by cancer patients. They noted that physicians often do not engage with patients outside the context of the medical discussions, resulting in a failure to accurately predict patients' treatment preferences. Specifically, doctors may not obtain information regarding patients' beliefs about treatments, religious values or discuss other items that may be influencing a patients' treatment decisions. Further, in a comparison of attitudes towards end-of-life decisions, Rietjens et al. (2005) found that the public accepted decisions to end life-sustaining

treatment in the case of terminal illness at higher rates compared to physicians (85% and 64%, respectively).

Making reactive treatment decisions has also been discussed as a function of family beliefs or preferences. In a review of end-of-life decisions, Wilson (2011) found that obtaining and providing familial support during the treatment decision process eased the decision-making process and prevented increases in stress. Matsui (2007) also found that discussion with family members about end-of-life decisions was important to older adults when completing advance directives.

Additional factors that influence reactive treatment decisions are medication acceptance, fear about quality of life, and control over end-of-life decisions. Patients who have not selected life-sustaining treatments often avoid new medication. A variety of explanations have been proposed including fear of additional side-effects of new medication (Herve, Mullet & Sorum, 2003; Sharf et al., 2005). In addition, some patients report that they refuse additional treatment recommendations because they want to assert individuality (i.e., maintain control) over how to live their lives (Radley & Payne, 2009). Finally, it is possible that patients anticipate that additional medication will decrease the quality of life they currently maintain and thus they select not to use the medication (Rotham et al., 2007; Sharf et al., 2005).

Although the existing research on end-of-life programs and treatment decisions is promising and provides evidence that discussing end-of-life decision-making is beneficial to patients and caretakers, the research has been limited to nursing home settings and/or those who are currently faced with such medical decisions (i.e., reactive decision

making). Thus, prior research has tended to focus on individuals who were medically impaired, advanced in age, at the end stages of life and/or individuals making the reactive decision for someone else in the end stages of life (Hickman et al., 2004; 2009; 2010; Limerick, 2007; Resnick et al., 2009; Wilson, 2011). Less focus has been given to proactive end-of-life decision choices, or those occurring prior to the end stages of life. Although it is possible that the factors influencing proactive end-of-life treatment decisions are similar to those influencing reactive treatment decisions, proactive decisions have yet to be explored.

In addition, reactive and proactive end-of-life programs require patients to make decisions about ending life-sustaining treatments in the case of varying diagnoses (e.g. loss of cognitive functioning, coma, severe brain damage) and life-sustaining measures (e.g. cardiopulmonary resuscitation, artificial nutrition). However, various combinations of diagnoses may influence how patients select their options. Therefore, in this study, two terminal conditions will be examined (terminal illness with loss of cognitive functioning and terminal illness with no additional ailments).

In a study on perceived loss of cognitive functioning, Price et al. (2011) found that many older adults perceive cognitive impairment as a severe condition and would prefer death rather than losing one's independence or being a burden upon loved ones. Further, research on public perceptions of cognitive impairment indicates that people are generally unaware of this developmental process. Anderson, Day, Beard, Reed, and Wu (2009) completed a meta-analytic review of scholarly articles assessing this topic and

they were able to ascertain that, in general, the public lacks knowledge about Alzheimer's disease and its current treatments.

Perceptions of care providers also contribute to the perceptions of cognitive functioning. Hwang, Rivas, Fremming, Rivas and Crane (2009) investigated the caregiving experience of respondents who cared for a family member with Alzheimer's disease. Results of this study indicate that caregivers felt burdened by the role due to perceived feelings of obligation, changes in personal lives (restriction of freedom), and lack of social support. Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, and Lopez-Pousa, (2010) assessed the difference in perceptions between older adults with AD and their family caregivers. Results from this study found that Alzheimer's disease patients themselves have a more positive perception of their quality of life than their caregivers report. Research by Boustani et al. (2011), found that medical caregivers of patients with Alzheimer's disease (compared to non-caregivers) were less enthusiastic about being screened for dementia and also reported that the perceived suffering of Alzheimer's disease patients to be higher.

Combined these findings indicate that there are negative stigmas surrounding loss of cognitive functioning and this stigma may influence how patients perceive their future quality of life. Therefore, life-sustaining treatment decisions may differ based on the perceived terminal illness diagnosis when paired with additional ailments, such as loss of cognitive functioning.

Since decline in cognitive functioning may begin to occur at middle-age (Shadlen & Larsen, 2012) and surrogate decisions are typically made by younger family members

(Wilson, 2011), investigating the end-of-life decision making process in younger and middle- aged adults is also important. Further, with the demographic shift expected in 2030 (USCB, 2004) younger and middle-aged adults may be the ones making reactive end-of-life decisions for others as well as proactive decisions for themselves as end-of-life programs continue to expand nationally and internationally.

To address whether end-of-life decision making varies by diagnosis and age, the current study varied a perceived diagnosis and tested both young adult and middle-aged adult participants. In addition, congruence in end-of-life decisions was examined by comparing young adult participants' decisions for themselves, for their selected middle-aged participant (i.e., parent, legal guardian, middle-aged friend) and decisions made by the middle-aged participants themselves. The current study also examined how factors associated with end-of-life decisions (e.g. hope that it will get better, making peace/ready to move on, physician recommendations, beliefs of friends/family, fear about quality of life, control of medical decisions over one's life, and not wanting the side effects of medication) predict selection of life-sustaining treatment. In addition to these factors, research suggests that being religious and the ability to maintain high self-control may predict patients' preferences for life-sustaining treatment decisions (Tangney, Baumiester, & Boone, 2004; Winter, Dennis, & Parker, 2009). Thus, the role of religion and self-control in life-sustaining treatment selection was also examined.

Religious Affiliation and Religiosity

Reliance on religious values and beliefs are important factors that influence life-sustaining treatment decisions. However, research on religion and end-of-life decision making has not properly distinguished an operational definition for the religion variable. Therefore, for the purposes of this study the focus will be on religious affiliation (identification with a religious organization) and religiosity (participation in religious activity and practice).

In a study by Winter, Dennis and Parker (2009), patients who reported being religiously affiliated indicated that life-sustaining treatment decisions were a function of their religious or spiritual beliefs. Winter et al. also found that participants who identified themselves as affiliated with a religion deferred to God's will when making treatment decisions and were more likely to opt for life-sustaining treatment. Nonetheless, current medical practices often fail to recognize the importance of religion in patient preferences (Amoah, 2011; King & Wells, 2003). Steinberg (2011) suggests that palliative care is a function of cultural and religious upbringing and that doctors should familiarize themselves with a patient's background information so decisions about treatment are made more jointly. In a literature review of the importance of religiousness in palliative care, Amoah (2011) indicated that some health professionals do not connect individual wellness to individual spiritual preferences. As a result, this disconnect may be preventing discussions that enhance the well-being of patients and their families. Similarly, in a study completed by King and Wells (2003), 66 percent of patients facing

end-of-life decisions were religious but only six and a half percent had spiritual histories documented in their chart, indicating that doctors may be failing to acknowledge the role that religion plays in the treatment needs of patients. Some research suggests that doctors believe it is appropriate to discuss religious values related to end-of-life care (King & Wells, 2003). However, physicians may not be trained to discuss religious values and beliefs and, as a result, may feel uncomfortable introducing the subject (Amoah, 2011; King & Wells, 2003; Sprung et al., 2007).

Findings on doctors' failures to acknowledge and discuss treatment preferences are particularly relevant because many religions require certain medical treatment decisions (Bülow et al., 2008). For some major religions [e.g. Roman Catholic, Conservative Protestant (Protestant churches that tend to stand strongly with Scripture are considered Conservative and those that see more need to change with society and changing morals are considered Mainline), Hindu, Sikh], refusals of treatment are only acceptable when death is deemed inevitable by a physician (Bülow et al., 2008). However, inevitable death is hard to define because most treatment options provide some probability of furthering survival (Bülow et al., 2008). In the Greek Orthodox tradition, the prolongation of life is required regardless of diagnosis (Bülow et al., 2008).

If doctors and patients fail to discuss a patient's religious preferences for treatment, the patient's end-of-life decisions may therefore not be accurately honored (King & Wells, 2003). It should be noted that differing treatment recommendations may also occur when the treating physician's religion is different from that of the patient

(King & Wells, 2003; Rietjens, van der Heide, Onwuteaka, van der Maas, & van der Wall, 2005).

The impact of religion on end-of-life decision-making is also consistent with theories of religious coping. For example, Pargament (1990) found that using religion as a coping mechanism allows some people to alleviate negative stressors and change the appraisal of negative events to an act of God. Religious coping mechanisms are used when high value is placed on the stressor (Krause, 1998), such as terminal illness in the case of end-of-life. Appraisals of the stressors may create negative coping strategies (e.g. anger at God, belief that the illness is the devil's work) or positive coping strategies (i.e. trust in God's will, spiritual connectedness) (Pargament, Smith, Koenig, & Perez, 1998). In a study completed by Pargament et al. (1998), positive religious coping strategies were correlated with fewer symptoms of psychological distress, psychological and spiritual growth as a result of the stressor, and higher cooperativeness. Conversely, negative religious coping patterns were correlated with emotional distress, depression, poorer quality of life, psychological symptoms, and callousness towards others (Pargament et al., 1998). When making end-of-life decisions prior to a diagnosis (i.e., proactively), people who are more religious may therefore use coping strategies. Krause's (1998) research contends those who are highly religious will utilize religious coping strategies when high-value is placed on a stressor, such as death. Further, when thinking about mortality, religious coping was utilized to alleviate the stressors (Krause, 1998).

Research also suggests that religious affiliation is associated with treatment seeking behaviors when participants are presented with fictitious circumstances about

end-of-life decisions. Van Ness, Tolle, O'Leary, and Fried (2008) found that deference to God's will or a higher belief in God, in older adults, resulted in patients increased preferences for life-sustaining treatment overtime. In addition, Cicerelli, MacLean and Cox (1999) found that elder participants who reported being religiously affiliated were significantly more likely to favor life extending treatment over assisted suicide and refusing treatment. Denk, Benson, Fletcher and Reigel (1997) examined Americans' recommendations to terminate life after a fictitious catastrophic event. Results of this study suggested termination choices (ending treatment) were higher when no end-of-life planning had occurred, when prognosis was worse, and among Mainline Protestants and participants with no religious affiliation. These findings were consistent research by Carr and Moorman (2009) which also found that Mainline Protestants were less likely to select life-sustaining treatment. Finally, Rietjens, van der Heide, Onwuteaka, van der Maas, and van der Wall (2005) examined perceptions of end-of-life decisions and found respondents who were less religious were more accepting of ending life-sustaining treatment for fictitious patients who were terminally ill. The contribution of this literature indicates two important findings regarding religion and end-of-life decision making. Participants who are identified as religious are more likely to select life-sustaining treatment. However, this finding is limited because Mainline Protestants were not as likely to select life-sustaining treatment.

Similar to research related to end-of-life programs, research on religiosity and end-of-life decisions has relied on nursing home settings and people who are currently faced with a reactive decision (Carr and Moorman, 2009; Van Ness et al., 2008; Winter et

al., 2009) regarding how people might choose to terminate life when influenced by religion. In addition, prior research in this area has conceptualized religiosity merely as religious affiliation, and has not considered the degree of religious involvement. The present study addresses these limitations by utilizing a younger sample of participants to explore the role of religiosity (both affiliation and degree of religious involvement) in end-of-life decision-making.

Self-Control

In addition to religiosity, self-control may also impact end-of-life treatment decisions. Defined by Tangney et al. (2004), self-control is the ability to override one's responses by interrupting undesired behaviors or impulses. Research on self-control suggests that high self-control is associated with well-being and lack of self-control has been linked to risky/impulsive behaviors (Mishra & Lalumiere, 2011; Tangney et al., 2004). In addition, Baumeister, Heatherton and Tice (1993) proposed that lack of self-control may be linked to personal and social problems. If people are unable to adapt and cope with their environments, the stressors that arise will cause maladaptive behaviors that interfere with personal and social interactions (Tangney et al., 2004).

