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Role of Age and Cognitive Abilities in Knowledge
of Life-Sustaining Treatments and Treatment Preferences

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Chapter I

Review of the Literature

Most research that has focused on end-of-life care decisions has studied older adults, as end-of-life care decisions are most relevant to this age group. As we age, the probability of death increases and, not surprisingly, older adults have the highest rates of death among any other age group (National Center for Health Statistics, 2012). Additionally, older adults comprise the largest group of consumers of health care services in the United States (National Center for Health Statistics, 2012). With this age group consuming significant healthcare resources for end-of-life care, there is a need to focus on older adults when examining these issues. According to the U.S. Census Bureau (2011), those who are or are soon-to-be older adults are the cohorts that are increasing the most rapidly in the country. The largest percent increase within the American population is those who are aged 60-64, followed by those who are 55-59 years of age. As the “baby boomer” generation continues to age, the number of people making end-of-life care decisions will increase exponentially.

End-of-life care is a major financial expenditure for hospitals, insurance companies, and individuals. Approximately one third of all deaths in the United States were inpatient hospital deaths, and of these deaths 71% happened to those 65 years of age or older (Zhao & Encinosa, 2009). With a significant proportion of deaths occurring during inpatient hospitalization, it is important to consider the economic impact of different treatment decisions related to end-of-life care. Medical care at the end-of-life

consumes 10%-20% of the total budget for healthcare and 27% of the budget for Medicare (Lubitz & Riley, 1993). For individuals who do not choose life-sustaining care options, the financial expenditure is reduced due to decreased time of hospitalization and the avoidance of potential future re-hospitalizations for a related medical problem. Therefore, clarification of the end-of-life care wishes of the patient can improve satisfaction with care and can prevent excessive consumption of resources. When discussing various end-of-life care options, it is important to also examine who makes these decisions.

Although surrogate decision-makers, such as spouses or children, often make end-of-life care decisions for older adults, there has been increased interest and legislation to maintain older adults' autonomy, including making advanced directives to plan for their own end-of-life care (Hiltunen, Medich, Chase, Peterson, & Forrow, 1999; Kim, Karlawish, & Caine, 2002; Laakkonen, Pitkala, Strandberg, Berglind, & Tilvis, 2005). The Patient Self Determination Act (PSDA) was enacted in 1990 and requires providers receiving Medicare or Medicaid to inform patients of their rights to accept or refuse medical treatment and the right to execute an advance directive. Additionally, the Joint Commission for the Accreditation of Healthcare Organizations guidelines requires hospitals to make advance directives available to all patients (Joint Commission on Accreditation of Healthcare Organizations, 1995). As older adults are encouraged to direct and document their preferences in end-of-life care, it is important to examine how these decisions are made.

The process of making end-of-life care decisions should be similar to the informed consent process, in that patients need to understand treatment possibilities as

well as their risks and benefits (Olick, 1991). Without the ability to understand the risks and benefits associated with different treatment options as well as knowledge about what each treatment entails, patients cannot truly give informed consent to procedures.

Beauchamp and Childress (2001) discussed the various meanings and definitions of informed consent, and stated the best definition includes five elements: competence, disclosure, understanding, voluntariness, and consent. An informed consent is an individual's competence to act, receipt of disclosure, comprehension of the disclosure, voluntary act, and consent to the intervention. Therefore, comprehension of what is disclosed is required for informed consent according to this definition.

The definition of informed consent evolved from a goal to enhance patient autonomy (Beauchamp & Childress, 2001). The right of an individual's self-determination is also recognized in the general principles of the Ethical Principles of Psychologists and Code of Conduct (American Psychological Association, 2010). Personal autonomy is self-rule that is free from limitations, such as inadequate understanding, and free from the interference of others (Beauchamp & Childress, 2001). In this sense, an informed consent occurs if a patient with adequate understanding intentionally authorizes a professional to do something. However, the literature suggests that many patients are not adequately informed of their end-of-life treatment options (Mirza, Kad, & Ellison, 2005; Rady & Johnson, 2004). Further, there is evidence that those who have not been adequately informed about their treatment options make different decisions regarding end-of-life care. Downar and colleagues (2011) found that those with greater familiarity with resuscitation discussions chose a *do not resuscitate* (DNR) code status. Most of those who chose to remain a full code status, meaning all

possible measures would be taken to resuscitate them, reported no previous experience with a discussion about life-sustaining treatment (LST) options. Fischer, Tulsky, Rose, Siminoff, and Arnold (1998) found that patients expressed strong preferences for treatments for which they did not have adequate understanding. In an effort to protect the informed consent process, there is a need to investigate how well older adults comprehend information about treatment options for end-of-life care and to explore how well they can retain the information presented to them in order to make informed decisions about their end-of-life care.

Older adults are faced with end-of-life decision-making more than any other group. At the same time, older adults experience age-related cognitive changes that may hinder their ability to acquire and utilize such information (see Park, 2000, for a review). In particular, working memory and processing speed have been identified as key cognitive processes that affect older adults' ability to learn health information (Brown & Park, 2002). However, there is insufficient literature on the impact of age-related cognitive changes on older adults' ability to learn specifically about LST options. Moreover, we do not know about the effects of cognitive changes on decisions regarding end-of-life care choices.

Age-Related Cognitive Changes

It has been well established in the literature that some cognitive processes change across time as individuals age (Park, 2000). Older adults show poorer performance on processing speed tasks and working memory tasks (Park et al., 1996; Salthouse & Babcock, 1991). Processing speed is a measure of how quickly an individual can process information. In a processing speed task, individuals make simple same-different

judgments about pairs of comparisons of letters, patterns, or symbols as quickly as possible (Park, 2000). The number of these judgments made within a short interval is used to assess processing speed. Working memory is a measure of an individual's ability to simultaneously store and manipulate information. It is distinguished from other types of memory because it uses both processing and storage. In a typical working memory task, the individual answers a question about a sentence or an equation, while simultaneously remembering an element of the sentence or equation (Park, 2000). The number of elements the individual is required to remember increases systematically until that person reaches his or her limit, as evidenced by making a pre-determined number of consecutive errors. It is important to note that age differences are not found on all memory tasks, but rather on those that are effortful and require substantial cognitive resources (Park, 2000).

In an effort to examine those tasks that may require varying levels of processing resources, Craik and McDowd (1987) compared the performance of younger (*M* age = 21 years) and older adults (*M* age = 73 years) on recall and recognition tasks. They also examined the processing difficulty of recall and recognition tasks to determine which requires more processing resources. To assess the processing difficulty of recall and recognition tests, the authors compared the effects of a secondary task that was performed simultaneously with the recall or recognition test. Participants performed a continuous reaction time task either independently or while simultaneously retrieving words in tests of recall or recognition (dual-task). The authors found age-related decrements in secondary task performance in both dual-task situations. Recall tasks evidenced the most impaired performance on a secondary task compared to recognition tasks, particularly for

older adults. The authors concluded that recall tasks demand more processing resources than recognition tasks. Due to the decreasing cognitive processing capacities of older adults, they are therefore disproportionately hindered in recall tasks. Although both younger and older adults evidenced poorer performance on recall tasks than on recognition tasks, older adults showed significantly greater impairment than their younger counterparts on recall tasks than on recognition tasks after statistically controlling for recognition performance. The authors interpreted their findings as demonstrating that recall tasks require more cognitive processing resources than recognition tasks. Therefore, older adults are at a greater disadvantage on recall tasks.

Older adults can evidence poor performance on other tasks that require significant resources as well. Working memory is considered a complex cognitive function, due to its requirement of the use of both storage and processing simultaneously. It has been suggested that age differences in working memory are attributable to the age-related declines in processing efficiency (Baddeley, 1986; Craik & Byrd, 1982). Salthouse and Babcock (1991) investigated the contribution of processing efficiency, storage capacity, and coordination effectiveness to age-related differences in working memory. In their first study, participants included 227 adults between 20 and 87 years of age. Participants completed several tasks including computation span, digit span, arithmetic, listening span, word span, sentence comprehension, and a coordination task. The authors found significant age-related declines in processing efficiency, storage capacity, and coordination effectiveness. However, after statistical controlling for age-associated variance, they found that processing efficiency influenced both storage capacity and coordination effectiveness, suggesting that processing efficiency was the major

determinant of the age differences in working memory. Salthouse and Babcock conducted a second study to obtain a more pure assessment of processing efficiency. The authors suggested that the tasks used to assess this construct in Study 1 were complex, thus the differences they found could be related to other processes in addition to processing efficiency. Therefore, Study 2 investigated the relationship among processing efficiency, storage capacity, and simple comparison speed. Participants in Study 2 included 233 adults between 18 and 82 years of age. Participants completed tasks including arithmetic, digit span, computation span, letter comparison, pattern comparison, sentence comprehension, word span, listening span, and the Digit Symbol Substitution test from the WAIS-R (Wechsler, 1981). The results indicated that all of the significant relationships between the age-related effects on processing efficiency, storage capacity, and working memory were indirect and were mediated through age-related reductions in the speed of executing elementary operations. Both studies found that increased age was associated with poorer performance on measures of working memory. Further, a substantial proportion of the age-related differences in working memory were mediated by reductions in processing efficiency. The authors suggested that processing efficiency, especially in simple operations, is an important factor in age-related declines in working memory.

Expanding on the research on the importance of processing speed, Lindenberger, Mayr, and Kliegl (1993) examined the relationship between processing speed and knowledge, reasoning, memory, and fluency. Participants included 149 individuals who were between 70 and 103 years old. To measure processing speed, a digit letter task,

digit symbol substitution, and identical picture task were used. The results showed that all of the cognitive abilities assessed were mediated through speed.

When discussing processing speed, one must also consider the methodological weaknesses inherent in its assessment: speed and performance accuracy are confounded. Most measures of processing speed include accuracy in the overall score of an individual's performance. Diamond et al. (2000) examined age differences in processing speed while holding performance accuracy constant to eliminate this confound. Participants consisted of 12 older adults (M age = 80 years) and 12 younger adults (M age = 26 years). Results indicated that older adults evidenced reduced processing efficiency, with slowing of processing in both visual and auditory domains. The authors stated their findings are consistent with the literature that suggests working memory and processing speed is significantly slower in older adults.

The combined work of Salthouse and Babcock (1991), Lindenberger et al. (1993), and Diamond et al. (2000) offers strong support that age differences in processing speed account for significant age-related variance on several cognitive tasks, including memory. However, Salthouse and Babcock's (1991) study examined working memory as the outcome measure, and Lindenberger et al. (1993) and Diamond et al. (2000) failed to include working memory as a measure, and so the effect of working memory on age-related variance was not examined by these studies. Park et al. (1996) examined performance on multiple measures of cognitive functioning, including working memory, processing speed, free recall, cued recall, and verbal ability. Participants included 301 adults between the ages of 20 to 90. Processing speed was assessed using the Digit Symbol subscale from the WAIS-R and the letter comparison and pattern comparison

tasks (Salthouse & Babcock, 1991). Working memory was measured using the Backward Digit Span subscale from the WAIS-R and using a reading span task and computation span task adapted from Salthouse and Babcock (1991). To measure free recall, participants were given two lists of 25 words and asked to free recall the words after each list was presented. To assess cued recall, participants received two lists of 22 word pairs, with the cue word in small letters and the target word in capital letters. Participants were later presented with the cue word and asked to recall the target word. Verbal ability was measured using the WAIS-R Vocabulary test, the Vocabulary section of the Shipley Institute of Living Scale (Shipley, 1986), and an adaptation of the Scholastic Aptitude Test (College Entrance Examination Board, 1990). The authors found age-related declines in performance on processing speed, working memory, free recall and cued recall tasks. However, the measure of verbal ability did not show a decline associated with age, and it appears that word knowledge remains relatively stable across the lifespan. Further, the study demonstrated that both processing speed and working memory accounted for variance in other types of memory. Speed of processing mediated age-related variance in working memory, which in turn predicted long-term memory function. The authors also found that working memory became more important in accounting for age-related variance as the effort required by different types of memory increases. After examining performance on multiple measures of cognitive functioning, processing speed and working memory were found to be important in understanding age-related variance in memory function.

