

Piloting EDMAC: The End-of-Life Decision Making and Memory Complaint Project

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Demographic trends and healthcare expenditures indicate the need for studies analyzing the effectiveness of advance directives. This study draws on Prospect Theory (Winter, Lawton, & Ruckdeschel, 2003), which states that individuals make decisions that are of the highest objective gain given subjective circumstances, as it applies to end-of-life decision making. We predicted that older adults given a large amount of information about life-sustaining treatments would choose to forego such treatments in comparison with individuals given little information. Data reported were derived from individual structured interviews. We also explored the relations of memory complaint, depression, and decisional conflict to end-of-life decision making. Based on preliminary results from eight participants (4 enhanced information and 4 usual information), we found that feeding tube initiation was less likely among individuals with enhanced information. We also found that individuals with enhanced information expressed more decisional conflict.

In recent years in the U.S., there has been much interest in the aging process with particular interest in end-of-life care. At some point in their lives, most Americans will have to make some medical decisions regarding end-of-life care, taking into account their physical and mental health. These decisions may involve the individuals themselves or a loved one. Previous studies of proxy informants have found that proxies report that individuals experience extreme burden and stress when faced with the challenges of end-of-life care. Most of these proxies report individuals about to die experience preventable symptoms that vary in intensity between “quite a bit” and “very much” (Tilden, Tolle, Drach, & Perrin,

2004). Such distress has been shown to be a predictor of desire to hasten death (i.e., quicken the dying process), with interest expressed in both euthanasia and physician-assisted suicide (Tilden et al., 2004). Although distress will most likely not be avoided completely, burdens can be at least partially alleviated by planning for the end of life (Tilden et al., 2004). One way of planning is by making careful and informed end-of-life decisions in advance through completing formal documents such as advance directives.

As recently as the 1990's many people, including those in government, began to take notice of the need for advance planning. In 1990 revolutionary legal judgments came into effect as a result of persons who were requesting relief for loved ones from lasting vegetative states in which the main concern was whether or not to forego life-sustaining treatment. In the case of *Cruzan v. Director of Missouri Department of Health, et al.* (1990), Nancy Cruzan's family requested, on her behalf, that feeding tubes and breathing aids be removed. Because Cruzan had not left any written account of her desires, the court ruled that Missouri must provide clear and undisputable evidence that the incapacitated individual would desire to forego life-sustaining treatment (*Cruzan v. Director, Missouri Department of Health, et al.*, 1990). More recently in the case of Terry Schiavo, disputes between family members reiterated the need for standards and policies regarding life-sustaining treatment (*Schiavo, ex rel. Schindler v. Schiavo* 2005).

As a result of these highly publicized legal cases, all fifty states, as well as the District of Columbia, have encouraged patient involvement in their own end-of-life decision making. As a result of the Cruzan case, the passage of the Patient Self Determination Act in 1990 provided the same encouragement at the federal level (Omnibus Budget Reconciliation Act of 1990). The act requires that health care institutions that receive governmental reimbursement (through sources such as Medicare and Medicaid) must provide patients with specific information. Such information includes details regarding advance directives, patients' rights, and policies the health care provider must implement according to the state's laws (Emanuel, Barry, Stoeckele, Ettelson, & Emanuel, 1991, as cited in Ditto, 2006).

The conflicts that arose during both the Cruzan and Schiavo cases could have been resolved through advance directives. Advance directives are statements given prior to the occurrence of illness that direct health care providers as to what actions to take in regards to life-sustaining treatment decisions (Ditto, 2006; Ditto & Hawkins, 2005). Advance directives have been earnestly promoted by leaders in many areas including ethics, law, health care, and medicine (Ditto & Hawkins, 2005; Dresser, 2003). To-

day's society is sensitive to patients who wish to make their own decisions regarding end-of-life care and life-sustaining treatments while the patient is still competent and before acute medical crisis occurs (Allen-Burge & Haley, 1997). According to Brock (1994), the highest ethical standard of medical practice is to uphold the autonomy of competent patients, including respecting the patients' end-of-life wishes. By using advance directives, patients ensure that their medical decisions have been made in an autonomous and precise manner (Allen-Burge & Haley, 1997).