Additional research also lends support to low self-control being linked to risky behavior. Both Cotter (2003) and Popham et al. (2011) suggest that those who are unable to exercise self-control over anxiety are more likely to engage in behaviors that involve risk. Further, Cotter's (2003) research examined adolescents' anxiety about death in relation to high risk behaviors and found that males were less likely to be anxious about death and demonstrated more high risk behaviors. These findings suggest low self-control may be related to low death anxiety. If so, participants who score low in self-control may be more likely to not select life-sustaining treatment and this prevalence should be higher in males.

Research has also found that high self-control may be influenced by religion. McCullough and Willoughby (2009) examined research on self-control and religion and

found that religion may promote self-control as well as influence how goals are selected, pursued, and organized. For example, those who were religious and had high self-control were more likely to fulfill goals and report better well-being than those reporting low self-control and no affiliation.

This study extends the self-control research by examining the relationship between self-control and life sustaining treatment decisions. Specifically, it is proposed that low self-control may be related to not selecting life-sustaining treatment because those with low self-control are less anxious about death. This study will also examine the interaction between self-control and religion and ascertain whether or not there are gender differences in treatment selection decisions. Finally, since the previous literature suggests that low self-control is related to risk-taking behavior, it is therefore possible that factors associated with not selecting life-sustaining treatment (fear about quality of life, not wanting the side effects of medication, and made peace/ready to move on) may be related to low self-control as well.

Hypotheses

The current research examined how end-of-life decisions differ for younger adults and middle-aged adults as well as assessed how perceived diagnosis, religiosity, and self-control are related to treatment decisions.

Hypothesis 1

In this study, young adults participated along with a middle-aged friend or family member. End-of-life decisions made by the young adults were compared to end-of-life decisions made by their chosen middle-aged adults. Young adults were also asked to make end-of-life decisions as a surrogate for their selected middle-aged adults. Thus, the young and middle aged adults' own end-of-life decisions were also compared to the surrogate decision.

Braun and McCullough (2011) suggest that if a patient's preferences for end-of-life treatment decisions are unknown, a surrogate is more likely to select all available treatment. Therefore, it was hypothesized that young adults in this study would be more likely to select treatment for their selected middle-aged participant compared to themselves and when compared to the middle-aged participants' own treatment decisions. In addition, research on POLST indicates that selection of life-sustaining treatments decreases with age (Hickman et al., 2004). Therefore, it is hypothesized the middle-aged adults will be less likely to select treatment for themselves compared to young adults' treatment selection for themselves. In summary, the following hypotheses were proposed:

$H1_a$: Young adults would select life-sustaining treatment more frequently for their selected middle-aged adults than for themselves (YA_{other} vs. YA_{self})

$H1_b$: Young adults would select life-sustaining treatment less frequently for themselves than middle-aged adults selected for themselves (YA_{self} vs. MA_{self}).

$H1_c$: Young adults would select life-sustaining treatment more frequently for their selected middle aged-adult than when the middle aged-adult made the choice for themselves (YA_{other} vs. MA_{self}).

Hypothesis 2

The relationship between perceived diagnosis (conditions: terminal illness or terminal illness with cognitive impairment) and treatment decisions was also assessed. Research on medication acceptance has found that some patients who have multiple medications and ailments may not want to seek additional treatment for fear of a decline in quality of life (Sharf, Stellies, & Gordon, 2005). As discussed earlier, research has also found that a majority of older adults prefer death over receiving a perceived diagnosis of dementia (Price et. al, 2011). Research has also suggested that age is related to treatment selection decisions (Hickman et al., 2004). Therefore, the following hypotheses were proposed:

$H2_a$: Participants in the terminally ill condition with loss of cognitive functioning would be less likely to select life-sustaining treatment than participants in the terminally ill condition with no additional ailment.

Hypothesis 3

Research has found that being more religious (Bülow el al., 2008; Cicerelli, MacLean & Cox, 1999), having hope that the disease will improve (Johnson, 2007; Rosseau, 2000) and asserting individuality by taking control over one's end-of-life (Radley & Payne, 2009) increase the likelihood of selecting life-sustaining treatment. In addition, fear about quality of life (Rotham et al., 2007; Sharf et al., 2005), not wanting the side effects of medication (Herve et al., 2003; Sharf et al., 2005), and making peace/ready to move on by accepting the 'futility' of the situation (Sharf et al., 2005; Wilson 2011) have been associated with not selecting life-sustaining treatment. Further, since the literature has identified friends/family beliefs (Matsui, 2007; Wilson, 2011) and doctor/nurse recommendations (Heyland et al., 2006; Radley & Payne, 2009) as factors influencing treatment choice (both positively and negatively) in older adult populations, this study will explore whether these two factors influence life-sustaining treatment decisions in young and middle-aged adults. Finally, since end-of-life programs are available to the pool of participants being used, the factor "previous end-of-life decision made" will be also be explored as a predictor of treatment selection.

$H3_a$: Factors associated with selecting life-sustaining treatment (religion, hope, self-control) or not selecting life-sustaining treatment (fear about quality of life, medication side effects, and making peace) will predict end-of-life decisions.

$H3_b$: Factors associated with selecting or not selecting life-sustaining treatment (friends/family beliefs, doctor/nurse recommendations and previous end-of-life decision made) will predict end-of-life decisions.

Hypothesis 4

The role of religiosity (degree of participants' religiosity) in end-of-life treatment choices will also be examined.

$H4_a$: Religiosity will be related to selecting life-sustaining treatment. Specifically, participants who score higher in religiosity will be more likely to select life-sustaining treatment. Participants who score lower on religiosity will be less likely to select life-sustaining treatment.

In addition, research by Carr and Moorman (2009), Denk et al. (1997) and Sprung et al. (2007), found that religious affiliation (independent of degree of religiosity) was associated with end-of-life treatment decisions. Specifically, non-conservative Protestants (mainline) were less likely to select life-sustaining treatment than other religions. This study will seek to replicate those findings and will explore the role of religious affiliation on end-of-life decision making.

$H4_b$: Participants who identify their religious affiliation as Protestant (mainline) will be less likely to select life-sustaining treatment.

Hypothesis 5

Self-control has also been found to influence decision-making (Mishra & Lalumiere, 2010; Tangney et al., 2004). Specifically, those with low self-control are more likely to engage in risk taking behaviors such as not selecting life-sustaining treatment measures when they are available. While no research has examined the relationship between low self-control and end-of-life treatment decisions, it was predicted that low self-control would be related to not selecting life-sustaining treatment.

In addition, since fear about quality of life, not wanting the side effects of medication, and making peace/ready to move on by accepting the futility of the situation have been associated with not selecting life-sustaining treatment, it was hypothesized that participants with low self-control would indicate that these factors were influential when making their end-of-life treatment decision. Therefore the following was hypothesized:

$H5_a$: Participants who score low in self-control will be less likely to select life-sustaining treatment.

$H5_b$: Low self-control scores should be related to the factors: fear about quality of life, not wanting the side effects of medication, and made peace/ready to move on.

Exploratory Question

Since research has also found that high self-control may be influenced by religion (McCullough and Willoughby, 2009), this study also explored the interaction between religiosity and self-control in predicting factors associated with proactive treatment decisions. No specific hypotheses were offered given the exploratory nature of the question.

Hypothesis 6

Prior research does support gender differences in behaviors that arise out of low self-control and suggests that men are more likely to engage in risk-taking behaviors than are women (Cotter, 2003; Courtenay, 2000).

H6: Men will be less likely than women to select life-sustaining treatment when making their own end-of-life decision.

Method

Participants

Two recruitment methods were used. First, a group of undergraduate students (n=106) was recruited at the University of Wisconsin Oshkosh. Young adults obtained course credit for participating in the study. Second, the young adults were asked to provide a mailing address and an email address of one middle-aged adult (n=55) for participation in the study. The student participants were told that this middle-aged adult should be a parent, legal guardian or a middle-aged friend between the ages of 36 and 55 (actual relationship was not assessed). Following completion of the survey, all participants received debriefing statements with information about the purpose of the study.

Analysis of the data was completed using SPSS statistics data software version 17.0. In regard to response rates, 51% (n = 55) of the middle-aged adults contacted returned surveys via email and mail. There were no age differences between the students whose middle-aged adults responded to the survey compared to those students whose middle-aged adults did not disclose their ages, $t(149) = 0.85$, $p > .05$, $d = 0.17$, year in school, $t(103) = -0.15$, $p > .05$, $d = 0.00$, race, χ^2 (4, n=106) = 0.30, $p > .05$, or gender, χ^2 (1, n=106) = 2.24, $p > .05$.

Due to incomplete responses, six percent (n = 3) of the middle-aged adult data were discarded; none of the young adult data were discarded. Data screening was

performed for each analysis and participant inclusion was determined based on completion of survey responses in relation to the specific hypothesis. Middle-aged and younger-aged participants were evenly represented among the two conditions (terminal illness plus cognitive decline and terminal illness only).

Of the young adult participants, 34 percent identified as male, the average age was 19.31 (SD = 1.43), and the average year in school was 13.21 (SD = .91). Of the middle-aged adult participants, 17.6 percent identified as male, the average age was 47.5 (SD = 5.89), and the average years of education were 14.84 (SD = 1.84). The majority of participants identified themselves as White/European American (*n* = 135, 83.85%) and as Catholic (*n* = 54, 34.4%) or Mainline Protestant (*n* = 49, 31.2%). See Table 1 for a list of all ethnicities and religious affiliations.

Table 1: *Ethnicity and Religious Affiliation by Age Group*

	Middle-Aged Adults, *n*(%)	Young Adults, *n* (%)
Ethnicity		
White/European American	89, (84%)	46, (90%)
Asian	7, (6.6%)	3, (5.9%)
Black African American	5, (4.7%)	1, (2%)
Mixed (Two or more races)	3 (2.8%)	1, (2%)
Latino/Hispanic	2, (1.9%)	0, (0%)
Affiliation		
Catholic	21, (41.2%)	33, (31.1%)
Protestant (mainline)	19, (37.3%)	30, (28.3%)
Christian, not specified	4, (7.8%)	20, (18.9%)
Atheist, Agnostic or none	3, (5.9%)	14, (13.2%)
Protestant (conservative)	3, (5.9%)	3, (2.8%)

Muslim	0, (0%)	1, (0.9%)
Other	0, (2%)	1, (0.9%)

Procedure

All surveys were available online via Qualtrics, an internet based survey tool. Middle-aged adults were also mailed a hard copy of the survey to accommodate those participants who did not have access to a computer or who were not familiar with computers. Prior to answering survey questions, the respondents were given a four digit identification number. This number was used to create a linked list between student and middle-aged adult respondents. For the online survey takers, participants were provided the number at the beginning of the study and were asked to enter it into the survey online. The number was written on the top right corner of the mailed survey.

After completing the informed consent (Appendix A), student participants read one of two typed vignettes in which they were asked to imagine themselves as being recently diagnosed with a terminal illness. Participants were assigned to one of two conditions: terminally ill with loss of cognitive functioning or terminally ill with no additional ailments (see conditions in student survey, Appendix C). A loss of cognitive functioning was defined in the survey as a loss of the ability to recall and create new memories and to organize thoughts appropriately. Participants were also informed that loss of cognitive functioning would diminish their ability to interact conversationally with others. In both conditions, participants read the following instructions:

> "With the following questions, we hope to explore how you would feel in this situation and discuss your end-of-life decision-making process that you would have to go through. As health declines, you would be expected

to make choices about the treatment you would receive as the condition progresses. Please answer the following questions and imagine you were given this survey after the diagnosis."

After reading the assigned vignette, all participants were asked to take a few seconds to consider the situation (i.e., being diagnosed with a terminal illness) and their emotional responses. As they continued reading, participants were informed that after the diagnosis the doctor would have indicated that selecting life-sustaining treatment may extend their life (or, in the case of surrogate decisions, the life of their selected middle-aged adult). They were also informed that not selecting life-sustaining treatment would prevent additional treatments and that death would likely occur within a month.