More recently, Waters and Caplan (2005) examined the relationship between processing speed, working memory, language comprehension, and age. Participants

included 48 younger adults aged 17 - 29 and 50 older adults aged 65 - 80 years old. To measure working memory, the alphabet span (Craik, 1986), subtract 2 span (Salthouse, 1988), and reading span (Waters & Caplan, 1996) were used. Processing speed was assessed using the digit symbol substitution task from the WAIS-R and an adaptation of the digit letter task (Lindenberger, Mayr, & Kliegl, 1993). They also measured visual and auditory language comprehension. The reading comprehension subtest of the Nelson-Denny Reading Test Form A (Nelson & Denny, 1960) was used to measure reading comprehension. Results revealed that older adults performed more poorly on measures of working memory and processing speed than younger adults. The authors also found a significant correlation between reading comprehension and working memory, suggesting that working memory is heavily involved in the comprehension of written information, and age-related declines in working memory functioning affect older adults' ability to comprehend this information.

Age Differences in Decision-Making

Compared to younger adults, older adults have evidenced decreased ability to hold and manipulate information in working memory and reduced speed of processing information. In concert with these declines affecting their information processing capacity, they are faced with many important decisions on a daily basis. Given older adults' impairments in basic cognitive processes, it is important to examine if these impairments affect their decision-making abilities as well. Decision-making is based on integrating information that is relevant to the decision. However, older adults are more likely to exhibit information selectivity, and they do not necessarily use all of the

information available to them in their decision-making processes (Rafaely, Dror, & Remington, 2006).

Rafaely et al. (2006) conducted three studies that examined information selectivity as a product of reduced information processing capacity. To control for experiential factors involved in decision-making, the authors chose decision problems that participants would be unable to solve based on prior knowledge. Participants were given unfamiliar decision problems and required to make an optimal decision, one that maximized utility, based on the available information to reach a desired goal. In Experiment 1, participants included 45 older adults between ages 61 and 85, and 42 younger adults between ages 18 and 23. All participants were required to play a game that involved chance to examine the extent they based their decision on outcome payoff. They played a card game and each decision resulted in either winning or losing points, with the goal of trying to win as many points as possible. The results showed that both older and younger adults based their decisions on payoff when there is one dimension of information, but the older adults did so to a lesser extent.

In their second experiment, Rafaely et al. (2006) examined older and younger adults' responses to two dimensions of information rather than one, increasing the information-processing demands placed on individuals. Participants included 53 older adults between ages 62 and 86, and 50 younger adults between ages 18 and 39. The results showed that younger adults based their decisions on both dimensions of information, whereas older adults based their decisions on only one dimension, suggesting they were unable to integrate all of the information presented to them. Although the results could reflect that the increased demands of the task exceeded the

processing capacity of the older adults, the authors could not rule out the possibility of reduced motivation of the older adults to engage in effortful processing. To attempt to increase the motivation of participants, the authors conducted a third experiment that made the payoff information more salient.

In Experiment 3 (Rafaely et al., 2006), the authors examined participants' responses to two dimensions of information in a decision tasks that provided instructional cues to promote payoff information. Participants included 38 older adults who were 60-80 years of age, and 36 younger adults who were 18 - 28 years of age. Despite the increased salience of the payoff information, the authors found that older adults based their decisions on only one dimension of information, whereas the younger adults integrated information from both dimensions to make their decisions. The results from these studies support the view that older adults experience reduced information processing capacity, which results in information selectivity during decision-making.

Information selectivity in decision-making can have important implications in many areas, including decisions about medical treatments. This selectivity is particularly important given the increased efforts for older adults to make their own medical decisions, rather than a surrogate or their physician. Due to age-related cognitive declines, older adults may be less able to make decisions regarding medical treatments (Zwahr, Park, & Shifren, 1999). The ability to remember and understand information provided is an important factor in evaluating proposed medical treatments (Beauchamp & Childress, 2001). In addition to cognitive abilities, personal experience and familiarity with the treatment options may also contribute to medical decision-making.

Zwahr and colleagues (1999) investigated the role of cognitive abilities, knowledge, personal experience, risk perception, and reactions to the amount of information provided in the process of making a medical decision. More specifically, they examined the decisions of women in choosing to accept or reject Estrogen Replacement Therapy (ERT). A total of 102 women aged 20 to 79 participated in the study. To assess their prior knowledge, participants first completed a questionnaire that contained short-answer and true-false items. They were then given a vignette about a hypothetical woman's postmenopausal medical dilemma as well as written information about the risks and benefits of ERT treatments. Participants then answered an open-ended question where they were asked to list the treatment options and were then required to give their treatment choice. To assess posttest knowledge, participants completed the same questionnaire that was used to assess pretest knowledge. The authors also assessed participants' perception of risk and reaction to the information. To assess cognitive ability, participants completed a text memory task and the Shipley Institute of Living Scale. Working memory was assessed using the Listening span task (Daneman & Carpenter, 1980). The Letter Comparison Test (Salthouse & Babcock, 1991) was used to measure perceptual speed. Finally, participants completed a questionnaire that asked about demographic information and personal experience with menopause. Regarding cognitive abilities, the results were consistent with the literature and showed significant age differences on measures of working memory and perceptual speed. Speed of processing information was related to working memory and text memory, and working memory was related to reasoning and text memory. Although age did not directly contribute to differences in the decision process, the authors found significant age-related

differences in treatment decisions, and these differences operated through cognitive abilities. Personal experience with menopause did not have a significant effect on decisions processes. The results of the study further indicated there are differences in how younger and older adults make medical decisions, partially due to changes in cognitive abilities.

Age-Differences in Learning Medical Information

Research has indicated that because of declines in basic cognitive abilities, older adults have difficulty comprehending and remembering medical information. Morrell, Park, and Poon (1989) found that older adults incorrectly comprehended 21% of the information on prescription labels when asked to use the information to make a medication schedule. After revising the instructions to make them more structured, older adults evidenced increased comprehension of the instructions. However, older adults consistently recalled less information than younger adults, regardless of the quality of the instructions or the amount of time participants had to study the information.

Hancock, Rogers, and Fisk (2001) found that older adults reported attending to warning information for over-the-counter medications and household products more than younger adults, yet older adults' comprehension of warning symbols was significantly more impaired in half of the warning symbols investigated in the study. To further explore these findings, Hancock, Fisk, and Rogers (2005) examined written warnings as well. The authors investigated age-related differences in the comprehension of explicit and implied warning information for over-the-counter medications and household products. More specifically, their experiments examined age-related differences in inferencing abilities, as well as differences in the comprehension of warning texts.

Experiment 1 investigated the role of memory in age-related variance in comprehension for knowledge-consistent warnings. Participants included 52 younger adults aged 18 to 23 years old, and 47 older adults aged 65 to 75 years old. Results showed that older adults performed more poorly than younger adults at recognizing explicitly stated information and making inferences. The memory of older adults was poorest when they were required to remember explicit details from the text. To force participants to rely more on their memory and less on product knowledge, Experiment 2 added a knowledge-inconsistent condition. Participants included 52 younger adults aged 18 to 22 years old, and 60 older adults aged 64 to 76 years old. The authors found that older adults evidenced poorer comprehension than younger adults of explicitly stated warning information. When it was not possible to use product knowledge, older adults were significantly hindered in their ability to make correct inferences. The authors suggested that the comprehension of implicit and explicit information declines when the retrieval of specific information from memory is required to fully understand the meaning. Results also indicated that regardless of whether memory was taxed, both younger and older groups had difficulty making correct inferences when they could not use prior knowledge. Overall, age-related memory deficits can hurt older adults' comprehension of warnings for over-the-counter medications and household products. As memory demands increased, older adults' comprehension decreased. These findings have important implications for older adults who are presented with novel medical information and are then expected to make informed decisions.

Miller, Gibson, Applegate, and de Dios (2011) examined the roles of prior knowledge and working memory capacity on the comprehension of written health

information in both younger and older adults. They also explored the influence of these abilities on learning through conceptual integration. Participants included 212 adults between the ages of 18-81. These individuals first completed a general nutrition knowledge test to assess baseline knowledge of a specific nutritional topic, as well as a passage-specific pretest that required participants to sort concepts. They then read two written passages about nutrition. After reading each passage, participants completed reading and learning assessments. Finally, participants completed two measures of working memory capacity that included a loaded sentence span task (Stine & Hindman, 1994) and the computation span (Salthouse & Babcock, 1991). Both tasks require participants to respond “True” or “False” to sets of statements that become increasingly larger. On the sentence span task, participants were required to repeat the last word of each sentence in the set, and on the computation span, they were required to repeat the second arguments in the number equation. The authors found that prior knowledge was a significant predictor of the acquisition of new knowledge about nutrition. Older adults evidenced age-related increases in their knowledge of nutrition and age-related declines in working memory capacity and learning about nutrition. The results also suggested that conceptual integration mediates the relationship between prior nutrition knowledge and working memory capacity and knowledge acquisition. The authors suggested that this study provides further support that working memory skills and knowledge are critical for health literacy.

The findings of Morrell et al. (1989) and Hancock et al. (2005) demonstrated that older adults have difficulty comprehending information that is complex or requires making inferences, such as medical information. This difficulty suggests that older adults

are at a disadvantage in their ability to learn medical information. Additionally, the findings of Hancock et al. (2005) and Miller et al. (2011) demonstrate that the prior knowledge of individuals plays an important role in learning medical information as well.

Brown and Park (2002) examined the effect of prior knowledge on older adults' ability to learn new health information compared to younger adults. Participants included 60 younger adult females aged 18-28 and 60 older adult females aged 60-84 years of age. Members of each age group were randomly assigned to one of three groups. Participants received written information about either a familiar disease (i.e., breast cancer), or an unfamiliar disease (i.e., acromegaly). Participants in the control group did not receive information about either disease. All participants completed an open-ended questionnaire followed by a multiple-choice test to assess their recollection and/or knowledge of the information. Participants also completed demographic and health questionnaires, as well as measures that assessed vocabulary, information processing speed, and working memory. The Shipley Vocabulary Test (1986) is a 40-item multiple-choice test that was used to measure vocabulary. Processing speed was measured by a Letter Comparison task and a Pattern Comparison task in which participants decide as quickly as possible whether letters or patterns are the same or different (Salthouse & Babcock, 1991). The Reading Span Task (Salthouse & Babcock, 1990) was used as a measure of working memory and requires participants to store and process verbal information simultaneously in memory. Individuals answered questions about progressively larger sets of sentences and then recalled the last word of every sentence in the set. The authors found that older adults had significantly reduced performance on measures of working memory and processing speed and higher scores on a vocabulary measure, which supported the

existing literature on cognitive aging (Park, 2000). Older adults consistently learned less than younger adults about new health information, regardless of their familiarity with the given subject. In addition, both age groups learned more about an unfamiliar disease than about a familiar disease. Brown and Park concluded that that older adults' capacity to consent to treatment may be compromised given their age-related cognitive declines and recommended that physicians provide older patients with written health information for future reference rather than rely on their memory for health information.