Although advance directives can take many forms, it is most helpful for them to be in the form of a legal document. There are two main types of legal advance directives: proxy and instructional. Proxy advance directives involve the designation of a surrogate, or proxy, to make end-of-life decisions for the patient. An example would be a durable power of attorney for health care. This type of advance directive would specify a particular person to make decisions on the patient's behalf if the patient were to become incompetent. In order to respect desires of the incapacitated individual, surrogate or proxy decision makers must try to predict what decision the patient would make him/herself if the patient were in a competent state (Allen-Burge & Haley, 1997; Fangerlin, Danks, Ditto, Houts, & Smucker, 2001). Research suggests, however, that the patient's autonomous wishes often do not coincide with such substituted judgments (Allen-Burge & Haley, 1997; Ditto, 2006).

The second main form of advance directive is instructional advance directives. Instructional advance directives differ from proxy advance directives in that they are a record of desires for what life-sustaining treatment, or lack thereof, a patient would like in regards to end-of-life care. One model of instructional advance directives is attorney Luis Kutner's "living will." Living wills may be very general contextually in that they may only state "no heroic measures," or they may be very specific in that they may state a specific medical treatment to be administered under specific medical conditions (Ditto, 2006; Ditto & Hawkins, 2005).

Research on End-of-Life Decisions

Although advance directives have been strongly encouraged, much developing research indicates there may be disadvantages and flaws in the process, as seen in both the Cruzan and Schiavo cases. This new growth of research in the area of advance directives questions its effectiveness in promoting improved end-of-life medical care. One concern is simply people's failure to complete advance directives such as living wills. In a study by Hawkins, Ditto, Danks, and Smucker (2005; as cited in Ditto & Hawkins, 2005), researchers found that although elderly participants

were typically positive about planning for end-of-life care, most did not desire to actually record their desires for medical treatment in specific situations. Their findings suggested that these individuals did not want any precise control over their own end-of-life care (Hawkins, Ditto, Danks, & Smucker, 2005, as cited in Ditto & Hawkins, 2005).

Other similar studies have shown that participants often indicate feeling comfortable leaving their end-of-life care decisions up to their family members instead of making the decisions for themselves in advance. Participants often preferred to only state general wishes and did not want to “micromanage” their death (Ditto & Hawkins, 2005; Hawkins et al., 2005, as cited in Ditto & Hawkins, 2005; Holley, Stackiewicz, Dacko, & Rault, 1997, as cited in Ditto & Hawkins, 2005). Recent research has found, however, that in many instances the surrogate decisions may actually reflect more closely what surrogates would choose for themselves, as opposed to what they feel the patient would choose. In one study using hypothetical vignettes, researchers found that surrogate decisions along with physician decisions did not consistently predict a patient’s life-sustaining treatment desires at a level of precision higher than expected by chance alone (Druley, Ditto, Moore, Danks, Townsend, & Smucker, 1993; Sulmasy, Weisman, Miller, Stallings, Vettese, & Haller, 1998; Uhlmann, Pearlman, & Cain, 1988, as cited in Fagerlin et al., 2001).

Much of the research to date regarding advanced directives has focused on proxy or surrogate decision making. However, more recent research has focused on the patient’s life-sustaining treatment preferences. Research in this area is limited in that previous studies have focused primarily on a narrow scope of medical treatments (Bookwala, Coppola, Fagerlin, Ditto, Danks, & Smucker, 2001) as well as generalized health scenarios such as “terminal illness” (Mills, Garrett, Harris, Norburn, Patrick, & Danis, 1993, as cited in Bookwala et al., 2001). In response to the lack of research in this area, a recent study focused on gender differences regarding life-sustaining treatment preferences for multiple treatment options, using a wide variety of health scenarios that were diverse in severity as well as type (Bookwala et al., 2001). The researchers developed the Life-Support Preferences Questionnaire which expresses nine hypothetical illness scenarios. These scenarios represent a large scope of illness conditions that vary on amount of pain, illness acuteness, and prognosis. Results indicated that although males and females indicated that end-of-life values were an important factor in their treatment preferences, when actually recording their treatment preferences, males were more likely to opt for life-sustaining treatments (Bookwala et al., 2001). This study is a step in the direction of identifying the impact that levels of information

have on patients' end-of-life decision making, which is of particular relevance to the current study.