Prior to making the treatment selection decision, participants were asked to write out their thought process regarding their choice. This allowed for participants to critically think about the decision they would make and acted as a buffer to prevent a hasty decision. The remainder of the survey asked participants to rate various factors influencing their decision to select or not select medical treatment, respond to questions regarding end-of-life decisions, and complete religiosity and self-control scales (see Appendix C). Following the completion of the assigned questions and scales, student participants were instructed to complete the treatment decision a second time, but for a middle-aged adult (i.e. they were asked to use perspective taking again, but imagine their middle-aged adult was the one who received the diagnosis). Participants were unable to reference their previous answers when making the treatment selection decision for the middle-aged adult so as to not influence their choice. After imagining their selected

middle-aged adult in the proposed condition and making the end-of-life decision, student participants answered the same rating scales about factors that might contribute to their treatment decision for their middle-aged adult (see Appendix C). Finally, young adults were asked to write about how they made the decision for the middle-aged adult and the thought process that guided them to this decision. Prior to leaving the study, participants provided a mailing and email address for their selected middle-aged adult. After providing the middle-aged adult's information, student participants were debriefed (Appendix E).

Middle-aged adults were then mailed and emailed the survey instruments to complete. The middle-aged adults received a prepared script indicating that the younger adult had just participated in a study on end-of-life decisions and that the research completed involves participation of young adults and a middle-aged adult the student selected. Middle-aged adults were made aware that the student had invited them via email/mail to participate. The packet emailed/mailed to the middle-aged adult included the invitation to participate (Appendix G & H), informed consent (Appendix B), the survey instrument (Appendix D) and a debriefing sheet (Appendix F).

Middle-aged adult respondents were asked to imagine themselves in the same assigned condition as the student respondents (i.e., terminal illness plus cognitive decline or terminal illness only) and then asked to complete the survey instrument for themselves. For online surveys, middle-aged adults were provided with the four digit number via email and instructed to enter the number to begin the survey (Appendix H). Respondents who replied via mail had the four digit number written on the survey instrument.

For all participants, demographic measures were obtained at the completion of the survey instrument. Information about gender, age, education level, ethnicity, and religious affiliation was collected. In addition, questions regarding prior experience with end-of-life decisions were also asked. Specifically, all participants were asked whether they or someone in their family has made an end-of-life decision in the past, whether they have ever consulted with someone *outside* of their family about an end-of-life decision, and whether they consulted with someone *inside* their family about an end-of-life decision.

Measures

Open-Ended Questions. To clarify and expand on the responses to the structured questions, all participants were asked open-ended questions about the end-of-life decision-making process and their experiences with these decisions. The first question asked participants to describe their decision-making process. They were asked to provide as many thoughts/answers as possible. Student participants were also asked to describe the differences between making the choice for themselves compared to their selected middle-aged adult in the hypothetical situation.

Inclusion of open-ended questions is particularly important given the limited research on familial collaboration in the end-of-life decision process and on this particular age group. Previous qualitative studies on end-of-life decisions (Limerick, 2007; Wilson, 2011) have found that the use of open-ended questions allows for the

identification of additional factors associated with treatment selection as well as provides additional explanation for treatment selection.

Treatment Decisions scale. Following the completion of the open-ended questions, participants were asked to rate various factors that might influence their life-sustaining treatment decisions. These factors were rated on a five point scale from one being not important to five being very important. The scale was developed for this study and is based on prior literature regarding factors that influence reactive end-of-life decision making. Consistent with previous research (Amoah, 2011; Bülow et al., 2008; Cicerilli et al., 1999; Denk et al.,1997; Herve, Mullet and Sorum, 2003; King & Wells, 2003; Matsui, 2007; Radley & Payne, 2009; Rietjens, et al., 2005; Rotham, Van Ness, O'Leary & Fried, 2007; Sharf, Stellies, & Gordon, 2005; Sprung et al., 2007; Steinberg, 2011; Wilson, 2011; Winter et al., 2009), the following factors were included: made peace/ready to move on, religious values, beliefs of friends/family, doctor/nurse recommendations, control over end-of-life, fear about quality of life, not wanting the side effects of medication, previous DNR orders, and hope that the disease will improve. There was also an open-ended item for participants to write in any additional factors which may have influenced their treatment choice.

Religiosity Measure. The Religiosity Measure scale (Rohrbaugh & Jessor, 1975) was chosen to identify participants' religious beliefs and participation in religious activities. This seven-item scale assesses various aspects of religious involvement, without identifying a particular religion. Items measure prayer practices, seeking

religious advice, beliefs, devotion, and comfort. An informational item, also included in the scale, asks participants to estimate their religious involvement within the past year.

In constructing the scale, careful wording of language was used to minimize participants referencing any specific religious doctrine (Rohrbaugh & Jessor, 1975). For the purposes of this study, minor adjustments to the wording of the scale were made. Specifically, the authors referred to God with masculine pronouns (i.e., "He" and "His"); these pronouns were removed. Scale scores were assigned a value of 0 to 4 for each item with higher scores indicating greater religiosity. Total Scores range from 0 to 32. Rohrbaugh and Jessor found that the scale has high internal consistency (Cronbach's alphas over .90). Nicholas and Durrheim (1996) confirmed the validity of the scale by analyzing the self-identified religious vs. nonreligious participants. Results indicated that religious participants responded to the religious response categories significantly more than non-religious participants.

In the current study, reliability for the religiosity measure was $\alpha = .78$, indicating a good degree of internal consistency among the seven items on the scale. The means of the items ranged from 2.96 to 4.14, with a mean on the total scale of 24.07 (SD = 5.49).

Self-Control Measure. The Brief Self Control Scale (BSCS) was developed by Tangney, Baumeister, and Boone, (2004). This scale consists of 13 statements, each of which is rated on a five-point scale from 1 (not at all like me) to 5 (very much like me). The range of possible scores on the Self-Control Scale is 13 to 65. Higher scores signify greater self-control. Tangney et al. (2004) found strong internal consistency (Cronbach's alpha =.89) in a sample of college students. Further, Hershberger, Zryd, Rodes, & Stolfi

(2010) indicated the BSCS maintains reliability nearly as high as the full scale. The scale has strong validity in the literature with participants with low-self control scores reporting significantly more risk-taking behaviors as well as more negative emotions and coping strategies (Tangney et al., 2004). Internal consistency and test–retest reliability are also high (0.83 and 0.87, respectively) (Hershberger, Zryd, Rodes, & Stolfi, 2010).

In this study, reliability for this measure was α =.74, indicating a good degree of internal consistency among the seven items on the scale. The means of the items ranged from 2.77 to 4.29, with a mean on the total scale of 43.07 (SD = 6.14).

Religious Affiliation Measure. Roof and McKinney (1987) and Keller (2000) illustrated the importance of identifying an individual's religious affiliation based on the belief system of that affiliation and its similarities/differences to other affiliations. To acknowledge the importance of identifying these similarities and differences, religious sects were grouped into categories. These categories, based on the works of Roof and McKinney (1987) and Keller (2000) are presented in Table 2. For the purposes of this study, religious affiliation was not selected from the items in Table 2, but was provided by the participants in an open-ended question. Based on the participants' response to the question, they were then grouped into one of the ten categories.

Table 2: *Religious Affiliation Categories* (Roof & McKinney, 1987; Keller, 2000)

Protestant (Mainline)	Angelican/Episcopal, Lutheran, Presbyterian, Non-denominational Protestant, Congregationalist (United Church of Christ), Methodist, Baptist, Reformed, Anabaptist, and Pietist.
Protestant (Conservative)	Pentecostal (Assemblies of God, Church of God in Christ), Presbyterian, Restorationist (Church of Christ, Disciples of Christ), Adventist (Seventh-Day Adventist), Church of Nazarene, Friends/Quaker.
Catholic	
Other Christian	LDS/Mormon, Jehovah's Witness, Orthodox (Greek Russian, other).
Christian	not specified
None	Atheist, Agnostic, Secular, unsure.
Jewish	Reform, Conservative, Orthodox
Muslim	Sunni, Shia
Buddhist/Hindu	Zen Buddhist, Theravada Buddhist, Tibetan Buddhist
Other	Unitarian, Native American Religions, New Age, Pagan

Data Analysis

Chi-square tests were used to examine whether proactively selecting or not selecting life-sustaining treatment was different by age, by surrogate choice and by perceived diagnoses (Hypotheses 1 and 2). Logistic regression was conducted to determine whether factors associated with treatment decision making were predictive of selecting life-sustaining treatment (Hypothesis 3). To ascertain whether scoring high in religiosity or low in self-control resulted in life-sustaining treatment selections (Hypotheses 4 and 5), data were analyzed via independent samples t-tests. In addition, to determine whether low self-control scores were related to factors associated with not selecting life-sustaining treatment, correlational analyses were conducted (Hypothesis 5). Another chi-square analysis was completed to examine whether participants of the Protestant (mainline) affiliation were less likely to select treatment than other religious groups (Hypothesis 4). Finally, an additional chi-square analysis explored whether gender differences emerge when selecting treatment options (Hypothesis 6).

Results

Differences in Treatment Selection by Age, Target of Treatment, and Gender (Hypotheses 1, 2 and 6)

Chi-square analyses were conducted to investigate treatment selection decisions for young adults making the decision for themselves (YA_{self}), young adults making the decision for their selected middle-aged adult (YA_{other}), and the middle-aged adults making decisions for themselves (MA_{self}). Using chi-square analyses, treatment selection decisions were also examined by diagnosis (e.g., terminal illness plus cognitive decline and terminal illness only). These analyses indicate whether life-sustaining treatment selection varied by age and/or surrogate position (Hypothesis 1) as well as perceived diagnoses (Hypothesis 2) and gender (Hypothesis 6).

Hypothesis 1. To examine Hypothesis 1 (differences in treatment selection by age and by target of the treatment), Chi-Square analyses were conducted. The first group of analyses examined the differences between young adults when choosing treatment for themselves versus their selected guardians (YA_{self} vs. YA_{other}, Hypothesis 1a). It was predicted that young adult participants would be more likely to select treatment for their selected middle-aged adults than for themselves. This prediction was confirmed, χ^2 (1, n=106) = 31.89, $p < .001$, with 75 percent of the young adults selecting life-sustaining treatment for their guardian and only 65 percent selected life-sustaining treatment for themselves.

The next analyses examined Hypothesis 1b and 1c. It was predicted that young adults would select treatment less frequently for themselves than middle-aged adults selected for themselves (Hypothesis 1b) and that young adults would select treatment more frequently for their selected middle-aged adult than when the middle-aged adult made the choice for themselves (Hypothesis 1c). Both Hypotheses were not supported; YA_{self} vs. MA_{self}, χ^2 (1, n=50) = .01, $p > .05$, and YA_{other} vs. MA_{self}, χ^2 (1, n=50) = .07, $p > .05$.

Hypothesis Two. In the second hypothesis, it was predicted that participants in the terminally ill condition with loss of cognitive functioning would be less likely to select life-sustaining treatment than participants in the terminally ill condition with no additional ailment, across age groups. To examine whether diagnosis influenced treatment decision, three Chi-Square analyses were conducted. There were no differences between treatment selections by condition for young adults in the YA_{self} group, χ^2 (1, n=50) = .004, $p > .05$, or the YA_{other} group, χ^2 (1, n=50) = 2.15, $p > .05$. Treatment selection was unrelated to diagnoses for younger adults when selecting treatment for themselves or for their selected middle-aged adult.

Support was found, however, for hypothesis two when examining the relationship between diagnoses (conditions: terminal illness or terminal illness with cognitive impairment) and treatment decisions among the middle-aged adult group, χ^2 (1, n=50) = 6.65, $p < .05$. Middle-aged adults selected treatment significantly less often in the terminal illness with loss of cognitive functioning condition (34 percent) compared to those in the terminal illness condition (65 percent).