Other studies have investigated age-related variance of memory for medical information as well. Jansen et al. (2008) examined older adults' memory for medical information. More specifically, the authors investigated older cancer patients' memory for information about chemotherapy treatment in a real-life, complex hospital setting. Participants included 69 Dutch hospital patients aged 65 - 85 years of age. All participants engaged in a videotaped education session with a nurse who provided information about the routines involved in chemotherapy, possible side effects, and recommendations for coping with the potential side effects. After the consultation, participants were asked to complete the Netherlands Patient Information Recall Questionnaire (Jansen et al., 2008), a structured questionnaire designed to measure recall of information about treatment and recommendations on coping with possible side effects. The authors found that older adults had difficulty remembering medical information. Recall scores were significantly higher for multiple-choice questions than for completion and open-ended questions. This finding is consistent with previous research on question type and quality of recall (Craik & McDowd, 1987; Park et al., 1996). Due to these differences related to question type on recall of information, separate

analyses were performed for the two question types. Patients averaged recalling 80.2% of the information about their treatment on multiple-choice questions as compared to 68.0% of information on open-ended questions. Overall, patients recalled an average of only 23.2% of the information on recommendations on coping with potential side effects. The authors suggested that given the more complex information processing and active retrieval required by open-ended questions, cognitive declines that occur with aging may result in even larger differences in recall scores of health information for older adults than for younger adults.

Age-Related Sensory Changes

When discussing how older adults learn about health information, it is important to also consider the delivery method of this information. Age-related sensory changes can hinder older adults in learning medical information. *Presbycusis* is the term for age-related hearing loss and is common in older adults. This loss can make it difficult for older adults to understand verbal information presented to them, especially in noisy environments such as hospitals (Brown, 2007). Although patients can use hearing aids, not all individuals use them, and they still may not fully compensate for the hearing deficit, which can then affect comprehension of the material. In addition, age-related visual changes in contrast sensitivity and visual acuity can make it difficult for older adults to process visual information. Brown (2007) suggested that providers of written health information use large font with high contrast to reduce the likelihood of older adults not understanding the information. Written information with at least 14-point font size and black text on a white background for high contrast is recommended for use with older adults (Bernard, Liao, & Mills, 2001; Parker & Scharff, 1998). It is important to

keep these sensory changes in mind when considering how health information should be delivered to older adults. Although sensory deficits can affect both auditory and visual senses, written information can be read at the patient's own pace, can be referred to at a later time, and appears to offer an advantage over verbal delivery. Brown and Park (2003) advised that health professionals should provide written information to older adults about their medical information and treatment choices. The authors posited this recommendation could minimize the effects of difficulties with comprehension and recall on their medical decisions.

Knowledge about Life-Sustaining Treatments

Although some research has focused on older adults' comprehension of advance directives (Upadya, Muralidharan, Thorevska, Amoateng-Adjepong, & Manthous, 2002), these documents do not provide thorough information about the risks and benefits of various treatment options. For example, an advance directive may define cardiopulmonary resuscitation (CPR), but does not provide statistics of survival odds. Fischer et al. (1998) found that most individuals believe they have a 70% chance of surviving to discharge after receiving CPR, yet this is true in only approximately 16% of cases (Peberdy et al., 2003; van Walraven et al., 2001). Advance directives provide brief accounts of the treatments and their risks and benefits, leaving much information to be inferred. However, as previously discussed, older adults have evidenced increased difficulty making correct inferences about written medical information (Hancock et al., 2005). Additionally, advance directives often use ambiguous language (Upadya et al., 2002). Every patient's situation is unique, thus it is recommended that physicians discuss the LST options with patients to answer their questions and provide more detailed

information. However, this discussion rarely takes place before or during hospital admission, even among seriously ill hospitalized patients, despite the fact that patients report they would not be upset by the discussion and wish to have the discussion with their physician (Gorton, Jayanthi, Lepping, & Scriven, 2008; Kernerman, Cook, & Griffith, 1997; Phillips et al., 1996). Not surprisingly, few hospitalized patients have advance directives, especially among ethnic minorities (Upadya et al., 2002). Therefore, patients need to be informed of their treatment options prior to hospital admission and given detailed information about the risks and benefits associated with their treatment.

Upadya et al. (2002) examined patients, family members, and physicians understanding of patients' living wills, a type of advance directive. Participants included 151 patients, 108 family members, and 70 physicians. Oral questionnaires were administered to all participants. Results indicated there is a lack of clarity among patients, family members, and physicians about treatment preferences under certain circumstances based on the living will. The study also found that for some patients, understanding of CPR was poor. The authors did not examine age differences and their assessment of comprehension was specific to living wills, not about resuscitation aspects in general.

Groarke, Gallagher, and McGovern (2010) examined the knowledge and perspectives about CPR of physicians, nurses, and the public in Ireland. Participants completed a questionnaire that contained both multiple-choice and closed questions to assess their factual and ethical knowledge and personal opinions of cardiopulmonary attacks and the nature of resuscitation attempts as well as their understanding of Do Not Attempt Resuscitation (DNAR) orders. Among the participants from the general public

group, no participant correctly estimated survival to discharge after cardiopulmonary resuscitation attempts; they all overestimated survival. Forty-two percent were not aware that resuscitation attempts could involve the use of drugs and tracheal intubation, whereas 58% reported they believed all forms of treatment are discontinued for a person with DNAR code status. Despite their poor knowledge, 75% of the public group reported they wanted to be involved in resuscitation decisions for either themselves or for a loved one. The authors only examined the knowledge and perspective about CPR; they did not investigate learning nor examine age-related differences of knowledge or learning about end-of-life treatment options.

Kaldjian et al. (2009) investigated the relationship between patients' code status preferences (DNR or all possible measures taken to resuscitate them) and their orders, their understanding of outcome probabilities, their goals, and any associations between goals of care and code status preference. Participants included 135 hospitalized inpatient adults. They were interviewed using a structured survey instrument that included questions about knowledge of CPR and its outcome probabilities, code status discussions and preferences, goals of care, advance directives, self-reported health status, depression screen, activities of daily living, and demographic variables. Participants were assessed based on both their perceived knowledge and actual knowledge for CPR and its three main components: cardiac defibrillation, chest compressions, and intubation with mechanical ventilation. Results showed that although 72.6% of participants believed they knew what CPR was an abbreviation for, only 29.6% of people actually had this knowledge. Further, 74.8% of participants reported having knowledge about the three main components of CPR, whereas only 58.5% had actual knowledge about chest

compressions, 27.4% about cardiac defibrillation, and 7.4% about intubation.

Participants also greatly overestimated the probability of survival. Results also showed that older adults were more likely to have discussed their code status with their physician, as were those with poorer health. Older adults and those with advance directives were less likely to prefer full code status. This finding that few patients were able to identify the three main components of CPR highlights the need to educate individual about their treatment options. However, this study did not examine the ability of older adults to learn this information.

Fischer et al. (1998) examined patients' comprehension of important concepts involved in end-of-life decision making, as well as physicians' understanding of patient preferences for care after discussions about advance directives. Participants were at least 65 years old or had a serious medical illness. Physicians discussed advance directives with participants, and these discussions were audiotaped. Afterwards, face-to-face interviews were conducted with the participants. A survey used open-ended and multiple choice questions to assess knowledge of LSTs. It also asked about whether a preferred surrogate decision maker had been chosen. Finally, participants responded to questions about their treatment preferences across 20 illness scenarios. The authors found that following discussions about advance directives with their physician, patients had significant misunderstandings about CPR and mechanical ventilation. Because this study only examined older adults, age-related variance in comprehension of end-of-life concepts was not assessed. It is important to consider the effect of health status and age on these results, as Upadya et al. (2002) discussed that these two variables have a relationship on end-of-life treatment decisions.

Highlighting the importance of educating older adults about LST decisions, Downar and colleagues (2011) conducted a qualitative study investigating the reasons patients agree to or refuse DNR code status. Those who chose DNR status were found to be significantly older than those with full code status, however no significant differences were found for admission diagnoses and comorbidities. DNR patients were more familiar with the subject of resuscitation and reported more positive experiences with resuscitation discussions than full code patients. Full code and DNR patients had very different understandings of resuscitation options. DNR patients understood resuscitation as graphic in nature and discussed suffering and futility of treatment, whereas full code patients understood resuscitation in an abstract sense, something that restores life.

Life-Sustaining Treatment Preferences

The literature has examined the knowledge of older adults either before or after receiving information about LST options. However, to the author's knowledge there are currently no studies that have specifically examined older adults' ability to learn information about LSTs compared to younger adults. Moreover, there is also a need to investigate the relationship between individuals' knowledge about LST options and their treatment preferences.

A great deal of research has focused on investigating preferences for LST decisions. Typically, participants are asked to imagine themselves in a specific future health scenario and asked to indicate their preference for LST (Bookwala et al., 2001; Coppola et al., 1999; Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991). Emanuel et al. (1991) examined patient preferences for different treatments in hypothetical states of illness including coma, persistent vegetative state, dementia, and dementia with terminal

illness. Patient preferences differed based on the treatment scenarios. Participants refused treatment more often in scenarios when the individual had dementia or was in a persistent vegetative state, than they did in the scenario that described the person having a coma with a chance of recovery. Fagerlin et al. (1996) investigated differences for older adults' preferences for four LSTs, which included antibiotics, CPR, surgery, and artificial nutrition and hydration (ANH). The authors found that receiving antibiotics was the most preferred treatment preference by older adults, and ANH was the least preferred treatment. These studies demonstrate that patient preference for end-of-life treatments varies by medical condition and treatment type.

Coppola and colleagues (1999) examined older adults' preferences for LSTs comparing the nature of impairment (cognitive versus physical), prognosis, and presence or absence of pain. Participants included 50 individuals who were 65 years of age or older. The Life-Support Preferences/Predictions Questionnaire (LSPQ) was developed by the authors and used to assess preferences for LST. Participants first read detailed descriptions of the four treatment options. Then they read hypothetical vignettes that varied the nature of impairment, prognosis, and presence or absence of pain. Participants were then required to imagine themselves in each scenario and indicated their preference for each treatment. The authors found that participants had a low overall desire for treatment. Results also indicated patients wanted LSTs less if they were cognitively impaired than if they were physically impaired. Prognosis was found to have a significant relationship with treatment preferences; participants chose LSTs more when there was a chance of recovery compared to no chance of recovery. Finally, the authors also found that treatment was preferred in the pain-absent conditions rather than in the

pain-present conditions. The study demonstrates that the nature of impairment, prognosis, and presence of pain affect older adults' preferences for LSTs.

Bookwala et al. (2001) also investigated gender differences for LSTs. Using a methodology similar to Coppola et al. (1999), the authors examined preferences for multiple LSTs across a range of scenarios that had varying consequences. Thirty-eight men (M age = 73.03 years) and 63 women (M age = 73.33 years) participated in the study. The LSPQ (Coppola et al., 1999) was used to assess preferences for LSTs. Participants also completed a questionnaire about the importance of end-of-life values (e.g., religious beliefs, worries about becoming a burden on family and friends) on their treatment decisions. Overall, men reported a stronger preference than women for LST. Regarding specific treatments, men expressed a stronger desire for surgery, CPR, and ANH. There was no gender difference found for the preference of antibiotics. Results also indicated that end-of-life values were important in end-of-life treatment preferences.

Laakkonen, Pitkala, Strandberg, and Tilvis (2005) investigated the relationships among resuscitation preferences, cognitive decline, physical functioning, depression, and attitude. The authors found that feeling needed significantly predicted treatment preference, whereas advanced age and cognitive impairment significantly predicted choosing to forego treatment. Interestingly, this study did not find that gender, physical functioning, having a living will, depression, or being widowed were significant predictors for LST preference. Although the authors did examine cognitive impairment, this term refers to impairment beyond that of normal aging.