Hypothesis Six. Additional Chi-Square analyses explored whether gender differences emerged when choosing treatment options. It was hypothesized that men would be less likely to select life-sustaining treatment. Overall, there were no differences in treatment selection by gender, χ^2 (1, n=156) = 1.52, $p > .05$. An additional analysis of gender also revealed no significant differences by participant condition: terminal illness with loss of cognitive functioning, χ^2 (1, n=77) = .19, $p > .05$, and terminal illness only, χ^2 (1, n=79) = 2.10, $p > .05$. Women and men were equally likely to select treatment regardless of condition.

Factors Contributing to End-of-Life Treatment Decisions (Hypothesis 3)

Various factors have been found to influence end-of-life decision making. It was hypothesized that the factors associated with selecting life sustaining treatment [high valuing of religion (Religion), hope that it will get better (Hope) and control over one's end of life (Control)] would predict participants choosing to select life-sustaining treatment in this study as well. Factors associated with not selecting life-sustaining treatment [fear about quality of life (QOL), not wanting the side effects of medication (Medicine), and made peace/ready to move on (Peace)] were predicted to result in participants choosing not to select life-sustaining treatment in this study. Further, factors contributing to both selecting and not selecting life-sustaining treatment were also explored [friends and/or family beliefs (Friends/Family), doctor/nurse recommendations (DoctorRec), and previous end-of-life decision (e.g., DNR)].

Logistic regression was conducted to determine which variables (listed above) were predictors of proactive treatment selection decisions (yes or no). Data screening led to the elimination of 10 participants due to failure to complete ratings on the factors being examined and/or not selecting a treatment decision. Regression results show the overall model as being significant, the -2 Log Likelihood = 146.19, $\chi^2(9, n=151)=51.87$, $p < .001$. Regression coefficients are presented in Table 3. Overall, the model correctly classified in 74.20 percent of the cases. Selecting treatment was classified 87.50 percent of the time and not selecting treatment was classified in 50.90 percent of the cases.

Within the model, hope and peace were individual predictors of treatment decisions. Participants who indicated hope as being influential when making an end of life decision were 3.42 times more likely to select life-sustaining treatment, Wald's $\chi^2(1, N=151)=20$, $p < .001$, $B=-1.23$, $SE=.28$. Participants who indicated that making peace/being ready to move was influential when making an end of life decision were 1.67 times more likely to not select life-sustaining treatment, Wald's $\chi^2(1, N=151)=4.91$, $p = .03$, $B=.51$, $SE=.23$.

Table 3: *Factors Contributing to Treatment Selection Decisions*

Predictor	*B (SE)*	*Wald's* χ^2	*df*	*P*	*EXP(B)*
Hope	1.23 (.28)	20	1	.000	3.42
Peace	.51 (.23)	4.91	1	.03	1.67
Religion	-.01 (.15)	.01	1	.92	.99
Friends/Family	-.23 (.21)	1.20	1	.27	.80
Doctor Rec	-.49 (.34)	2.06	1	.15	.61
DNR	.07 (.18)	.13	1	.72	1.07
Control	.11 (.19)	.33	1	.57	1.11
QOL	-.19 (.19)	1.03	1	.31	.83
Medicine	-.20 (.18)	1.27	1	0.26	.82
Constant	6.12 (2.16)	8.01	1	.005	

Religiosity and Religious Affiliation (Hypothesis 4)

Composite religiosity scores were determined from participants' responses on the Rohrbaugh and Jessor (1975) Religiosity scale. On average, participants reported a religiosity score of 24.07 (SD = 5.49) with a range of 9-35. Attendance at religious services varied among participants, with the majority of respondents attending church fewer than ten times per year (35.1%), not attending church within the past year (14.6%), or attending church 50 or more times within the past year (13.6%).

It was predicted that participants who scored higher in religiosity would be more likely to select life-sustaining treatment (hypothesis 4). An independent samples t-test indicated no differences in religiosity scores between those who selected treatment (M = 24.99, SD = 5.57) and those who did not (M = 25.04, SD = 5.78), $t(149) = -0.05$, two-tailed, $p > .05$, $d = 0.01$. This was true for both young adults, $t(103) = 0.35$, two-tailed, $p > .05$, $d = 0.07$, and middle-aged adults, $t(44) = -0.39$, $p > .05$, two-tailed, $d = 0.12$.

It was also hypothesized that participants who indicated a Mainline Protestant affiliation would select life-sustaining treatment less often than other religious sects. Contrary to the hypothesis, there were no significant differences in treatment choice based on Protestant affiliation, χ^2 (1, n=151) = .11, $p > .05$. This was true for younger and middle-aged adults ($\chi^2(1, N=105)=0.07$, $p > .05$ and $\chi^2(1, N=46)=0.76$, $p > .05$, respectively).

An exploratory chi-square analysis was conducted to determine if there were differences in treatment selections between all religious affiliations. Although there were ten identified categories, the categories that had enough respondents to include in

analyses were Protestant, Catholic, Christian, and Atheist/Agnostic/None. There were no differences in treatment choice by these affiliations, χ^2 (3, n=142) = .59, $p > .05$.

Self-Control (Hypothesis 5)

Composite self-control scores were determined from participants' responses on the Baumiester et al. (1993) Brief Self-Control Scale (BSCS). On average, participants reported a self-control score of 43.07 (SD = 6.14) with a range of 28-62. To ascertain whether participants who scored lower in self-control were less likely to select life-sustaining treatment, an independent samples t-test was computed. Overall, there were no differences between self-control scores for those who selected treatment (M = 47.03, SD = 6.59) when compared to those who did not (M = 46.58, SD = 6.71), $t(152) = 0.41$, $p > .05$, $d = 0.07$. In addition, there were no differences between younger adults' self-control scores for those who selected treatment (M = 46.44, SD = 6.77) when compared to those who did not (M = 46.86, SD = 6.54), $t(104) = -0.35$, $d = 0.06$, nor were there differences between middle-aged adults' self-control scores for those who selected treatment (M = 48.46, SD = 5.98) when compared to those who did not (M = 46.05, SD = 7.14), $t(46) = 1.27$, $p > .05$, $d = 0.37$.

It was proposed that low self-control scores would also be related to factors associated with not selecting life-sustaining treatment. The factors associated with not selecting life-sustaining treatment were unrelated to self-control, including fear about quality of life, $r(151) = 0.02$, $p > .05$, not wanting the side effects of medication, $r(151) = 0.03$, $p > .05$, and making peace/ready to move, $r(151) = -0.00$, $p > .05$.

Exploratory Question

To determine if there was an interaction between religion and control in predicting treatment selection decisions, a logistic regression was conducted. An interaction variable was created combining the religiosity and self-control variable. This interaction variable along with the religiosity and self-control variables were then tested as predictors of treatment selection decisions. The model was not significant, $\chi^2(3, n=151)=2.62$, $p > .05$, $R^2=.02$, indicating that there was no interaction between these variables when predicting treatment selection decisions.

Informational Questions

Next, participants were asked whether they or someone in their family has had to make an end-of-life decision in the past. Of the middle aged adults, 47 percent indicated that this had occurred whereas 37.3 percent of the young adults said they had been involved in an end-of-life decision. Participants were also questioned on whether they had ever consulted with someone outside of their family regarding end-of-life decisions. Thirty-seven percent of middle-aged adults and 14 percent of young adults indicated that they had consulted with *outside* sources regarding end-of-life decisions. They were then asked whether they consulted with someone *inside* their family about end-of-life decisions. Thirty-four percent of the young adults reported discussing end-of-life decisions with their families compared to 62.7% of middle-aged adults.

Discussion

The results of the current study demonstrate some similarities and differences between younger and middle-aged adults in proactive decisions regarding end-of-life treatment. While some life-sustaining treatment decisions differed by age, some were consistent with prior research on older adults. Hypothesis 1 proposed three comparisons. The first comparison was found to be significant; young adults were more likely to choose life-sustaining treatment options for their selected middle-aged adult (surrogate decision) than for themselves. Contrary to the hypotheses, middle aged adults' treatment decisions for themselves were not significantly different from young adults' surrogate decisions or young adults' treatment decisions for themselves (comparison two and three).

Similar to past research on middle-aged adults' surrogate decisions for older adults (Limmerick, 2007; Wilson, 2011), this study also found that young adults, when taking surrogate roles, are more likely to select life-sustaining treatment for others than for themselves. Braun and McCullough (2011) suggest that the stress related to making decisions to end another's life may cause the surrogate to select treatment more frequently. However, in this study, young adults' surrogate choices did not differ from the middle-aged adults choices for themselves. This suggests that young adults may be more attuned to what middle-aged adults' choices would be. These findings also differ from past research that suggests that few (i.e., one-third) surrogates in fictitious circumstances were able to accurately predict the patient's desired treatment (Shalowitz,

Garrett-Meyer, and Wendler, 2006). This finding should be interpreted with caution, however, since the majority of young and middle-aged adults chose treatment regardless of the target of the treatment.

In this study, it was also predicted that there would be differences in life-sustaining treatment decisions by age. Research on older adults who are near the end of life has found that as age increases, choosing life-sustaining treatment decreases (Hickman et al., 2004). However, in this study there were no differences in life-sustaining treatment selection between younger and middle-aged adults. These findings may imply many different things. For example, as Hickman et al. (2004) suggests, life-sustaining treatment selection only decreases near the end-of-life. It is possible that a proactive fictitious decision as given in the current study does not elicit the same decisions as they do when faced with an actual decision. It is also possible that the lack of responses from middle-aged adults prevented the data from representing actual differences between young and middle-aged adults. On the other hand, there may not be a difference in treatment decisions for younger and middle-aged adults as there are between middle-aged and older adults.

Similar to previous findings that there is a negative stigma associated with loss of cognitive functioning (Boustani et al., 2011; Conde-Sala, 2010; Price et al., 2011), this study also found a relationship between end-of-life treatment decisions and perceived diagnosis. Specifically, this study found that middle-aged adults selected life-sustaining treatment significantly less often in the terminal illness with loss of cognitive functioning condition than in the terminal illness alone condition. Thus, like older adults, middle-

aged adults may fear a perceived diagnosis of dementia because it involves losing one's independence (Price et al., 2011).

For young adults, there were no differences in treatment selection options between the illness conditions. It is possible that in contrast to the middle-aged adults, the young adults did not understand the differences in the conditions (i.e., the potential impact of cognitive decline). Research on public perceptions of cognitive impairment indicates that people lack knowledge about cognitive impairment (Anderson, Day, Beard, Reed, & Wu, 2009). This may be true for younger adults in this sample, whereas middle-aged adults may have some understanding due to age-related experience. It is also possible that young adults perceived both conditions as equally negative. Fritsche et al.'s (2008) research suggests that thinking about death produces an aversive state that creates an avoidance reaction. In addition, Popham et al. (2011) found that young adults' fear of aging and ageist attitudes causes them to distance themselves from their awareness of their own mortality. Therefore, anxiety about death may have been equally triggered in both conditions.

Prior research on reactive end-of-life treatment decisions in older adults has also indicated several factors that influence end-of-life treatment decisions (Hypothesis 3). This study found evidence that two such factors also influence young and middle-aged adults' proactive treatment decisions: "hope that it will get better" and "made peace/being ready to move on." Similar to past research, participants who reported that hoping the terminal illness would get better was influential in making a treatment decision, and were more likely to select life-sustaining treatment (Johnson, 2007; Rousseau, 2000). In

addition, participants who reported that making peace and being ready to move on was influential in making their treatment decision were less likely to select life-sustaining treatment (Rotham et al., 2007, Sharf et al., 2005). These results were consistent across age and treatment conditions. Participants were also given the opportunity to add additional factors related to treatment conditions. Many participants highlighted the importance of perceived burdensomeness (e.g., "burden left on family"). Researchers have found this factor to be predictive of treatment preferences for older adults and their surrogates, but have not assessed the relationship between burdensomeness and end-of-life treatment decisions among younger and middle aged adults (McPherson, Wilson, & Murray, 2007; Winter & Parks, 2012). It will be important for future research to confirm the role of perceived burdensomeness in these populations. Other factors found in previous research on end-of-life treatment decisions were not found to be predictive in this sample (i.e., religion, control over the end of one's life, fear about quality of life, not wanting the side effects of medication, friends and/or family beliefs, doctor/nurse recommendations, and previous end-of-life decision). These factors may not have been predictive of treatment selection because they may influence decisions to select or not select treatment equally, or it could be that proactive decision making is not influenced by these items in the same way as reactive decision making.