The literature indicates that older adults have increased difficulty learning information compared to younger adults as a result of age-related cognitive declines in

working memory and processing speed abilities (e.g., Brown & Park, 2002; Park et al., 1996; Waters & Caplan, 2005; Zwahr et al., 1999). Further, these declines can also affect the decision-making processes of older adults (e.g., Rafaely et al., 2006; Zwahr et al., 1999). Yet older adults are increasingly encouraged to make end-of-life decisions, of which they may have little understanding. To this author's knowledge, no studies have investigated the effects of age-related cognitive decline on the ability to learn about information specifically about end-of-life treatments. Further, no studies have explored possible differences in LST decisions related to cognitive changes and retention of written information. Therefore, there is a need to expand the research to investigate age-related cognitive changes and treatment knowledge on LST preferences.

Chapter II

Rationale and Hypotheses

Following the enactment of the PSDA in 1990, there has been an increased initiative for older adults to be active participants in the end-of-life decision-making process, maintaining their autonomy. In order for individuals to give informed consent for LSTs, they must be able to comprehend the information and have an adequate understanding of the treatments (Beauchamp & Childress, 2001). However, cognitive changes that occur as part of the normal aging process, including declines in processing speed and working memory, can negatively affect older adults' comprehension of medical information (Brown & Park, 2002). These cognitive changes also influence older adults' decision-making abilities, particularly for medical treatments (Zwahr et al., 1999). Therefore, there is a question of how well informed older adults are about their treatment options and whether comprehension of information influences subsequent decisions at the end-of-life. However, to this author's knowledge no studies have investigated age differences in the ability to learn information about LSTs, nor explored the relationship between age-related cognitive decline and LST decisions. The present study will investigate the relationship between age-related cognitive decline and the ability to learn about LSTs. It will also explore the relationship between age-related cognitive decline and LST decisions.

Hypotheses

Research has shown that some cognitive processes decline as part of the normal aging process (Park, 2000). More specifically, older adults evidence poorer performance on processing speed tasks and working memory tasks compared to younger adults (Park et al., 1996; Salthouse & Babcock, 1991). Impaired performance on these two processes has been found to hinder the ability to learn and retrieve information (Brown & Park, 2002; Park et al., 1996). Based on the literature reviewed previously, the following hypothesis is proposed and will be tested using an alpha level of $p < .05$:

H_1 Older adults will perform significantly worse on tasks measuring working memory and processing speed than young adults.

Young and older adult participants will be assigned to one of two groups: educational information about LSTs or educational information about general health issues. Brown and Park (2002) found that older adults learned less than younger adults about health information, which suggests that cognitive abilities affect knowledge acquisition. Based on this research the following hypothesis is proposed and will be tested using an alpha level of $p < .05$:

H_2 It is predicted that there will be a main effect of Age on Knowledge of LSTs (K-LST) and a main effect of Information Type on K-LST. It is also predicted that there will be an Age x Information Type interaction due to young adults benefiting from the information about LST more than the older adults.

If H_2 is supported, an exploratory analysis will be conducted investigating the effects of Age and Information controlling for cognitive abilities. Therefore, the following null hypothesis will be tested:

H_{0a} There will be no main effects or interactions for Age and Information Type when controlling for cognitive abilities.

Researchers have found that due to age-related cognitive declines, including declines in working memory and processing speed, older adults are hindered in their ability to comprehend and remember medical information, and therefore may make different medical treatment decisions than younger adults (Zwahr et al., 1999). More specifically, using path analysis Zwahr and colleagues (1999) showed that age itself did not have a direct effect on treatment decisions, but rather operated through cognitive abilities. Based on this previous research, the following hypothesis will be tested using an alpha level of $p < .05$:

H_3 It is predicted that there will be a main effect of Age on LST Preferences (LST-P) and a main effect of Information Type on LST-P. It is also predicted that there will be an Age x Information Type interaction due to young adults benefiting from the information about LST more than the older adults.

If H_3 is supported, an exploratory analysis will be conducted investigating the effects of Age and Information Type controlling for K-LST. Therefore, the following null hypothesis will be tested:

H_{0b} There will be no main effects or interactions for Age and Information Type when controlling for K-LST.

Chapter III

Method

Participants

A power analysis was conducted to determine the appropriate number of participants to be included in the proposed study. The average effect size relating age and disease knowledge found by Brown and Park (2002) was estimated to be .26, a medium effect size. Therefore, to achieve similar estimates with a power of .80 and an alpha level of .05, the power analysis conducted using the online G*Power program (Faul, Erdfelder, Lang, & Buchner, et al., 2007) indicates the proposed study will require 119 participants. To divide participants into equal groups, 120 participants will be recruited. Participants in the current study will consist of 60 younger adults, aged 18 - 25 and 60 older adults, aged 60 and older. Younger adults will be recruited from a Midwestern university's Psychology Department Participant Pool and will receive course credit or extra credit for participating, at the discretion of their instructors. Older adults will be recruited from local community centers and churches, and will have a 10% chance of winning a \$25 gift card as compensation for their participation. Participants will be excluded if they are unwilling or unable to give consent, report any uncorrected visual or auditory impairments, have less than an eighth-grade education, or if English is not their primary language. To reduce the impact of scores from adults with cognitive decline beyond that expected from normal aging, scores that are identified as outliers, as

indicated by scoring below two standard deviations of the mean on measures of working memory and processing speed, will be excluded from the study.

Measures

Demographic questionnaire (Appendix A). A self-report survey will be used to collect descriptive information on age, sex, race, marital status, primary language, education, general health status, and information about an advance directive for health care. The font will be 14-point Times New Roman and will be printed with black text on white background for high contrast to accommodate age-related vision changes as recommended by the literature (Bernard, Liao, & Mills, 2001; Parker & Scharff, 1998).

Cognitive measures. The present study will assess processing speed and working memory. When attempting to measure a cognitive construct, it can be difficult to determine the extent one is truly measuring the pure construct, as other factors are often involved in order to perform task demands. To minimize the variance associated with specific materials or procedures, Salthouse and Babcock (1991) recommended the use of multiple measures to assess these constructs. These authors suggested that the measures for each construct be combined to form mean scores, which are better reflections of the constructs due to the minimization of variance. Therefore, two independent tasks that are theoretically similar will be used to assess each construct: working memory and processing speed.

Letter comparison task (Appendix B). The letter comparison task (Salthouse & Babcock, 1991) was developed to measure processing speed. It has been utilized in numerous studies as a measure of processing speed (e.g., Bowles & Salthouse, 2008; Brown & Park, 2002; Levitt, Fugelsang, & Crossley, 2006; Park et al., 1996; Salthouse &

Babcock, 1991; Zwahr et al., 1999). This instrument is a paper-and-pencil task that requires the participant to determine whether two strings of letters are the “same” or “different” as quickly as possible within 20 s. Participants are instructed to write an “S” if the letters are the same or a “D” if the letters are different. One half of the pairs are the same, and the other half are different. Pairs that are classified as different only differ based on one letter that is randomized to be at the beginning, middle, or end of the letter string. The letters are randomly selected consonants, and they are arranged in sets of three, six, or nine letters. Participants are given 20 s to complete each of the two sections. The dependent measure is the total number of correct decisions made in each 20 s period. The letter comparison task has demonstrated high test-retest reliability ($r = .94$; Salthouse & Babcock, 1991).

Listening span task (Appendix C). The listening span task (Salthouse & Babcock, 1991) was developed to measure working memory. This measure has been utilized in numerous studies as a measure of working memory (e.g., Levitt et al., 2006; Salthouse & Babcock, 1991; Zwahr et al., 1999). Participants are required to select the correct answer to questions about orally presented sentences while simultaneously remembering the last word in each sentence (target words). In the instructions, emphasis is given for participants to concentrate on answering the content questions correctly, rather than focusing on the recall of the target words. The content questions must be answered correctly in order for the recall responses to be evaluated. Sentences are between 6 and 10 words long and are read at a normal rate. The final word of each sentence never exceeds two syllables, is common enough to find in a children’s dictionary, and never appears more than once. Salthouse and Babcock (1991) attempted

to keep the comprehension questions for each sentence simple (e.g., who? when? where?). Target words are never included in the comprehension questions or in the answer choices. Participants are given an answer sheet with answer choices and are instructed to choose one of three answers about the sentences. After completion of a designated number of sentences, participants turn to the back of the paper and are instructed to write the target words in the order they were presented. Salthouse and Babcock (1991) found age correlation estimates of $-.52$ as age increased and the measure has also demonstrated adequate test-retest reliability ($r = .86$).

Scoring cognitive measures. The letter comparison task is scored by counting the number of item pairs correctly identified in the designated time. To assess processing speed, a z score will be calculated for the task. For listening span, items are only considered correct and subsequently scored if the individual first answered the corresponding sentence comprehension questions correctly. If this criterion is met, then scores for the task become the highest number of items with correct responses on at least two of the three trials of the given sequence length. To assess working memory, a z score will be calculated for the task. Zwahr and colleagues (1999) conducted a factor analysis on several cognitive variables including processing speed and working memory. They found that processing speed and working memory loaded on the same factor, and summed the z scores together to create a composite cognitive score. Therefore, a composite cognitive score will be calculated from the sum of the processing speed z score and working memory z score.

Life-Support Preferences/Predictions Questionnaire (LSPQ; Appendix D).

The LSPQ (Ditto et al., 2001) is an instrument that was developed to assess individuals'

preferences for LSTs. It includes nine realistic vignettes that capture a variety of medical conditions and range in severity, nature of impairment, prognosis, and level of pain. It requires participants to read detailed descriptions of LSTs (e.g., CPR for loss of breathing or heart beat). This description will be omitted for the present study, as it would provide educational information to all participants thereby confounding the information manipulation of the current study. Then participants are presented with vignettes that include diagnosis and functional description of the condition. The nine vignettes include: Alzheimer's disease, emphysema, coma following a stroke with no chance of recovery, coma following a stroke with slight chance of recovery, stroke resulting in significant limitations with no chance of improvement, stroke resulting in significant limitations with slight chance of improvement, colon cancer without pain, colon cancer with severe pain, and the participant's current health. For the current study a subset of four vignettes will be used to decrease participant burden (Coppola et al., 1999). Vignettes were chosen based on what was thought to produce the most variability in responses according to data from Ditto et al.'s (2001) study. The four scenarios will include: Alzheimer's disease, coma with slight chance of recovery, emphysema, and stroke with slight chance of recovery. Participants are asked to imagine themselves in each vignette's situation and to then indicate their preference for receiving different LSTs. These treatment options include: antibiotics, CPR, surgery, and ANH. Participants indicate their treatment preferences using a 5-point Likert scale that ranges from "definitely want this treatment" to "definitely do not want this treatment." A continuous score will be calculated by summing the responses for the four vignettes, resulting in a range of 16 to 80, with a higher number indicating the participant is more likely to want LST. Responses can also

be treated as a dichotomous variable. Ditto et al. (2001) dichotomized the responses into: want treatment and don't want treatment. The "unsure" response option is grouped into the "want treatment" category because in a real-life hospital setting, the default is to receive treatment unless specifically stated otherwise (Ditto et al, 2001). Preferences for each scenario have evidenced high internal consistency (Cronbach's α from .86 - .96; Coppola et al., 1999). The vignettes are written at an eighth-grade reading level. The font will be 14-point Times New Roman and will be printed with black text on white background for high contrast to accommodate age-related vision changes as recommended by the literature (Bernard, Liao, & Mills, 2001; Parker & Scharff, 1998).

Medical Comprehension Questionnaire (MCQ; Appendix E). The MCQ (Porensky & Carpenter, 2008) is a measure designed to assess individuals' knowledge of LSTs and conditions that are often included in advance directives. It was originally developed as a semi-structured interview and contains 68 yes-or-no questions. Questions assess knowledge of CPR, mechanical ventilation, feeding tubes, coma, and persistent vegetative state. Participants are asked several yes-or-no questions about the term. Questions for each section are grouped into three domains: what the treatment involves, what the treatment is for, and the potential consequences of receiving the treatment. Of the 68 questions, 29 of the questions are correctly scored "No" and 39 of the questions are correctly scored "Yes." A continuous score is calculated by summing the number of correct responses, resulting in a range of 0 to 68, with a higher number indicating the participant is more knowledgeable about LSTs. For the purposes of the current study, this measure will be administered as a paper-and-pencil test. There is currently no published data concerning the reliability or validity of this measure. However, as

Thorevska et al. (2005) noted, there are not currently any validated tools available for assessing lay knowledge of LSTs.

Procedure

Approval to conduct this study will be obtained from the Xavier University Institutional Review Board prior to the commencement of data collection. Once approved, information about this study will be posted on the participant pool bulletin board and on bulletin boards of local churches and community centers. After consenting to the study, participants will then be assigned a participant number that will be on all of their materials. To ensure anonymity, no information will be recorded that matches participants with their participant number. Participants who choose to proceed will be randomly assigned to one of two information types: educational information about LSTs (LST) or educational information about general health issues (General). The LST Information is a three-page document that presents information about the procedures, risks and benefits, and terminology related to LSTs (Appendix H). It was created for an eighth grade reading level and scored a 60.9 using the Microsoft Word Flesch Reading Ease test. It was developed based on information from the MCQ (Porensky & Carpenter, 2008). The general information presents information on diet and exercise and is three pages long (Appendix I). It was created for an eighth grade reading level and scored a 61.0 on the Flesch Reading Ease test. It was developed based on information from Mayo Clinic Staff (2011). Both documents use 14-point Times New Roman font. All participants will first complete the demographic questionnaire. Those in the LST information group will then receive written educational information about LSTs. Those in the general information group will receive educational information about diet and

exercise. All participants will be instructed to read the information as they normally would at their own pace. Participants will be informed that they may be tested later assessing their memory for the information. All participants will then complete the letter comparison and listening span tasks. For the LST information group, these measures will serve as filler tasks, allowing the long-term retention of the information to be assessed later. The order of these two tasks will be counterbalanced to control for possible sequence effects (e.g., fatigue). After these tasks have been completed, participants will complete the LSPQ. The order of the four vignettes will be counterbalanced to control for possible sequence effects. Finally, participants will then complete the MCQ. Upon completion of the study, all participants will be given debriefing information, the older adults will be entered into a drawing to win a \$25 gift card, and the young adults will receive their course credit.

Chapter IV

Proposed Analyses

The purpose of the current study is to examine the relationships between age, K-LST, and treatment preferences. To test the hypotheses, an alpha level of $p < .05$ will be used.

To test H_1 two independent samples t -tests will be conducted: one t -test between age and working memory, and another t -test between age and processing speed.

To test H_2 an Age (young vs. older adults) x Information Type (LST vs. general) analysis of variance (ANOVA) on the K-LST scores will be conducted.

To test H_{0a} an Age (young vs. older adults) x Information Type (LST vs. general) analysis of covariance (ANCOVA) on the K-LST scores will be conducted with composite cognition score as a covariate.

To test H_3 an Age (young vs. older adults) x Information Type (LST vs. general) ANOVA on LST preferences will be conducted.

To test H_{0b} an Age (young vs. older adults) x Information Type (LST vs. general) ANCOVA on LST preferences will be conducted with K-LST as a covariate.

Limitations

There are some limitations to the proposed study. First, a convenience sample will be used. Therefore, the sample may not be truly representative of the population being studied and therefore generalizability of these results may be limited. Second, the

current study will use the MCQ as a measure of K-LST. This measure has not been validated, and therefore calls into question whether this measure is truly assessing K-LST. However, there are currently no other measures available to measure this construct at this time. Future research should attempt to establish reliability and validity for the MCQ. Third, this study will use hypothetical vignettes rather than assessing individuals' actual LST preferences. It is possible that individuals would make different choices when actually in the described situations than they report. Fourth, the proposed study will examine age differences in learning written information on LSTs. Future work should examine age differences in learning this information in a more complex real-life setting, where individuals receive information verbally with little time to review the information.

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Appendix A
Demographic Questionnaire

1. What is your age in years? _____
2. What is your sex?
____ Male
____ Female
3. What is your ethnicity?
____ Hispanic or Latino
____ Not Hispanic or Latino
4. What is your race?
____ Asian
____ Black or African-American
____ American Indian/Alaska Native
____ Native Hawaiian or Other Pacific Islander
____ White/Caucasian
____ Biracial/Multiracial
____ Other
5. What is your marital status?
____ Single
____ Married
____ Separated
____ Divorced
____ Widowed
____ In a committed relationship

10. If you typically wear hearing aids, are you wearing them now?

_____ Yes

_____ No

_____ I do not need hearing aids

11. Do you currently have an advance directive for health care decisions?

_____ Yes

_____ No

_____ Not sure

Appendix B

Letter Comparison Task

The Letter Comparison Task is not reproduced in this document. This measure is used and described in several publications (Bowles & Salthouse, 2008; Brown & Park, 2002; Levitt et al., 2006; Park et al., 1996; Salthouse & Babcock, 1991; Zwahr et al., 1999) and is available from T. A. Salthouse.

Appendix C

Listening Span Task

The Listening Span Task is not reproduced in this document. This measure is used and described in several publications (Levitt et al., 2006; Salthouse & Babcock, 1991; Zwahr et al., 1999) and is available from T. A. Salthouse.

Appendix D**Life-Support Preferences/Predictions Questionnaire (LSPQ)**

The LSPQ is not reproduced in this document. This measure is used and described in several publications (Bookwala et al., 2001; Coppola et al., 1999; Ditto et al., 2001) and is available from P. H. Ditto.

Appendix E**Medical Comprehension Questionnaire (MCQ)**

The MCQ is not reproduced in this document. This measure is available online at <http://www.apa.org/pubs/databases/psyc-tests/>.

Appendix F

LST Information

Please read the following information carefully, at your own pace. You may be tested on this information later.

Information on Life-Sustaining Treatments

When people become seriously ill or have a life-threatening medical problem, there are several treatment options available to try to prolong life. People are given the choice to have all, some, or none of the treatment options. The following information will explain the procedures involved in the treatments, the risks and benefits, and some common terms.

Cardiopulmonary Resuscitation (CPR)

CPR involves artificial breathing and forceful pressure on the chest to try to restart the heart. It usually involves electric shock (defibrillation) and a plastic tube inserted through the mouth or nose, down the throat into the windpipe to assist breathing (intubation) if people cannot breathe on their own. This tube is connected to a breathing machine (mechanical ventilator). CPR means that all medical treatments will be done to prolong life when the heart stops or breathing stops, including being placed on a mechanical

ventilator, being transferred to the hospital, and being given medications intravenously (through an IV). CPR may prolong life. If CPR is not used, the person will become unconscious almost immediately and will die in 5 to 10 minutes. Fewer than 20% of people who have CPR done live long enough to leave the hospital. Even fewer are able to function in the same way they used to. Some people have permanent brain damage as a result of their heart stopping. Pressing on the chest with force can cause a sore chest, broken ribs, or a collapsed lung.

Mechanical Ventilator (MV)

A mechanical ventilator takes over breathing for people who cannot breathe on their own. It involves an intubation tube (see above) that is connected to a breathing machine (the mechanical ventilator). Most patients who are on a MV remain on it for a few hours or days in the intensive care unit. The person will find it difficult or impossible to talk. He or she will be fully dependent on others for basic needs (dressing, bathing, eating) while on the MV. The MV could cause the person to develop pneumonia or a collapsed lung. Not everyone recovers enough to be removed from the MV, and the person could become permanently dependent on the MV to breathe.

Feeding Tube

A feeding tube is often referred to as artificially supplied nutrition and hydration. It provides nourishment when a person can no longer eat or drink. It is given through a tube passed through either the nose or through the skin directly into the stomach, which involves surgery. It may be needed for a short while or permanently. People may still be able to breathe on their own and function on their own while using a feeding tube. The use of a

feeding tube may cause pain or discomfort and puts the person at risk for getting an infection. Without it, if the person cannot eat or drink the person will die.

Coma

A coma is a state of unconsciousness in which a person cannot be aroused and does not respond to pain, touch, sound, or light. A coma may be temporary or permanent. If the person gains consciousness there is a risk the person will have brain damage. The person is fully dependent on others for all needs (feeding, toileting, bathing).

Persistent Vegetative State (PVS)

In a PVS, people are able to be awake but are completely unaware of themselves and their surroundings. Their eyes may open or they may have automatic responses to other things like pain, touch, sound, or light, but they cannot do anything with purpose. The person is fully dependent on others for all needs (feeding, toileting, bathing).

Appendix G

General Information

Please read the following information carefully, at your own pace. You may be tested on this information later.

Information on Diet and Exercise

The health gains of weekly exercise and a balanced diet can affect everyone, regardless of age, gender, or physical ability. The following information will explain some of the benefits of living a healthy lifestyle that involves weekly exercise and a balanced diet.

Weight Control

Weekly exercise and a healthy diet can stop a person from gaining too much weight or help a person to lose excess weight. The harder the person works out, the more calories a person's body burns. The fewer calories a person eats, the fewer he or she needs to burn by working out. Together, a healthy diet and weekly exercise will allow people to keep a healthy weight.

Too much exercise can cause a person to get hurt, and eating too few calories can also be bad for a person's health. The key is to find a good balance to control weight.

Combat Health Conditions and Diseases

Weekly exercise and a balanced diet can help people stop a wide range of health problems and concerns. Some of these include: stroke, heart disease, type 2 diabetes, depression, cancer, arthritis, and falls. While some of these health problems are linked to keeping a healthy weight, exercise at any weight is helpful and can help prevent certain health conditions. Some exercise can lead to injury for those who are overweight, so some people may need to talk with their doctor to make sure they do not get hurt.

Increase Energy

Exercise and some foods can give some people more energy. Weekly exercise can improve muscle strength and increase endurance, which makes people feel more energized. Weekly exercise also takes oxygen and nutrients to tissues in a person's body, which allows their body to work better. The body working better results in more energy. Exercising too much can cause a person to have lower energy levels, and injury that results from too much exercise also lowers a person's energy.

Improve Mood

Weekly exercise and certain foods boost some brain chemicals that can leave people to feel happier and more relaxed. Having a healthy lifestyle can also leave people to feel better about how they look, which can make them feel more confident and improve their self-esteem. Weekly

exercise can decrease people's physical response to stress, which leaves them feeling better after they are done with their workout.

Improve Sleep

Weekly exercise can help people sleep. It helps people to fall asleep faster and also to reach a deeper sleep. Because exercise can boost energy, people should not workout too close to bedtime, or they may have too much energy to be able to fall asleep. Some foods and drinks, like those with caffeine, should not be consumed before bed to allow for a more restful sleep. Although some people feel drowsy after drinking alcohol, it should also be avoided because it keeps people from reaching deeper levels of sleep and leads people to feel even more tired the next day.