Prior research on treatment decisions also indicates the importance of religion in the treatment decision process (Hypothesis 4). Specifically, religious individuals are more likely to select life-sustaining treatment than non-religious individuals (Bulow et al., 2008, Cicerelli et al., 1999; Rietjens et al., 2005; Van Ness et al., 2008; Winter et al.,

2009), with the exception of mainline Protestants who report being less likely to seek treatment (Carr & Moorman 2009; Denk et al., 1997). Unlike prior research, in this study proactive treatment decisions were not influenced by religiosity (as measured by the Rohrbaugh and Jessor Religiosity Scale) or by religious affiliation. Similarly, regardless of age, participants in both conditions indicated that their religion would not influence their end-of-life decisions. It is possible that these findings are demonstrating the differences between reactive and proactive decision making. Specifically, older adults facing reactive decisions may be influenced more by religious values compared to younger and middle-aged adults making proactive fictitious decisions. On the other hand, religion may not be an influential factor when younger and middle-aged adults make end-of life decisions. These findings may also suggest that fictitious diagnoses may not activate religious thought to the same extent as living with a terminal condition. Furthermore, treatment decisions in young, middle and older-aged adult populations may be influenced by different factors (and not influenced by religiosity). Finally, these results may also be a function of the sample surveyed. The survey was only distributed in one region, which limits its ecological validity. Further, the majority of participants in this study were religiously affiliated (86.1%), which is comparatively high (King & Wells, 2003).

Similar to the findings for religion, self-control was not related to proactive treatment decisions (Hypothesis 5a). It was expected that the relationship between low self-control and risk taking behaviors (Baumiester et al., 1993; Mishra & Lalumiere, 2011; Tangney et al., 2004) would influence the participant's likelihood to select life-

sustaining treatment. However, self-control did not influence decision making, nor were there relationships between scores on the Brief Self Control Scale and the hypothesized factors: fear about the quality of life; not wanting the side-effects of medication; and made peace/ready to move on. It is possible that the homogeneity of responses for the self-control variable (all participants scored high on the measure) restricted the ability to detect a relationship between self-control and treatment decisions/factors. However, scoring high in self-control is consistent with a highly religious sample (McCullough & Willoughby, 2009) such as this one.

Previous research in the area of self-control also supported gender differences (Cotter, 2003; Courtenay, 2000). Specifically, men are more likely to engage in risk taking behavior (Hypothesis 6). However, there were no differences in treatment selection decisions when comparing men and women in this sample. These findings suggest that the proposed relationship between treatment selection and risk taking may not be real. The majority of young and middle-aged adult participants were women (77% and 83%, respectively) which may also have prevented the ability to find reliable gender differences.

Limitations

Similar to past research on older adults' treatments decisions, this study found that younger and middle-aged adults are more likely to choose treatment for others than for themselves and that hope and making peace influence treatment decisions. Unlike the older adult research, this study found no relationship between treatment decisions and

religiosity, religious affiliation, or self-control. Considering these findings, it is important to note some potential limitations to this study. The response rate of the middle-aged adult participants was low (50%). A larger sample may have allowed for more confidence in the findings by reducing the likelihood of Type II errors. Specifically, if more participants would have responded, the responses may have become less homogeneous and allowed for more differences to emerge. In addition, the overrepresentation of women in the sample, particularly among middle-aged adults (83%) may have allowed for a Type II error. Cotter (2003) suggests that women and men's anxiety about death differ. Thus, a more representative sample may have allowed gender differences to emerge and influenced the findings on Hypothesis 5 and 6.

There may be additional limitations due to the characteristics of the sample. First, participants in this study reported high religious affiliation and scored high in self-control, reducing overall variability within these two factors. Second, the order of the presentation of materials may have influenced the results of this study. For example, although participants were given time to write about their thoughts regarding whether or not to select life-sustaining treatment, most participants still made their treatment choices at the beginning of the study. Perhaps if they had more time to think about the decision their choices would have varied more. Further, since the manipulation of conditions had no effect on the younger adults, more time may have allowed for them to consider the differences between conditions. Research also suggests a priming effect for religion. Specifically, having a participant identify their religion prior to making choices on a survey causes the religious values and identification to become salient, thus influencing

the behavior and choices (Inzlicht & Tullett, 2009; Randolph-Seng & Neilsen, 2007; Saraglou, Corneille, & Van Cappellen, 2009; Shariff & Norenzayan, 2007). Reordering the questionnaires may therefore have led to a stronger relationship between religion and treatment decisions because religious thought would have been primed. Further, since the young adults' treatment decisions for the middle-aged adult were completed after answering the Rohrbaugh and Jessor Religiosity Survey, the priming of religion may have occurred. Thus, the finding that young adults chose treatment for their middle-aged adults may be confounded by the effect of priming.

Future Directions

Considering the findings and limitations, there are a number of future directions that research on proactive end-of-life treatment decision making can take. First, future research should attempt to replicate and confirm the differences found between older adults and younger/middle-aged adults when assessing religiosity, religious affiliation, and self-control. As of yet, few studies have assessed the relationship between affiliation and treatment selection decisions (Carr & Moorman, 2009; Denk et al., 1997; Sprung et al., 2007) and these studies focused on those who are faced with end-of-life decisions. Thus, it may be beneficial to replicate the finding that end-of-life decisions made in the older adult group are influenced more by religion than those made in young and middle-aged groups.

Larger samples from more diverse communities may also allow for a better examination of the relationship between these variables and proactive treatment

decisions. It will also be important to examine the concept of "burden" in future research on factors that influence treatment decisions in young and middle-aged adults as well as identify other factors that may be important in proactive decision making. Considering that 75 percent of the population does not understand the relationship between age and changes that may occur in cognitive functioning due to dementia (Anderson et al., 2009), future research on the impact of diagnosis may also benefit from having clearer definitions of loss of cognitive functioning.

Implications

The findings of this study indicate that some end-of-life treatment decisions do differ by age and that certain beliefs and diagnoses influence these decisions. Not unlike the POLST form, this study asked participants to select treatment decisions based on varying diagnoses. Since responses were found to vary by age and diagnosis (at least among middle-aged adults), it is possible that patients' responses to POLST forms may also differ by age and condition described. Further, considering that less than 50 percent of participants in this study discussed end-of-life decisions with their families/doctors, programs such as POLST may be useful in increasing the number of related conversations among family members and treating physicians.

Research also suggests that lack of knowledge on age-related cognitive impairments influences perceptions of patients with such ailments (Staples & Killian, 2012). Staples and Killian (2012) found that providing more information on cognitive decline may promote more informed decision making. Therefore, it is important for

treating physicians to engage families and patients with end-of-life programs because it will open discussions about possible future diagnoses. Further, providing this informational data to young and middle-aged adults as well as caregivers may influence their life-sustaining treatment choices for themselves and for others.

The implication that fear about quality of life is predictive of not selecting treatment also suggests the importance of proactive discussions about the end of life. If the fear is to be overcome, programs such as POLST and Five Wishes may provide young and middle aged adults with the necessary tools to begin having discussions with their families and their doctors.

Conclusion

The results of the current study provide evidence that when faced with an end-of-life treatment decision, choices are influenced by being a surrogate, age and diagnosis (at least for middle-aged adults) as well as hoping the condition will improve and making peace/being ready to move on. Consistent with research on older adults, the results of the current study also suggest that, regardless of age, surrogates are more likely to seek treatment for others who are faced with a terminal illness than for themselves. However, only middle-aged adults were less likely to select treatment when faced with a terminal illness that also included cognitive impairments. In this study, as well as other studies on older adults, having hope that the disease will get better was a significant predictor of selecting life-sustaining treatment while making peace and being ready to move on was predictive of not selecting life-sustaining treatment. Unlike the older adult reactive

treatment decision research, this study found no relationship between religiosity, religious affiliation, and self-control and treatment decisions. This study contributes to prior research by examining age differences and by demonstrating the potential differences between differing diagnoses when selecting life-sustaining treatment.

Appendix A
Student Consent Form

Eric Beck, B.S., of the Department of Psychology at the University of Wisconsin Oshkosh, is conducting a study of how students think about end of life decisions. We would appreciate your participation in this as it will assist us in making recommendations about the implementation of end of life decision programs within the United States.

As part of this study, we are going to ask questions about how you would make decisions surrounding the end of life. We do not anticipate that the study will present any medical or social risk to you, other than the inconvenience of extra time required for you to answer the questionnaire. Participation in this study may not benefit you directly, but may provoke communication between family members about end of life decisions. If you or your family is currently facing such decisions, please keep in mind that participation in this study is voluntary.

The information we gather through the questionnaire will be recorded confidentially. While the information collected will be linked to a person you know who participated in the research, all information will be kept confidential and private. We will not release information about you or to anyone else in a way that could identify you.

If you want to withdraw from the study at any time, you may do so without penalty and will still earn credit. The information collected from you up to that point would be destroyed if you so desire. Once the study is completed, we would be glad to give the results to you. In the meantime, if you have any questions, please contact:

Eric Beck, B.S.
Becke66@uwosh.edu
Department of Psychology
UW Oshkosh
Oshkosh, WI 54901

Erin Winterrowd, PhD.
Department of Psychology
UW Oshkosh
Oshkosh, WI 54901
920/424-7175

If you have any complaints about your treatment as a participant in this study, please call or write:

Chair, Institutional Review Board
For Protection of Human Participants
c/o Grants Office
UW Oshkosh
Oshkosh, WI 54901
920/424-1415

Although the chairperson may ask for your name, all complaints are kept in confidence.

I have received an explanation of the study and agree to participate. I understand that my participation in this study is strictly voluntary.

_____

PRINTED NAME SIGNATURE DATE

This research project has been approved by the University of Wisconsin Oshkosh IRB for Protection of Human Participants for a 1-year period, valid until (one year from the IRB approval).

Appendix B
Middle-Aged Adult Consent Form

Eric Beck, B.S., of the Department of Psychology at the University of Wisconsin Oshkosh, is conducting a study of how students think about end of life decisions. We would appreciate your participation in this as it will assist us in making recommendations about the implementation of end of life decision programs within the United States.

As part of this study, we are going to ask questions about how you would make decisions surrounding the end of life. We do not anticipate that the study will present any medical or social risk to you, other than the inconvenience of extra time required for you to answer the questionnaire. Participation in this study may not benefit you directly, but may provoke communication between family members about end of life decisions. If you or your family is currently facing such decisions, please keep in mind that participation in this study is voluntary.

The information we gather through the questionnaire will be recorded confidentially. While the information collected will be linked to a person you know who participated in the research, all information will be kept confidential and private. We will not release information about you or to anyone else in a way that could identify you. In addition, completing this survey will not benefit the student who requested your participation, nor will it impact their grade.

If you want to withdraw from the study at any time, you may do so without penalty. The information collected from you up to that point would be destroyed if you so desire. Once the study is completed, we would be glad to give the results to you. In the meantime, if you have any questions, please contact:

Eric Beck, B.S.
Becke66@uwosh.edu
Department of Psychology
UW Oshkosh
Oshkosh, WI 54901

Erin Winterrowd, PhD.
Department of Psychology
UW Oshkosh
Oshkosh, WI 54901
920/424-7175

If you have any complaints about your treatment as a participant in this study, please call or write:

Chair, Institutional Review Board
For Protection of Human Participants
c/o Grants Office
UW Oshkosh
Oshkosh, WI 54901
920/424-1415

Although the chairperson may ask for your name, all complaints are kept in confidence.

I have received an explanation of the study and agree to participate. I understand that my participation in this study is strictly voluntary.

PRINTED NAME SIGNATURE DATE

This research project has been approved by the University of Wisconsin Oshkosh IRB for Protection of Human Participants for a 1-year period, valid until (one year from the IRB approval).

Appendix C
Student Survey

The purpose of this study is to examine the end of life decision making process.

_____

Condition 1:
Please imagine that you have been recently diagnosed with a terminal illness and were told you have one month to live.