Chapter V: Dissertation

Abstract

There has been an increased initiative for older adults to be active participants in the end-of-life decision-making process. Cognitive changes that occur as part of the normal aging process, including declines in processing speed and working memory, can negatively affect older adults' comprehension of medical information. The present study investigated the relationship between age-related cognitive decline and the ability to learn about life-sustaining treatments (LSTs). It also explored the relationship between age-related cognitive decline and LST decisions. Participants were 58 undergraduate students and 58 community-dwelling older adults. Results indicated older adults evidenced significantly worse cognitive abilities than young adults. Participants who read information specific to LSTs were significantly more knowledgeable about LSTs than those who read information on general health, even after adjusting for cognitive abilities. Neither age group was more knowledgeable about LSTs in either information group. Older adults were significantly less likely to choose LSTs, even after adjusting for knowledge of LSTs. Reading information about LSTs did not affect preferences for LSTs. These results suggest older adults can learn as well as young adults about LSTs, despite cognitive decline. Finally, age, rather than knowledge of LSTs, appears to be related to preferences for LSTs.

Keywords: aging, life-sustaining treatments, cognitive decline

Role of Age and Cognitive Abilities on Life-Sustaining Treatments and Treatment Preferences

Most research that has focused on end-of-life care decisions has studied older adults, as end-of-life care decisions are most relevant to this age group. Additionally, older adults comprise the largest group of consumers of health care services in the United States (National Center for Health Statistics, 2012). With this age group consuming significant healthcare resources for end-of-life care, there is a need to focus on older adults when examining these issues. According to the U.S. Census Bureau (2011), individuals who are or are soon-to-be older adults are the cohorts that are increasing the most rapidly in the country. The largest percent increase within the American population is in individuals who are aged 60-64, followed by individuals who are 55-59 years of age. As the “baby boomer” generation continues to age, the number of older adults making end-of-life care decisions will increase exponentially.

Although surrogate decision-makers, such as spouses or children, often make end-of-life care decisions for older adults, there has been increased interest and legislation to maintain older adults’ autonomy, including making advanced directives to plan for their own end-of-life care (Hiltunen, Medich, Chase, Peterson, & Forrow, 1999; Kim, Karlawish, & Caine, 2002; Laakkonen, Pitkala, Strandberg, Berglind, & Tilvis, 2005). The Patient Self Determination Act (PSDA) was enacted in 1990 and requires providers receiving Medicare or Medicaid to inform patients of their rights to accept or refuse medical treatment and the right to execute an advance directive. As older adults are encouraged to direct and document their preferences in end-of-life care, it is important to examine how these decisions are made.

The process of making end-of-life care decisions should be similar to the informed consent process, in that patients need to understand treatment possibilities as well as their risks and benefits (Olick, 1991). Without the ability to understand the risks and benefits associated with different life-sustaining treatment (LST) options as well as knowledge about what each treatment entails, patients cannot truly give informed consent to procedures. Beauchamp and Childress (2001) discussed the various meanings and definitions of informed consent, and discussed that comprehension of what is disclosed is required for informed consent. In this sense, an informed consent occurs if a patient with adequate understanding intentionally authorizes a professional to do something. However, the literature suggests that many patients are not adequately informed of their end-of-life treatment options (Mirza, Kad, & Ellison, 2005; Rady & Johnson, 2004). Further, there is evidence that patients who have not been adequately informed about their LST options make different decisions regarding end-of-life care. In an effort to protect the informed consent process, there is a need to investigate how well older adults comprehend information about LST options for end-of-life care and to explore how well they can retain the information presented to them in order to make informed decisions about their end-of-life care.

Older adults are faced with end-of-life decision-making more than any other group. At the same time, older adults experience age-related cognitive changes that may hinder their ability to acquire and utilize such information (see Park, 2000, for a review). Older adults show poorer performance on processing speed tasks and working memory tasks (Park et al., 1996; Salthouse & Babcock, 1991). Compared to younger adults, older adults have evidenced decreased ability to hold and manipulate information in working

memory and reduced speed of processing information. In concert with these declines affecting their information processing capacity, they are faced with many important decisions on a daily basis. In particular, working memory and processing speed have been identified as key cognitive processes that affect older adults' ability to learn health information (Brown & Park, 2002). However, there is insufficient literature on the impact of age-related cognitive changes on older adults' ability to learn specifically about LST options. Moreover, the effects of cognitive changes on decisions regarding end-of-life care choices are unknown.

Given the natural decline in older adults' basic cognitive processes, it is important to examine if these impairments affect their decision-making abilities as well. Decision-making is based on integrating information that is relevant to the decision. However, older adults are more likely to selectively use information presented to them, and do not necessarily use all of the information available to them in their decision-making processes (Rafaely, Dror, & Remington, 2006). This selectivity is particularly important given the increased efforts for older adults to make their own medical decisions, rather than a surrogate or their physician. Due to age-related cognitive declines, older adults may be less able to make decisions regarding medical treatments (Zwahr, Park, & Shifren, 1999). The ability to remember and understand information provided is an important factor in evaluating proposed medical treatments (Beauchamp & Childress, 2001).

Research has indicated that because of declines in basic cognitive abilities, older adults have difficulty comprehending and remembering medical information (Hancock et al., 2005; Morrell et al., 1989). Specifically, the literature indicates that older adults have

increased difficulty learning information compared to younger adults as a result of age-related cognitive declines in working memory and processing speed abilities (e.g., Brown & Park, 2002; Park et al., 1996; Waters & Caplan, 2005; Zwahr et al., 1999). Further, these declines can also affect the decision-making processes of older adults (e.g., Rafaely et al., 2006; Zwahr et al., 1999). Yet older adults are increasingly encouraged to make end-of-life decisions, of which they may have little understanding. To this author's knowledge, no studies have investigated the effects of age-related cognitive decline on the ability to learn about information specifically about end-of-life treatments. Further, no studies have explored possible differences in LST decisions related to cognitive changes and retention of written information. Therefore, the present study investigated age-related cognitive changes and treatment knowledge on LST preferences.

Method

Participants

One hundred and ninety-one participants were recruited for the present study. Of the 191 participants, 125 young adults were undergraduate students at a Midwestern university, and 66 older adults were recruited from the university's alumni association, Midwestern churches, senior living communities, and senior recreation centers from two cities. Of the 191 participants who completed the study, 2 young adults and 1 older adult provided incomplete data and were not included in the data analysis. Twenty-one young adults and 5 older adults reported uncorrected vision and/or auditory impairment and were excluded from data analysis. Ten young adults and 2 older adults were above or below two standard deviations of the mean on the cognitive measures and were not included in the analysis, which left 92 young adults and 58 older adults. Of the 58 older

adults, 28 participants were in the control group and 30 participants were in the experimental group. To have equal sample sizes for data analysis, 34 young adults were excluded from data analysis using a random number generator. The final sample consisted of 58 older adults and 58 young adults.

The average age of the young adults was 20.34 years ($SD = 1.33$). Additional demographic data is presented in Table 1. The young adult sample identified predominantly as “not Hispanic or Latino” (96.6%) and as White/Caucasian (82.8%). The majority of young adults identified themselves as single (79.3%) and most of them reported their highest level of education completed was some college (79.3%). Seventeen young adults reported their health was excellent, 28 reported their health was very good, 12 good, and 1 fair. Three young adults reported they currently had an advance directive for healthcare decisions, 20 reported they did not, and 35 reported they were “not sure.”

The average age of the older adults was 68.72 years ($SD = 8.10$). Additional demographic data is presented in Table 1. The older adult sample identified predominantly as “not Hispanic or Latino” (94.8%) and as White/Caucasian (93.1%). The majority of older adults identified themselves as married (65.5%) and most of them reported their highest level of education completed was a graduate degree (41.4%). Ten older adults reported their health was excellent, 24 reported their health as very good, 20 as good, 3 as fair, and 1 as poor. Thirty-two older adults reported they currently had an advance directive for healthcare decisions, 16 reported they did not, and 10 reported they were “not sure.”

Measures

Demographic questionnaire. A self-report survey was used to collect descriptive information on age, sex, race, marital status, primary language, education, general health status, and information about an advance directive for health care. The font used was 14-point Times New Roman and was printed with black text on white background for high contrast to accommodate age-related vision changes as recommended by the literature (Bernard, Liao, & Mills, 2001; Parker & Scharff, 1998).

Cognitive measures. The present study assessed processing speed and working memory. When attempting to measure a cognitive construct, it can be difficult to determine the extent one is truly measuring the pure construct, as other factors are often involved in order to perform task demands. To minimize the variance associated with specific materials or procedures, Salthouse and Babcock (1991) recommended the use of multiple measures to assess these constructs. Therefore, two independent tasks that are theoretically similar were used to assess each construct: working memory and processing speed.

Letter comparison task. The letter comparison task (Salthouse & Babcock, 1991) was developed to measure processing speed. It has been utilized in numerous studies as a measure of processing speed (e.g., Bowles & Salthouse, 2008; Brown & Park, 2002; Levitt, Fugelsang, & Crossley, 2006; Park et al., 1996; Salthouse & Babcock, 1991; Zwahr et al., 1999). This instrument is a paper-and-pencil task that requires the participant to determine whether two strings of letters presented visually on the paper are the “same” or “different” as quickly as possible within 20 s. Participants are instructed to write an “S” if the letters are the same or a “D” if the letters are different. One half of the

pairs are the same, and the other half are different. Pairs that are classified as different only differ based on one letter that is randomized to be at the beginning, middle, or end of the letter string. The letters are randomly selected consonants, and they are arranged in sets of three, six, or nine letters. Participants are given 20 s to complete each of the two sections. The dependent measure is the total number of correct decisions made in each 20 s period. The letter comparison task has demonstrated high test-retest reliability ($r = .94$; Salthouse & Babcock, 1991).

Listening span task. The listening span task (Salthouse & Babcock, 1991) was developed to measure working memory. This measure has been utilized in numerous studies as a measure of working memory (e.g., Levitt et al., 2006; Salthouse & Babcock, 1991; Zwahr et al., 1999). Participants are required to select the correct answer to questions about orally presented sentences while simultaneously remembering the last word in each sentence (target words). In the instructions, emphasis is given for participants to concentrate on answering the content questions correctly, rather than focusing on the recall of the target words. The content questions must be answered correctly in order for the recall responses to be evaluated. Sentences are between 6 and 10 words long and are read at a normal rate. The final word of each sentence never exceeds two syllables, is common enough to find in a children's dictionary, and never appears more than once. Salthouse and Babcock (1991) attempted to keep the comprehension questions for each sentence simple (e.g., who? when? where?). Target words are never included in the comprehension questions or in the answer choices. Participants are given an answer sheet with answer choices and are instructed to choose one of three answers about the sentences. After completion of a designated number of

sentences, participants turn to the back of the paper and are instructed to write the target words in the order they were presented. Salthouse and Babcock (1991) found age correlation estimates of $-.52$ as age increased and the measure has also demonstrated adequate test-retest reliability ($r = .86$).

Scoring cognitive measures. The letter comparison task is scored by counting the number of item pairs correctly identified in the designated time. To assess processing speed, a z score was calculated for the task based on the number of pairs correctly identified across both 20 s trials. For listening span, items are only considered correct and subsequently scored if the individual first answered the corresponding sentence comprehension questions correctly. If this criterion is met, then scores for the task become the highest number of items with correct responses on at least two of the three trials of the given sequence length. To assess working memory, a z score was calculated based on the highest number of trials achieved. Zwahr and colleagues (1999) conducted a factor analysis on several cognitive variables including processing speed and working memory. They found that processing speed and working memory loaded on the same factor, and summed the z scores together to create a composite cognitive score. Therefore, a composite cognitive score was calculated from the sum of the processing speed z score and working memory z score.

Life-Support Preferences/Predictions Questionnaire (LSPQ). The LSPQ (Ditto et al., 2001) is an instrument that was developed to assess individuals' preferences for LSTs. It includes nine realistic vignettes that capture a variety of medical conditions and range in severity, nature of impairment, prognosis, and level of pain. It requires participants to read detailed descriptions of LSTs (e.g., cardiopulmonary resuscitation for

loss of breathing or heart beat). This description will be omitted for the present study, as it would provide educational information to all participants thereby confounding the information manipulation of the current study. Then participants are presented with vignettes that include diagnosis and functional description of the condition. The nine vignettes include: Alzheimer's disease, emphysema, coma following a stroke with no chance of recovery, coma following a stroke with slight chance of recovery, stroke resulting in significant limitations with no chance of improvement, stroke resulting in significant limitations with slight chance of improvement, colon cancer without pain, colon cancer with severe pain, and the participant's current health. For the current study a subset of four vignettes will be used to decrease participant burden (Coppola et al., 1999). Vignettes were chosen based on what was thought to produce the most variability in responses according to data from Ditto et al.'s (2001) study. The four scenarios will include: Alzheimer's disease, coma with slight chance of recovery, emphysema, and stroke with slight chance of recovery. Participants are asked to imagine themselves in each vignette's situation and to then indicate their preference for receiving different LSTs. These treatment options include: antibiotics, cardiopulmonary resuscitation (CPR), surgery, and artificial nutrition and hydration (ANH). Participants indicate their treatment preferences using a 5-point Likert scale that ranges from "definitely want this treatment" to "definitely do not want this treatment." A continuous score was calculated by summing the responses for the four vignettes, resulting in a range of 16 to 80, with a higher number indicating the participant is more likely to want LST. Responses can also be treated as a dichotomous variable. Ditto et al. (2001) dichotomized the responses into: want treatment and don't want treatment. The "unsure" response option is grouped into

the “want treatment” category because in a real-life hospital setting, the default is to receive treatment unless specifically stated otherwise (Ditto et al, 2001). Preferences for each scenario have evidenced high internal consistency (Cronbach’s α from .86 - .96; Coppola et al., 1999). The vignettes are written at an eighth-grade reading level. The font was 14-point Times New Roman and was printed with black text on white background for high contrast to accommodate age-related vision changes as recommended by the literature (Bernard, Liao, & Mills, 2001; Parker & Scharff, 1998).

Medical Comprehension Questionnaire (MCQ). The MCQ (Porensky & Carpenter, 2008) is a measure designed to assess individuals’ knowledge of LSTs and conditions that are often included in advance directives. It was originally developed as a semi-structured interview and contains 68 yes-or-no questions. Questions assess knowledge of CPR, mechanical ventilation, feeding tubes, coma, and persistent vegetative state. Participants are asked several yes-or-no questions about the term. Questions for each section are grouped into three domains: what the treatment involves, what the treatment is for, and the potential consequences of receiving the treatment. Of the 68 questions, 29 of the questions are correctly scored “No” and 39 of the questions are correctly scored “Yes.” A continuous score is calculated by summing the number of correct responses, resulting in a range of 0 to 68, with a higher number indicating the participant is more knowledgeable about LSTs. For the purposes of the current study, this measure was administered as a paper-and-pencil test. There is currently no published data concerning the reliability or validity of this measure. However, as Thorevska et al. (2005) noted, there are not currently any validated tools available for assessing lay knowledge of LSTs.

Procedure

The university's Institutional Review Board gave approval to conduct this study prior to the commencement of data collection (see Appendix A). Participants were randomly assigned a packet that contained one of two information types: educational information about LSTs (LST) or educational information about general health issues (General). The LST Information is a 3-page document that presents information about the procedures, risks and benefits, and terminology related to LSTs. It was created for an eighth grade reading level and scored a 60.9 using the Microsoft Word Flesch Reading Ease test. It was developed based on information from the MCQ (Porensky & Carpenter, 2008). The general information presents information on diet and exercise in a 3-page document based on information from Mayo Clinic Staff (2011). It was created for an eighth grade reading level and scored a 61.0 on the Flesch Reading Ease test. Both documents used 14-point Times New Roman font. All participants first completed the demographic questionnaire. Then participants read information documents. Participants in the LST information group received written educational information about LSTs. Participants in the general information group received educational information about diet and exercise. All participants were instructed to read the information as they normally would at their own pace. Participants were informed that they may be tested later assessing their memory for the information. All participants then completed the letter comparison and listening span tasks. For the LST information group, these measures served as filler tasks, allowing the long-term retention of the information to be assessed later. The order of these two tasks was counterbalanced to control for possible sequence effects (e.g., fatigue). After these tasks were completed, participants completed the

LSPQ. The order of the four vignettes was counterbalanced to control for possible sequence effects. Finally, participants then completed the MCQ. The older adults were given the choice to record their name and phone number on a separate sheet of paper that does not link their name to their data. Those who chose to provide that information were entered into a drawing to win a \$25 gift card, and the young adults received course credit.

Results

Data for the present study were collected by multiple examiners. The two cognitive tasks, letter comparison and listening span, were the only measures administered by an examiner; the other measures were self-report questionnaires. A one-way analysis of variance (ANOVA) indicated that the examiner (principal investigator vs. research assistants) did not affect the composite cognitive scores for young adults, $F(1, 56) = 1.89, p = .18$. Another one-way ANOVA indicated that the examiner (principal investigator vs. research assistants) did not affect the composite cognitive scores for older adults, $F(1, 56) = 1.43, p = .24$. Therefore, examiner effects were not considered in any subsequent analyses.

Data for older adults were collected from two cities. A one-way ANOVA conducted on the older adult sample indicated that location (City 1 vs. City 2) did not affect the composite cognitive score, $F(1, 56) = 1.43, p = .24$. A one-way ANOVA also indicated that location (City 1 vs. City 2) did not affect knowledge of LSTs, $F(1, 56) = .72, p = .40$. Finally, a one-way ANOVA indicated that location (City 1 vs. City 2) did not affect LST preferences, $F(1, 56) = .05, p = .83$. Therefore, participants in the two cities did not differ significantly on the dependent variables, and their data were grouped together for subsequent analyses.

An independent-samples *t*-test was conducted to determine whether older adults performed significantly worse than young adults on working memory as measured by the *z* score calculated from the Listening Span score. The results indicated that young adults ($M = .36, SD = .72$) had significantly higher *z* scores on the working memory measure than older adults ($M = -.55, SD = 1.22$), $t(92.82) = 4.86, p < .001$ (equal variances not assumed). Another independent-samples *t*-test was conducted to determine whether older adults performed significantly worse than young adults on processing speed as measured by the *z* score calculated from the Letter Comparison score. The results indicated that young adults ($M = .50, SD = .68$) had significantly higher scores on the processing speed measure than older adults ($M = -.50, SD = 1.02$), $t(99.41) = 6.28, p < .001$ (equal variances not assumed). Therefore, Hypothesis 1 was supported as older adults performed significantly worse on both cognitive measures than young adults.

A 2 x 2 ANOVA was conducted to evaluate the effects of Age (young vs. older adults) and Information Type (LST vs. general) on Knowledge of LSTs. The ANOVA indicated a significant main effect for Information Type, $F(1, 112) = 26.13, p < .001$, but no significant main effect for Age, $F(1, 112) = .33, p = .57$, and no significant interaction between Age and Information Type, $F(1, 112) = 2.61, p = .11$. The Information Type main effect was due to participants who read information specific to LSTs being significantly more knowledgeable about LSTs than those who read information on general health. However, there were no age differences in knowledge of LSTs. Therefore, Hypothesis 2 was partially supported.

An exploratory analysis was conducted using a one-way analysis of covariance (ANCOVA) to evaluate the main effect for Information Type on Knowledge of LSTs

when controlling for the composite cognitive score. After adjustment for the composite cognitive score, there was a statistically significant difference in knowledge of LSTs between the Information Types, $F(1, 113) = 28.32, p < .001$. A post hoc analysis with a Bonferroni adjustment indicated that participants who read LST information had significantly more knowledge of LSTs than participants who read general information ($p < .001$).

A 2 x 2 ANOVA was conducted to evaluate the effects of Age (young vs. older adult) and Information Type (LST vs. general) on LST preferences. The ANOVA indicated a significant main effect for Age, $F(1, 112) = 41.34, p < .001$, but no significant main effect for Information Type, $F(1, 112) = .04, p = .83$, and no significant interaction between Age and Information Type, $F(1, 112) = .90, p = .35$. The main effect of age was due to young adults being significantly more likely to choose LSTs than older adults. Reading information specific to LSTs or about general health did not affect preference for LSTs. Therefore, Hypothesis 3 was partially supported.

An exploratory analysis was conducted using a one-way ANCOVA to evaluate the main effect for Age on LST Preferences when controlling for Knowledge of LSTs. After adjustment for Knowledge of LSTs, there was a statistically significant difference in LST Preferences between the age groups, $F(1, 113) = 40.72, p < .001$. Post hoc analysis was performed with a Bonferroni adjustment. Older adults were significantly less likely to choose LSTs compared to young adults ($p < .001$).

Discussion

The present study found that older adults had significantly reduced performance on measures of working memory and processing speed, which is supported by the

existing literature on cognitive aging (Park, 2000). As adults age, certain cognitive processes, including working memory and processing speed, decline. The results on cognitive tasks were comparable to figures in previous studies. On the working memory task, the correlation between Age and Listening Span was $-.54$ ($p < .01$), which is similar to a correlation of $-.52$ ($p < .01$) found in previous research (Salthouse & Babcock, 1991). Similarly, for processing speed the correlation between Age and Letter Comparison was $-.57$ ($p < .01$), and is comparable to a correlation of $-.59$ from a previous study (Salthouse & Babcock, 1991). Therefore, the present study's sample appears representative of that found in other studies. It supports the literature that suggests as age increases, working memory and processing speed abilities decline.

The results of the present study suggest that despite cognitive decline associated with normal aging, older adults are not at a greater disadvantage of learning information about LSTs than young adults. Both older and young adults significantly benefitted from receiving LST information in their knowledge of LSTs. Interestingly, although young adults performed significantly better than older adults on cognitive measures associated with learning, young adults were not significantly more knowledgeable about LSTs than older adults. Further, receiving LST information did not affect participant preferences for LSTs, although older adults were less likely to prefer LSTs than young adults.

With regard to knowledge about LSTs, the present study did not find that age was associated with knowledge of LSTs, contrary to what was hypothesized. There were no significant age differences in knowledge of LSTs for those who did not receive information about LSTs. This finding suggests that baseline knowledge of LSTs is similar between young and older adults. Older adults did not perform significantly better

or worse than young adults, for those who received information about LSTs. This finding suggests that older adults can learn as much as young adults about LSTs. Previous research has indicated that although people have a basic understanding of some LSTs, they often have misconceptions about these treatments (Groarke, Gallagher & McGovern, 2010; Kaldjian et al., 2009; Upadya, Muralidharan, Thorevska, Amoateng-Adjepong, & Manthous, 2002). In the present study, older adult participants' knowledge was comparable to figures in previous research (Porensky & Carpenter (2008a). Older adults in the general information group answered an average of 78% ($SD = 5.7\%$) of questions correctly on a measure of knowledge of LSTs and older adults in the LST information group answered an average of 82% ($SD = 7.6\%$) of questions correctly. Porensky and Carpenter (2008a) found older adult participants in their study answered an average of 78% ($SD = 6.5\%$) of questions correctly on the same measure of knowledge of LSTs. To this author's knowledge there are no comparable results for the young adults, as previous research has only examined the performance of older adults on this measure of knowledge of LSTs. In the present study, young adults did not differ significantly from older adults in either information group. Young adults in the general information group answered an average of 75% ($SD = 6.5\%$) of questions correctly, and young adults in the LST information group answered an average of 84% ($SD = 7.1\%$) correctly. It is important to note, however, that there was substantial range (63% - 99%) in accuracy across individuals in both age groups. In addition to this range in accuracy, 26% of young adults and 21% of older adults answered fewer than 75% of questions correctly, indicating that a noteworthy minority of participants lacks a basic understanding of LSTs.