Condition 2:
Please imagine that you have been recently diagnosed with a terminal illness as well as a diagnosis of loss of cognitive functioning and were told you have one month to live. A loss of cognitive functioning involves a loss of the ability to recall and create new memories, to organize thoughts appropriately, and will diminish one's ability to interact conversationally with others.

_____

Please take a few seconds to imagine what this experience would be like. With the following questions, we hope to explore how you would feel in this situation and discuss the end-of-life decision making process that you would have to go through. As health declines, you would be expected to make choices about the treatment you would receive as the condition progresses. Please answer the following questions and imagine you were given this survey after the diagnosis.

After taking a few seconds to think about what you would do if this happened, please read and answer the following questions.

Please imagine that after the diagnosis you are asked to consider how you would make a choice to **select** life-sustaining treatment or **not select** life-sustaining treatment. For example, after the diagnosis your doctor will indicate that selecting life-sustaining treatment may extend your life. On the other hand, not selecting life-sustaining treatment will prevent additional treatments and end-of-life will likely occur within a month.

How did you go about selecting the decision you made for yourself? What was your thought process? Please provide as many thoughts/answers as possible.

_____

_____

_____

_____

_____

_____

Please indicate based on the information you wrote above whether or not you would select life-sustaining treatment (please circle the option that best represents what you would do).

Yes, I would select treatment. No, I would not select treatment

Have you or someone in your family been in this situation before? Please circle yes or no.

YES NO

Have you ever consulted with someone outside of your family about end of life decisions? Please circle yes or no.

YES NO

Have you ever consulted with your family about end-of-life decisions? Please circle yes or no.

YES NO

Please rate the following items on how important they would be in assisting you to make the decision to select or not select life-sustaining treatment for yourself. Please circle the number that best represents your choice,

	Not important	Very important
1. Hope that it will get better	1———2———3———4———5	
2. Religious values	1———2———3———4———5	
3. Friends/Family beliefs	1———2———3———4———5	
4. Doctor/nurse recommendation	1———2———3———4———5	
5. Made peace, ready to move on	1———2———3———4———5	
6. Previous end-of-life decision made	1———2———3———4———5	
7. Control over end of life	1———2———3———4———5	
8. Fear about quality of life	1———2———3———4———5	
9. Not wanting side effects of medication:	1———2———3———4———5	
10. Other: Please describe:	1———2———3———4———5	

_____

_____

Using the scale provided, please indicate to what extent each of the following statements reflects you. Circle the number that best matches.

	Not at all				Very much
1. I am good at resisting temptation.	1	2	3	4	5
2. I have a hard time breaking bad habits.	1	2	3	4	5
3. I am lazy.	1	2	3	4	5
4. I say inappropriate things.	1	2	3	4	5
5. I do certain things that are bad for me, if they are fun.	1	2	3	4	5
6. I refuse things that are bad for me.	1	2	3	4	5
7. I wish I had more self-discipline.	1	2	3	4	5
8. People would say that I have iron self- discipline.	1	2	3	4	5
9. Pleasure and fun sometimes keep me from getting work done.	1	2	3	4	5
10. I have trouble concentrating.	1	2	3	4	5
11. I am able to work effectively toward long-term goals.	1	2	3	4	5
12. Sometimes I can't stop myself from doing something, even if I know it is wrong.	1	2	3	4	5
13. I often act without thinking through all the alternatives.	1	2	3	4	5

Please answer the following questions.

1. How often have you attended religious services during the past year? _____times.

2. Which of the following best describes your practice of prayer or religious meditation?
   a) Prayer is a regular part of my daily life.
   b) I usually pray in times of stress or need but rarely at any other time.
   c) I pray only during formal ceremonies.
   d) Prayer has little importance in my life.
   e) I never pray

   ANSWER: _____

3. When you have a serious personal problem how often do you take religious advice or teaching into consideration?
   a) Almost always
   b) Usually
   c) Sometimes
   d) Rarely
   e) Never

   ANSWER: _____

4. How much of an influence would you say that religion has on the way that you choose to act and the way that you choose to spend your time each day?
   a) No influence
   b) A small influence
   c) Some influence
   d) A fair amount of influence
   e) A large influence

   ANSWER: _____

5. Which of the following statements comes closest to your belief about God?
   a) I am sure that God really exists and that GOD is active in my life.
   b) Although I sometimes question God's existence, I do believe in God and believe God knows of me as a person.
   c) I don't know if there is a personal God, but I do believe in a higher power of some kind.
   d) I don't know if there IS a personal God or a higher power of some kind, and I don't know if I will ever know.
   e) I don't believe in a personal God or in a higher power. ANSWER: _____

6. Which of the following statements comes closest to your belief about life after death?
   a) I believe in a personal life after death, a soul existing as a specific individual.
   b) I believe in a soul existing after death as a part of a universal spirit.
   c) I believe in a life after death of some kind, but I really don't know what it would be like.
   d) I don't know whether there is any kind of life after death, and I don't know if I will ever know.
   e) I don't believe in life after death. ANSWER: _____

7. During the past year, how often have you experienced a feeling of religious reverence or devotion?
   a) Almost daily d) Rarely
   b) Frequently e) Never
   c) Sometimes . ANSWER: _____

8. Do you agree with the following statement? "Religion gives me a great amount of comfort and security in life".
   a) Strongly disagree d) Agree
   b) Disagree e) Strongly Agree
   c) Uncertain ANSWER: _____

As stated earlier, the purpose of this study is to examine the end of life decision making process. Prior to the study you were asked to bring your middle-aged adult's (i.e. parent, legal guardian, middle-aged friend) contact information. Please imagine your selected middle-aged adult in the following condition and then answer the following questions.

_____

Condition 1:
Please imagine that your selected middle-aged adult has been recently diagnosed with a terminal illness and were told they only have one month to live.

Condition 2:
Please imagine that your selected middle-aged adult has been recently diagnosed with a terminal illness as well as a diagnosis of loss of cognitive functioning and were told you have one month to live. A loss of cognitive functioning involves a loss of the ability to recall and create new memories, to organize thoughts appropriately, and will diminish one's ability to interact conversationally with others.

_____

Please take a few seconds to imagine what this experience would be like. With the following questions, we hope to explore how you would feel in this situation and discuss the end-of-life decision making process that you would have to go through for your selected middle-aged adult. As health declines, you will be expected to make choices about the treatment your selected middle-aged adult will receive as their condition progresses. Please answer the following questions and imagine you were given this survey after the diagnosis.

After taking a few seconds to think about what you would do if this happened, please read and answer the following questions.

Please imagine that after the diagnosis you are asked to consider how you would make a choice to **select** life-sustaining treatment or **not select** life-sustaining treatment. For example, after the diagnosis the doctor will indicate that selecting life-sustaining treatment may extend the life of your selected middle-aged adult. On the other hand, not selecting life-sustaining treatment will prevent additional treatments and end-of-life will likely occur within a month.

Please indicate based on the information the doctor provided you, whether or not you would select life-sustaining treatment for your selected middle-aged adult (please circle the option that best represents what you would do).

Yes, I would select treatment. No, I would not select treatment

Please rate the following options on how important they would be in assisting you in making the decision to select or not select life-sustaining treatment for your selected middle-aged adult. Please circle the number that best represents your choice.

	Not important	Very important
1. Hope that it will get better	1——2——3——4——5	
2. Religious values	1——2——3——4——5	
3. Friends/Family beliefs	1——2——3——4——5	
4. Doctor/nurse recommendation	1——2——3——4——5	
5. Made peace, ready to move on	1——2——3——4——5	
6. Previous end-of-life decision made	1——2——3——4——5	
7. Control over end of life	1——2——3——4——5	
8. Fear about quality of life	1——2——3——4——5	
9. Not wanting side effects of medication:	1——2——3——4——5	
10. Other: Please describe:	1——2——3——4——5	

_____

_____

How is the decision different when making the choice for yourself compared to making the choice for your selected middle-aged adult? How did you go about selecting the decision you made for your selected middle-aged adult? What was your thought process? Please provide as many thoughts/answers as possible.

_____

_____

_____

_____

_____

Please fill out the following information about yourself. This information will be used for statistical comparisons, and will not be used to determine your identity.

1. Sex _____

2. Age (in years) _____

3. Years of school completed _____

4. Ethnicity: (Please fill in a circle for ALL that apply to you; you can fill in more than one circle)
   - ○ Asian American
   - ○ Black/African American
   - ○ White/European American
   - ○ Latino/Hispanic American
   - ○ Mixed Racial (two or more races)
   - ○ American Indian/Native American
   - ○ Other→ If other, please specify_____

5. Religious affiliation: _____

6. Any comments or recommendations about this study?

_____

_____

_____

Appendix D
Middle-Aged Adult Survey

The purpose of this study is to examine the end of life decision making process.

_____

Condition 1:
Please imagine that you have been recently diagnosed with a terminal illness and were told you only have one month to live.

Condition 2:
Please imagine that you have been recently diagnosed with a terminal illness as well as a diagnosis of loss of cognitive functioning and were told you only have one month to live. A loss of cognitive functioning involves a loss of the ability to recall and create new memories, to organize thoughts appropriately, and will diminish one's ability to interact conversationally with others.

_____

Please take a few seconds to imagine what this experience would be like. With the following questions, we hope to explore how you would feel in this situation and discuss the end-of-life decision making process that you would have to go through. As health declines, you would be expected to make choices about the treatment you would receive as the condition progresses. Please answer the following questions and imagine you were given this survey after the diagnosis.

After taking a few seconds to think about what you would do if this happened, please answer the following questions.

Please imagine that after the diagnosis you are asked to consider how you would make a choice to **select** life-sustaining treatment or **not select** life-sustaining treatment. For example, after the diagnosis your doctor will indicate that selecting life-sustaining treatment may extend your life. On the other hand, not selecting life-sustaining treatment will prevent additional treatments and end-of-life will likely occur within a month.

Please try and describe what you would do. How did you go about selecting the decision you made for yourself? What was your thought process? Please provide as many thoughts/answers as possible.

_____

_____

_____

_____

_____

_____

Please indicate based on the information you wrote above whether or not you would select life-sustaining treatment (please circle the option that best represents what you would do).

Yes, I would select treatment. No, I would not select treatment

Have you or someone in your family been in this situation before? Please circle yes or no.

YES NO

Have you ever consulted with someone outside of your family about end of life decisions? Please circle yes or no.

YES NO

Have you ever consulted with your family about end-of-life decisions? Please circle yes or no.

YES NO

Please rate the following items on how important they would be in assisting you to make the decision to select or not select life-sustaining treatment for yourself. Please circle the number that best represents your choice,

	Not important	Very important
1. Hope that it will get better	1———2———3———4———5	
2. Religious values	1———2———3———4———5	
3. Friends/Family beliefs	1———2———3———4———5	
4. Doctor/nurse recommendation	1———2———3———4———5	
5. Made peace, ready to move on	1———2———3———4———5	
6. Previous end-of-life decision made	1———2———3———4———5	
7. Control over end of life	1———2———3———4———5	
8. Fear about quality of life	1———2———3———4———5	
9. Not wanting side effects of medication:	1———2———3———4———5	
10. Other: Please describe:	1———2———3———4———5	

_____

_____

Using the scale provided, please indicate to what extent each of the following statements reflects you. Circle the number that best matches.

	Not at all				Very much
1. I am good at resisting temptation.	1	2	3	4	5
2. I have a hard time breaking bad habits.	1	2	3	4	5
3. I am lazy.	1	2	3	4	5
4. I say inappropriate things.	1	2	3	4	5
5. I do certain things that are bad for me, if they are fun.	1	2	3	4	5
6. I refuse things that are bad for me.	1	2	3	4	5
7. I wish I had more self-discipline.	1	2	3	4	5
8. People would say that I have iron self- discipline.	1	2	3	4	5
9. Pleasure and fun sometimes keep me from getting work done.	1	2	3	4	5
10. I have trouble concentrating.	1	2	3	4	5
11. I am able to work effectively toward long-term goals.	1	2	3	4	5
12. Sometimes I can't stop myself from doing something, even if I know it is wrong.	1	2	3	4	5
13. I often act without thinking through all the alternatives.	1	2	3	4	5

Please answer the following questions.