This finding suggests that it may be important for clinicians to be aware of potential gaps in knowledge of LSTs, and for patients to question their perceived knowledge.

The findings of the present study supported the hypothesis of a significant difference between participants who read information specific to LSTs and participants who read information on general health. Participants who received information about LSTs had more knowledge about LSTs when assessed later, which suggests that all participants benefitted from receiving LST information regardless of age.

With regard to preferences for LSTs, young adults were more likely than older adults to choose treatments that would extend their life. This finding is consistent with previous literature that found older adults have a low overall preference for LSTs, and as age increases the likelihood of choosing LSTs decreases (Coppola et al, 1999; Downar et al., 2011). The difference cannot be accounted for by knowledge of LSTs alone. Further, reading information specific to LSTs versus general health did not affect preferences for LSTs. The hypothetical vignettes asked participants to imagine themselves at their current age in different health conditions, and so it is not surprising that age differences emerged on this measure of LST preferences as older adults are more likely to have poor health and are at increased risk of death (National Center for Health Statistics, 2012). To this author's knowledge, no other studies have examined the effects of LST knowledge on LST preferences, and this should be re-examined in the future.

There were several limitations to the present study. Most notably, the present study used a non-validated measure, the MCQ, as a measure of knowledge of LSTs. This calls into question whether the MCQ is truly assessing knowledge of LSTs. However, there are currently no other measures available to measure this construct at this time

(Porensky & Carpenter, 2008a). Future research should attempt to establish reliability and validity for the MCQ, or validate another measure of knowledge of LSTs.

Another limitation is that a convenience sample was used. Therefore, the sample may not accurately represent the population being studied and the generalizability of these results is limited. Additionally, this study used hypothetical vignettes rather than assessing individuals' actual LST preferences. It is possible that individuals would make different choices when actually in the described situations than they reported.

The present study examined age differences in learning written information on LSTs. Participants only read the informational material once and were not permitted to review the information again, which is unrealistic in a real-life setting where people could have access to the information again. Therefore the generalizability of the results is limited. Future work should examine age differences in learning this information in a more complex real-life setting.

Although results from the present study did not find that older adults were impaired in their ability to recall information about LSTs, it should be noted that participants were given the greatest chance for successfully recalling the information. All participants were assessed for their knowledge of LSTs just 20 minutes after they had been presented with information. Environmental distractions were kept to a minimum. Additionally, "yes-or-no" questions were used to assess for knowledge of LSTs rather than open-ended questions. It is possible that age differences could emerge if recall was assessed days or weeks later, as is more likely in a real-life situation. Further, age-related differences in recall for health information are more likely to emerge in situations that are more effortful and require substantial cognitive resources, such as when using open-

ended questions (Jansen et al., 2008; Park, 2000). Therefore, it would be beneficial for future research to examine if age differences are found when assessing for knowledge of LSTs in a more complex, real-life setting.

Finally, the results of the study have positive implications for the older adult population. Despite evidencing poorer performance on cognitive tasks, older adults appeared to benefit as much from the written information as young adults. The findings support previous literature that recommends health professionals provide written information to older adults about their medical information and treatment choices (Brown & Park, 2003). Written delivery of information offers an advantage over verbal delivery of information as it can be read at the patient's own pace and can be referred to at a later time. Previous research supports the use of large font with high contrast for written materials intended for older adults (Brown, 2007). It is likely that the older adults in the present study indeed benefitted from material designed to decrease visual burden. Future research should further examine methods to deliver information to older adults in order to optimize understanding and retention of LSTs in this population.

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Table 1

Demographic Summary and Distribution Percentage of Participants

	Young Adults		Older Adults	
Age Range	18-24		60-95	
Sex	(n = 58)	%	(n = 58)	%
Male	34	58.6	27	46.6
Female	24	41.4	31	53.4
Ethnicity	(n = 58)	%	(n = 58)	%
Hispanic or Latino	2	3.4	0	0
Not Hispanic or Latino	56	96.6	55	94.8
Prefer not to respond	0	0	3	5.2
Race	(n = 58)	%	(n = 58)	%
Asian	2	3.4	0	0
Black or African American	7	12.1	1	1.7
American Indian/Alaska Native	0	0	0	0
Native Hawaiian or Other Pacific Islander	0	0	1	1.7
White/Caucasian	48	82.8	54	93.1
Biracial/Multiracial	1	1.7	1	1.7
Other	0	0	0	0
Prefer not to respond	0	0	1	1.7
Marital Status	(n = 58)	%	(n = 58)	%
Single	46	79.3	4	6.9
Married	1	1.7	38	65.5
Separated	0	0	0	0
Divorced	0	0	2	2.4
Widowed	0	0	14	24.1
In a committed relationship	11	19	0	0
Highest Level of Education Completed	(n = 58)	%	(n = 58)	%
Less than 8 th grade	0	0	0	0
8 th grade – 11 th grade	0	0	1	1.7
High School/GED	6	10.3	13	22.4
Some College	46	79.3	5	8.6
2 year College Degree	2	3.4	2	3.4
4 year College Degree	3	5.2	13	22.4
Graduate Degree	1	1.7	24	41.4
Health	(n = 58)	%	(n = 58)	%
Excellent	17	29.3	10	17.2
Very good	28	48.3	24	41.4
Good	12	20.7	20	34.5
Fair	1	1.7	3	5.2
Poor	0	0	1	1.7
Have an Advance Directive	(n = 58)	%	(n = 58)	%
Yes	3	5.2	32	55.2
No	20	34.5	16	27.6
Not Sure	35	60.3	10	17.2

Appendix A

Approval Letter from Xavier University Institutional Review Board

March 26, 2013

Lauren Cerk
10 E. Lake Shore Dr. #28
Cincinnati, OH 45237

Dear Ms. Cerk:

The IRB has completed the review of your protocol #1270, Role of Age and Cognitive Abilities in Knowledge of Life-sustaining Treatments and Treatment preferences using expedited review procedures. We appreciate your thorough treatment of the issues raised and your timely response. Your study is approved in the Expedited category under Federal Regulation 45CFR46. Approval expires March 29, 2014. A progress report, available at <http://www.xavier.edu/irb/forms.cfm>, is due by that date.

If you wish to modify your study, including any changes to the approved Informed Consent form, it will be necessary to obtain IRB approval prior to implementing the modification. If any adverse events occur, please notify the IRB immediately.

We wish you success with your research!

Sincerely,

A handwritten signature in black ink, reading "Morell E. Mullins, Jr." with a stylized "AD" at the end.

Morell E. Mullins, Jr., Ph.D.
Chair, Institutional Review Board
Xavier University

MEM/sb

C: Cyntiha Dulaney, Advisor

enclosures: stamped informed consents

Summary

Title: Role of Age and Cognitive Abilities in Knowledge of Life-Sustaining Treatments and Treatment Preferences

Problem. Following the enactment of the Patient Self Determination Act (PSDA) in 1990, there has been an increased initiative for older adults to be active participants in the end-of-life decision-making process, maintaining their autonomy. In order for individuals to give informed consent for life-sustaining treatments (LSTs), they must be able to comprehend the information and have an adequate understanding of the treatments (Beauchamp & Childress, 2001). However, cognitive changes that occur as part of the normal aging process, including declines in processing speed and working memory, can negatively affect older adults' comprehension of medical information (Brown & Park, 2002). These cognitive changes also influence older adults' decision-making abilities, particularly for medical treatments (Zwahr et al., 1999). Therefore, it is unclear how well informed older adults are about their treatment options and whether comprehension of information influences subsequent decisions at the end-of-life. The purpose of this study was to investigate the relationship between age-related cognitive decline and the ability to learn about LSTs. It also explored the relationship between age-related cognitive decline and LST preferences.

Method. Of the 191 participants in this study, 125 young adults were recruited from a Midwestern university's Psychology Department, and 66 older adults were recruited from the university's alumni association, Midwestern churches, senior living communities, and senior recreation centers from two cities. Of those participants, 33 young adults and 8 older adults either provided incomplete data, did not meet inclusion criteria, or were

outliers, and were subsequently not included in the data analysis. Thirty-four young adults were then randomly chosen to be excluded from analyses in order to have equal sample sizes between young and older adults. Of the 58 young adult participants, 24 were female and 34 were male. The average age of the young adults was 20.34 years, with the ages ranging from 18 to 24. Of the 58 older adults, 31 were female and 26 were male. The average age of the older adults was 68.72 years, with ages ranging from 60 to 95. Participants were required to complete the demographic questionnaire, the letter comparison task, the listening span task, the LSPQ, and the MCQ. They were also randomly selected to read information either about life-sustaining treatments or diet and exercise.

Findings. An independent-samples *t*-test indicated that young adults ($M = .36$, $SD = .72$) had significantly higher *z* scores on the working memory measure than older adults ($M = -.55$, $SD = 1.22$), $t(92.82) = 4.86$, $p < .001$ (equal variances not assumed). Another independent-samples *t*-test indicated that young adults ($M = .50$, $SD = .68$) had significantly higher scores on the processing speed measure than older adults ($M = -.50$, $SD = 1.02$), $t(99.41) = 6.28$, $p < .001$ (equal variances not assumed). Therefore, older adults performed significantly worse on both cognitive measures than young adults.

A 2 x 2 ANOVA indicated a significant main effect for Information Type, $F(1, 112) = 26.13$, $p < .001$, but no significant main effect for Age, $F(1, 112) = .33$, $p = .57$, and no significant interaction between Age and Information Type, $F(1, 112) = 2.61$, $p = .11$. The Information Type main effect was due to participants who read information specific to LSTs being significantly more knowledgeable about LSTs than those who

read information on general health. Neither age group was more likely to have more knowledge of LSTs than the other.

An exploratory one-way analysis of covariance (ANCOVA) revealed a statistically significant difference in knowledge of LSTs between the Information Types after adjusting for composite cognitive score, $F(1, 113) = 28.32, p < .001$, and indicated that participants who read LST information had significantly more knowledge of LSTs than participants who read general information ($p < .001$).

A 2 x 2 ANOVA indicated a significant main effect for Age, $F(1, 112) = 41.34, p < .001$, but no significant main effect for Information type, $F(1, 112) = .04, p = .83$, and no significant interaction between age and LST preferences, $F(1, 112) = .90, p = .35$. The main effect of age was due to young adults being significantly more likely to choose LSTs than older adults. Reading information specific to LSTs or about general health did not affect preference for LSTs.

An exploratory ANCOVA revealed a statistically significant difference in LST preferences between the age groups after adjusting for knowledge, $F(1, 113) = 40.72, p < .001$, and indicated older adults were significantly less likely to choose LSTs compared to young adults ($p < .001$).

Implications. The results of the study have positive implications for the older adult population. Despite evidencing poorer performance on cognitive tasks, older adults appeared to benefit as much from the written information as young adults. The findings support previous literature that recommends health professionals provide written information to older adults about their medical information and treatment choices (Brown and Park, 2003). Written information offers an advantage over verbal delivery of

information as it can be read at the patient's own pace and can be referred to at a later time. Previous research supports the use of large font with high contrast for written materials intended for older adults (Brown, 2007). It is likely that the older adults in the present study indeed benefitted from material designed to decrease visual burden. Future research should further examine methods to deliver information to older adults in order to optimize understanding and retention of LSTs in this population.