1. How often have you attended religious services during the past year? _____times.

2. Which of the following best describes your practice of prayer or religious meditation?
   a) Prayer is a regular part of my daily life.
   b) I usually pray in times of stress or need but rarely at any other time.
   c) I pray only during formal ceremonies.
   d) Prayer has little importance in my life.
   e) I never pray

   ANSWER: _____

3. When you have a serious personal problem how often do you take religious advice or teaching into consideration?
   a) Almost always
   b) Usually
   c) Sometimes
   d) Rarely
   e) Never

   ANSWER: _____

4. How much of an influence would you say that religion has on the way that you choose to act and the way that you choose to spend your time each day?
   a) No influence
   b) A small influence
   d) A fair amount of influence
   e) A large influence

c) Some influence ANSWER: _____

5. Which of the following statements comes closest to your belief about God?
   a) I am sure that God really exists and that GOD is active in my life.
   b) Although I sometimes question God's existence, I do believe in God and believe God knows of me as a person.
   c) I don't know if there is a personal God, but I do believe in a higher power of some kind.
   d) I don't know if there IS a personal God or a higher power of some kind, and I don't know if I will ever know.
   e) I don't believe in a personal God or in a higher power. ANSWER: _____

6. Which of the following statements comes closest to your belief about life after death?
   a) I believe in a personal life after death, a soul existing as a specific individual.
   b) I believe in a soul existing after death as a part of a universal spirit.
   c) I believe in a life after death of some kind, but I really don't know what it would be like.
   d) I don't know whether there is any kind of life after death, and I don't know if I will ever know.
   e) I don't believe in life after death. ANSWER: _____

7. During the past year, how often have you experienced a feeling of religious reverence or devotion?
   a) Almost daily d) Rarely
   b) Frequently e) Never
   c) Sometimes ANSWER: _____

8. Do you agree with the following statement? "Religion gives me a great amount of comfort and security in life".
   a) Strongly disagree d) Agree
   b) Disagree e) Strongly Agree
   c) Uncertain ANSWER: _____

Please fill out the following information about yourself. This information will be used for statistical comparisons, and will not be used to determine your identity.

1. Sex _____

2. Age (in years) _____

3. Years of school completed _____

4. Ethnicity: (Please fill in a circle for ALL that apply to you; you can fill in more than one circle)
   - ○ Asian American
   - ○ Black/African American
   - ○ White/European American
   - ○ Latino/Hispanic American
   - ○ Mixed Racial (two or more races)
   - ○ American Indian/Native American
   - ○ Other→ If other, please specify_____

5. Religious affiliation: _____

5. Any comments or recommendations about this study?

_____

_____

_____

Appendix E
Debriefing Statement for Students

An Examination of End-of-Life Decisions

Life is full of decisions. We decide when we need to go to the grocery store, we plan for holidays and vacations, and we plan for our future and our children's future. However, most people fail to plan for the end of their life. Research indicates that this failure is an avoidance that may be caused by a fear of death. Since this fear can be overwhelming and prevent us from making end-of-life decisions, the choices are sometimes left to our families. Such decisions are often emotionally overwhelming for families.

The importance of discussing end-of-life decisions and having familial input and shared knowledge about these decisions has never been more pressing. According to the United States Census Bureau, the projected population increase from 2010 to 2030 will be 17.7 percent. Adults over the age of 65 in 2030 will total 71.5 million. This is an increase of 44 percent in 20 years. This tremendous increase in the aging population is particularly significant because despite the importance of end-of-life decision making most states don't require patients to complete end-of-life decision forms. Since the increase in older adults will cause these decisions to be made more frequently, it is very important that these decisions be discussed or documented.

The information generated by this study may be useful in promoting the medical community to adopt a program that allows patients to keep end-of-life decisions in their medical files. The current system in place by hospitals (advanced directives) allows for doctors to see treatment preferences, but does not allow them to see life-sustaining preferences. In addition, this research will assist us in understanding some factors that are related to end-of-life decisions as well as examine how religious participation and self-control play a part in reasons for partaking or abstaining from life-sustaining treatment.

We appreciate your participation in this research project. We hope that you have learned something about the process of psychological research and gained some insight about what type of choices you would make for yourself if faced with an end-of-life decision. We also hope this research will spark a conversation within your own family so you can learn about each other's treatment preferences.

If your participation in this research has caused any distress, please consider talking with someone about it. The University Counseling Center is located on the University of Wisconsin campus in the Student Success Center, Suite 240, 750 Elmwood Ave. The Counseling Center is open during the 14-week semesters from
Monday 8:00 a.m. - 7:00 p.m., Tuesday through Friday 8:00 a.m. - 4:30 p.m., and for all other times the schedule is Monday through Friday 8:00 a.m. - 4:30 p.m. Student counseling sessions are free. To schedule an appointment you may call (920) 424-2061. The University Counseling Center provides an after-hours emergency phone: 1-800-273-TALK (8255). If you have an immediate emergency or need after-hours care, please call 911.

If you have any questions about this research, please feel free to contact:

Eric Beck, B.S.
Becke66@uwosh.edu
Department of Psychology
UW Oshkosh
Oshkosh, WI 54901

Erin Winterrowd, PhD.
Department of Psychology
UW Oshkosh
Oshkosh, WI 54901
920/424-7175

Appendix F
Debriefing Statement for Middle-Aged Adults

An Examination on End-of-Life Decisions

Life is full of decisions. We decide when we need to go to the grocery store, we plan for holidays and vacations, and we plan for our future and our children's future. However, most people fail to plan for the end of their life. Research indicates that this failure is an avoidance that may be caused by a fear of death. Since this fear can be overwhelming and prevent us from making end-of-life decisions, the choices are sometimes left to our families. Such decisions are often emotionally overwhelming for families.

The importance of discussing end-of-life decisions and having familial input and shared knowledge about these decisions has never been more pressing. According to the United States Census Bureau, the projected population increase from 2010 to 2030 will be 17.7 percent. Adults over the age of 65 in 2030 will total 71.5 million. This is an increase of 44 percent in 20 years. This tremendous increase in the aging population is particularly significant because despite the importance of end-of-life decision making most states don't require patients to complete end-of-life decision forms. Since the increase in older adults will cause these decisions to be made more frequently, it is very important that these decisions be discussed or documented.

The information generated by this study may be useful in promoting the medical community to adopt a program that allows patients to keep end-of-life decisions in their medical files. The current system in place by hospitals (advanced directives) allows for doctors to see treatment preferences, but does not allow them to see life-sustaining preferences. In addition, this research will assist us in understanding some factors that are related to end-of-life decisions as well as examine how religious participation and self-control play a part in reasons for partaking or abstaining from life-sustaining treatment.

We appreciate your participation in this research project. We hope that you have learned something about the process of psychological research and gained some insight about what type of choices you would make for yourself if faced with an end-of-life decision. We also hope this research will spark a conversation within your own family so you can learn about each other's treatment preferences.

If your participation in this research has caused any distress, please consider talking with someone about it. The Winnebago County Crisis Helpline is open 24 hours a day and 7 days a week. To speak with someone you may call (920) 233-7707. If you have an immediate emergency, please call 911.

If you have any questions about this research, please feel free to contact:

Eric Beck, B.S.
Becke66@uwosh.edu
Department of Psychology
UW Oshkosh
Oshkosh, WI 54901

Erin Winterrowd, PhD.
Department of Psychology
UW Oshkosh
Oshkosh, WI 54901
920/424-7175

Appendix G
Middle-Aged Adult Letter from Student (Mail Version)

Dear _____:

Your family member or friend _____ has participated in a research study on end-of-life decisions. The research, which is being conducted by Eric Beck, B.S. and Dr. Erin Winterrowd at the Department of Psychology at the University of Wisconsin-Oshkosh, focuses on thoughts and perceptions surrounding the end-of-life decision process.

The research involves the participation of students and their adult friends or family members. A friend or family member has addressed this envelope to you so that you may be invited to participate.

The student who invited you to participate does not receive a grade for participating in this study. In addition, your participation in this study does not impact the student. Your participation is completely voluntary, and you may withdraw from this study at any time with no penalty. By signing and returning the enclosed informed consent form, you are consenting to participate in this research study. There are no known risks or benefits associated with participation in this research. Participation in this study may not benefit you directly, but may provoke communication between family members about end-of-life decisions and what it is like to participate in psychological research.

Please read the informed consent form carefully, initial each page and date and sign at the end. One copy will be for your records, the other copy is to be returned to us along with the questionnaire.

Please fill-out the enclosed questionnaire and return it to Eric Beck; we would appreciate prompt attention. You are asked to complete the questionnaire with includes a short demographic survey. There are no right or wrong answers on any of the measures. You may keep this letter for your own records. At no time will you be asked to use your name on the questionnaire. Instead, questionnaires will be identified through the use of code numbers. The informed consent form will be separated from the questionnaire. All responses will remain confidential and will be stored in a locked lab. Your referring family member or friend will not see your responses to the questionnaire and vice versa. The questionnaire takes about 20-30 minutes to complete.

Please keep the enclosed debriefing form and a copy of the informed consent form for your records. The debriefing form contains valuable information about the end-of-life decision process and discusses the importance of making these decisions.

Thank you for your help.

Sincerely,

_____

Eric Beck, B.S.
Masters Student, Department of Psychology

Appendix H
Middle-Aged Adult Letter from Student (Email Version)

Dear _____,

Your family member or friend _____ has participated in a research study on end-of-life decisions. The research, which is being conducted by Eric Beck, B.S. and Dr. Erin Winterrowd at the Department of Psychology at the University of Wisconsin-Oshkosh, focuses on thoughts and perceptions surrounding the end-of-life decision process.

The research involves the participation of students and their adult friends or family members. A friend or family member has provided your contact information so that you may be invited to participate. The student who invited you to participate does not receive a grade for participating in this study. In addition, your participation in this study does not impact the student. Your participation is completely voluntary, and you may withdraw from this study at any time with no penalty.

Below you will see a link to an online survey and a participation number. By completing the online survey after electronically signing a consent form, you are consenting to participate in this research study. There are no known risks or benefits associated with participation in this research. Participation in this study may not benefit you directly, but may provoke communication between family members about end-of-life decisions and what it is like to participate in psychological research.

Please paste the link below into your browser and follow the instructions. You will first be prompted to read the informed consent form carefully, electronically sign acknowledgement of reading and then enter the participant number. Following this you will begin the survey. Please fill-out the survey and follow the prompts on each page; we would appreciate prompt attention. There is no right or wrong answers on any of the measures. You may keep this email for your own records. At no time will you be asked to use your name on the questionnaire. Instead, questionnaires will be identified through the use of code numbers. All responses will remain confidential and will be stored in a locked lab. Your referring family member or friend will not see your responses to the questionnaire and vice versa. The questionnaire takes about 20-30 minutes to complete.

Hard copies of this survey will also be mailed to you. When received, please keep the debriefing form and a copy of the informed consent form for your records. The debriefing form contains valuable information about the end-of-life decision process and discusses the importance of making these decisions. In addition, if you wish to complete the survey via hard copy instead of online, please mail back the survey measures. There will be prepaid postage to do so.

Survey Link: http://oshkosh.qualtrics.com/SE/?SID=SV_2mkLIASsG4RZGEQ
Participant Number: TI05

Thank you for your help.

Sincerely,

Eric Beck, B.S.
Masters Student, Department of Psychology

References

Anderson, L. A., Day, K. L., Beard, R. L., Reed, P. S., & Wu, B. (2009). The public's perceptions about cognitive health and Alzheimer's disease among the U.S. population: A national review. *Gerontologist*, *49, 1*, S3-S11.

Aging with Dignity. (2011). Retrieved November 8, 2011, from http://www.agingwithdignity.org/forms/5wishes.pdf

Amoah, C. (2011). The central importance of spirituality in palliative care. *International Journal Of Palliative Nursing*, *17*, 353-358.

Baumeister, R. F., Heatherton, T. F., & Tice, D. M. (1993). When ego threats lead to self-regulation failure: Negative consequences of high self-esteem. *Journal of Personality and Social Psychology, 64,* 141-156.

Bomba, P., & Sabatino, C. P. (2009). POLST: An emerging model for end-of-life care planning. *Elder Law Report*, *20*, 1-5.

Boustani, M. A., Justiss, M. D., Frame, A., Austrom, M. G., Perkins, A. J., Cai, X., & ... Hendrie, H. C. (2011). Caregiver and noncaregiver attitudes toward dementia screening. *Journal Of The American Geriatrics Society*, *59*, 681-686. doi:10.1111/j.1532-5415.2011.03327.x

Braun, U. K., & McCullough, L. B. (2011). Preventing life-sustaining treatment by default. *Annals of Family Medicine*, *9*, 250-256. doi:10.1370/afm.1227

Bülow, H.H., Sprung, C.L., Reinhart, K., Prayag, S., Du, B., Armaganidis, A., Abroug,

F., & Levy, M.M. (2008). The world's major religions' points of view on end-of-life decisions in the intensive care unit. *Intensive Care Medicine, 34,* 423-430.

Carr, D. & Moorman, S. M. (2009). End-of-life treatment preferences among older adults: An assessment of psychosocial influences. *Sociological Forum, 24, 4,* 754-778. doi: 10.1111/j.1573-7861.2009.01135.x

Cicirelli, V.G., MacLean, A.P., & Cox L.S. (2000). Hastening death: A comparison of two end-of-life decisions. *Death Studies, 24,* 401–419.

Conde-Sala, J. L., Garre-Olmo, J. J., Turró-Garriga, O. O., Vilalta-Franch, J. J., & López-Pousa, S. S. (2010). Quality of life of patients with Alzheimer's disease: Differential perceptions between spouse and adult child caregivers. *Dementia And Geriatric Cognitive Disorders*, *29*, 97-108. doi:10.1159/000272423

Cotter, R.P. (2003). Health risk behaviors in adolescence and their relationship to death anxiety and death personifications. *OMEGA*, *47*, 119-137.

Courtenay, W.H. (2000) Engendering Health: A Social constructionist examination of men's health beliefs and behaviors. *Psychology of Men and Masculinity, 1, 1*, 4-15.

Denk, C.E. , Benson, J.M. , Fletcher, J.C. ,& Reigel, T.M. (1997). How do Americans want to die? A factorial vignette survey of public attitudes about end-of-life medical decision-making. *Social Science Research*, *26*, 95-120.

Fritsche, I., Jonas, E., & Fankhanel, T. (2008). The role of control motivation in mortality salience effects on ingroup support and defense. *Journal of Personality and Social Psychology, 95*, 524-541.

Hershberger, P. J., Zryd, T. W., Rodes, M., & Stolfi, A. (2010). Professionalism: Self-control matters. *Medical Teacher*, *32*, 36-41. doi:10.3109/01421590903199676

Herve, C., Mullet, E., & Sorum, P.C. (2003). Age and medication acceptance. *Experimental Aging Research, 30*, 253-273.

Heyland, D. K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., Shortt, S., Tranmer, J., Kutsogiannis, J., & Lam, M. et al. (2006). What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal, 174,* 1-9.

Hickman, S.E., Tolle, S.W., Brummel-Smith, K., & Murphy Carley, M. (2004) Use of the physician orders for life-sustaining treatment program in Oregon nursing facilities: Beyond resuscitation status. *Journal of the American Geriatric Society,52,* 1424–1429.

Hickman, S.E., Nelson, C.A., Moss, A.H., Hammes, B.J., Terwilliger, A., Jackson, A., & Tolle, S.W. (2009). Use of the physician orders for life-sustaining treatment (POLST) paradigm program in the hospice setting. *Journal of Palliative Medicine, 12,* 133-141. doi: 10.1089/jpm2008.0196

Hickman, S., Nelson, C., Perrin, N., Moss, A., Hammes, B., Tolle, S. (2010). A comparison of methods to communicate treatment preferences in nursing facilities: traditional practices versus the physician orders for life-sustaining treatment program. *Journal of the American Geriatrics Society*, *58,* 1241-1248.

Hwang, J. R. Rivas, J.G., Fremming, R., Rivas, M.M., Crane, K.R. (2009). Relationship between perceived burden of caring for a family member with Alzheimer's

disease and decreased participation in meaningful activities. *Occupational Therapy in Health Care*, *23*(4), 249. doi:10.3109/07380570903214788

Inzlicht, M., & Tullett, A. M. (2010). Reflection on God: Religious primes can reduce neurophysiological response to errors. *Psychological Science, 21*, 1184-1190.

Johnson, S. (2007). Hope in terminal illness: an evolutionary concept analysis. *International Journal of Palliative Nursing*, *13, 9*, 451-459.

Keller, R. R. (2000). Religious diversity in North America. In P. S. Richards &A. E. Bergin (Eds.), *Handbook of psychotherapy and religious diversity* (pp. 27–55). Washington, DC: American Psychological Association.

King, D.E., & Wells, B.J. (2003). End-of-life issues and spiritual histories. *Southern Medical Journal, 96*, 391-393.

Krause, N. (1998). Stressors in highly valued roles, religious coping, and mortality. *Psychology and Aging*, *13*, 242-255. doi:10.1037/0882-7974.13.2.242

Limerick, M. (2007). The process used by surrogate decision makers to withhold and withdraw life-sustaining in an intensive care environment. *Oncology Nursing Forum, 34*, 331-339.

Matsui, M. (2007). Perspectives of elderly people on advance directives in Japan. *Journal Of Nursing Scholarship: An Official Publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau*, *39*, 172-176.

McCullough, M. E., & Willoughby, B.L.B. (2009). Religion, self-regulation, and self-control: Associations, explanations, and implications. *Psychological Bulletin, 135*, 69-93. doi: 10.1037/a0014213

McPherson, C. J., Wilson, K. G., & Murray, M. (2007). Feeling like a burden to others: A systematic review focusing on the end of life. *Palliative Medicine*, *21, 2*, 115-128.

Mishra, S., & Lalumiere, M.L. (2010) Individual differences in risk-propensity: Associations between personality and behavioral measures of risk. *Personality and Individual Differences, 50,* 869-873.

Nicholas, L. J., & Durrheim, K. (1996). Validity of the Rohrbaugh and Jessor religiosity scale. *Perceptual and Motor Skills*, *83*, 89-90.

Pargament, K. I. (1990). God help me: Toward a theoretical framework of coping for the psychology of religion. *Research in the Social Scientific Study of Religion, 2,* 195-224.

Pargament, K. I., Smith, B. W., Koenig, H. G., & Perez, L. (1998). Patterns of Positive and Negative Religious Coping with Major Life Stressors. *Journal For The Scientific Study Of Religion*, *37*, 710-724.

Physicians Orders for Life Sustaining Treatment (2011). Retrieved November 8, 2011, from http://www.ohsu.edu/polst/programs/index.htm.

Popham L.E., Kennison, S.M., & Bradley, K.I. (2011). Ageism and risk-taking in young adults: Evidence for a link between death anxiety and ageism. *Death Studies*, *35,* 751-763.

Price, A. E., Corwin, S. J., Friedman, D. B., Laditka, S. B., Colabianchi, N., & Montgomery, K. M. (2011). Older adults' perceptions of physical activity and cognitive health: Implications for health communication. *Health Education &*

Behavior, *38, 1*, 15-24.

Radley, A., & Payne, S. (2009). A sociological commentary on the refusal of treatment by patients with cancer. *Mortality, 14*, 309-324.

Randolph-Seng, B., & Nielsen, M. E. (2007). Honesty: One effect of primed religious representations. *The International Journal for the Psychology of Religion, 17*, 303-315.

Resnick, H., Foster, G., & Hickman, S. (2009). Nursing Home participation in end-of-life programs: United States, 2004. *The American Journal of Hospice & Palliative Care*, *26*, 354-360.

Rietjens, J.A., van der Heide, A., Onwuteaka-Philipsen, B.D., van der Maas, P.J., & van der Wal, G.A. (2005). A comparison of attitudes towards end-of-life decisions: survey among the Dutch general public and physicians. *Social Science and Medicine, 61,* 1723-1732.

Rohrbaugh, J., & Jessor, R. (1975). Religiosity in youth: A personal control against deviant behavior. *Journal of Personality, 43,* 136-155.

Roof, W.C. & McKinney, W. (1987). The fragmented mainline. *American Mainline Religion: Changing Shape and Future* (pp. 72-105). New Brunswick and London: Rutgers University Press.

Rothman, M., Van Ness, P., O'Leary, J., & Fried, T. (2007). Refusal of medical and surgical interventions by older persons with advanced chronic disease. *Journal Of General Internal Medicine*, *22, 7*, 982-987.

Rousseau, P. (2000). Hope in the terminally ill. *The Western Journal of Medicine*, *173*,

117-118.

Sabatino, C. (2010). The evolution of health care advance planning law and policy. *Milbank Quarterly*, *88*, 211-239. doi:10.1111/j.1468-0009.2010.00596.x

Saroglou, V., Corneille, O., & Van Cappellen, P. (2009). "Speak, Lord, your servant is listening:" Religious priming activates submissive thoughts and behaviors. *The International Journal for the Psychology of Religion, 19*, 143-154

Shalowitz, A.I., Garrett-Mayer, E., Wendler, D. (2006).The accuracy of surrogate decision makers. *Arch Intern Med, 166*, 493-497.

Shadlen M-F. Larson, E. (2012) Risk factors for dementia. *Wolters Kuwer Health.* http://www.uptodate.com/home/index.html. Accessed April 20, 2012.

Shariff, A. F., & Norenzayan, A. (2007). God is watching you: Priming God concepts increases prosocial behavior in an anonymous economic game. *Psychological Science, 18*, 803-809.

Sharf, B.F., Stellies, L.A., & Gordon, H.S. (2005). 'A little bitty spot and I'm a big man': Patients' perspective on refusing diagnosis or treatment for lung cancer. *Psycho-Oncology, 14*, 636-646.

Sprung, C.L., Maia, P., Bülow, H.H., Ricou, B., Armaganidis, A., Baras, M., Wennberg, E., Reinhart, K., Cohen, S.L., Fries, D.R., Nakos, G., & Thijs, L. (2007). The importance of religious affiliation and culture on end-of-life decisions in European intensive care units. *Intensive Care Medicine, 33,* 1732-1739.

Staples, W. H., & Killian, C. B. (2012). Education affects attitudes of physical therapy: Providers toward people with dementia. *Educational Gerontology*, *38*, *5*, 350-361.

Steinberg, S.M. (2011). Cultural and religious aspects of palliative care. *International Journal of Critical Illness and Injury Science, 1*, 154-156.

Tangney, J. P., Baumeister, R. F., & Boone, A. (2004). High self-control predicts good adjustment, less pathology, better grades, and interpersonal success. *Journal of Personality*, *72*, 271-324.

U. S. Census Bureau. (2004). *U.S. population projections: Table 5.* Retrieved from http://www.census.gov/population/www/projections/projectionsagesex.html

VanNess, P. H., Towle, V. R., O'Leary, J. R. & Fried, T. R. (2008). Religion, risk, and medical decision making at the end of life. *Journal of Aging and Health, 20, 5,* 545-559. doi: 10.1177/0898264308317538

Wilson, D., (2011). Quality care at the end-of-life: The lived experience of surrogate decision makers. *Journal of Hospice and Palliative Nursing, 13,* 249-256. doi: 10.1097/NJG.0b013e3182186bbo

Winter L., Dennis, M.P., & Parker, B. (2009). Preferences for life-prolonging medical treatments and deference to the will of God. *Journal of Religious Health, 48,* 418-430.

Winter, L., & Parks, S. M. (2012). The reluctance to burden others as a value in end-of-life decision making: A source of inaccuracy in substituted judgment. *Journal Of Health Psychology*, *17*, *2*, 179-188. doi:10.1177/1359105311414956