Another area of advance directive research involves the stability of preferences in older adults' end-of-life treatment decisions. An important aspect of advance directives, as the term implies, is that they are decisions made in advance. Thus, such decisions may not remain stable because wishes actually change as the health care status of the individual changes. In a study conducted by Ditto, Smucker, Danks, Gready, Jacobson, Houts, Fagerlin, and Coppola (2003), researchers examined life-sustaining preferences for hypothetical health scenarios over the course of two years. The participants' preference stability was compared across a variety of medical health and treatment scenarios. Findings suggested that although participants' preference for life-sustaining treatment was moderately stable, the preferences were most stable for scenarios that were either most or least serious. A study by Ditto and Hawkins (2005) which focused on scenarios regarding cancer had similar findings in relation to stability.

Prospect Theory

Prospect Theory (Kahneman & Tversky, 1979) can explain many of these findings. Prospect Theory can be applied as a structure for understanding how individuals make decisions between choices in regards to life-sustaining treatment. The theory proposes that individuals choose the option that has the highest objective gain (Schneider & Lopes, 1986). Regarding the studies by Ditto et al. (2003) as well as Ditto and Hawkins (2005), Prospect Theory explains why instability in preferences occurs, namely, because individuals who are ill reevaluate and redefine their quality of life. These ill individuals are more likely to choose life-sustaining treatment. In contrast, healthy individuals are less likely to choose life-sustaining treatment when trying to decide what their treatment preferences might be, given compromised health in the future. Healthy individuals would like to keep living with a high quality of life for a shorter period of time as opposed to a perceived lower quality of life with medical morbidity brought about due to the burden and restrictions of life-limiting illness for a longer period of time (Winter, Lawton, & Ruckdeschel, 2003).

Some recent advance directive research has focused on patients' level of knowledge. Across a number of studies, researchers have found patients' understanding of medical treatments as well as medical conditions to be minimal. For example, in an advance planning study regarding intubation and mechanical ventilation in chronic obstructive pulmonary disease (COPD), researchers found that patients with COPD exhibited a great

need for information about the disease, the decline of health, and end-of-life care. In fact, researchers found that at baseline, most participants had minimal, if any, knowledge of mechanical ventilation (Wilson, Aaron, Vandemheen, Hébert, McKim Fiset, Graham, Sevigny, & O'Connor, 2005).

Prospect Theory can also be applied to these studies in terms of the amount of knowledge the patient has about life-sustaining treatment. When choosing to either forego or opt for life-sustaining treatment, knowledge level of treatment options may play an important role as to what is perceived as the condition of highest objective gain (Grisso & Appelbaum, 1996; Kahneman & Tversky, 1979). If individuals do not understand their treatment options or their medical condition, they may not choose the same option that they would if they did have greater understanding regarding their treatment options and medical state. When patients cannot make informed decisions due to insufficient education about the treatment and illness, they will likely be unable to make decisions that are of the highest objective gain.

Finally, advance directive decisions may be influenced by the way that questions used to determine decisions are framed. Even small changes in the way that questions are framed can affect life-sustaining treatment choices considerably, as seen in other types of medical decisions (Forrow, Taylor, & Arnold, 1992; Malloy, Wington, Meeske, & Tape, 1992; McNeil, Pauker, Sox, & Tversky, 1982; Tversky & Kahneman, 1986). According to Tversky and Kahneman (1986), Prospect Theory examines two phases of making a decision: a framing and editing phase and an evaluation phase (Kahneman & Tversky, 1979). Framing is considered to be controlled by the way that the decision to be made is presented as well as the lifestyle and beliefs of the person who is making the decision (Tversky & Kahneman, 1986). Therefore, differences in descriptions of a decision often cause different preferences (Tversky & Kahneman, 1986). Patients without high levels of understanding regarding life-sustaining treatment could be particularly susceptible to adverse effects of question framing. Questions that are framed with little information may result in different decisions than questions that are framed with a great deal of information. Also, whether or not the information is framed in a positive, negative, or neutral light could influence decisions (Malloy, Wington, Meeske, & Tape, 1992).

To date, most of the work with Prospect Theory has focused on physical health. Little to no research has taken Prospect Theory into account regarding mental health concerns such as symptoms of depression or memory complaints. Research has found that older adults who have memory

complaints find great difficulty in recalling previous experiences such as events, emotions, and relationships and thus experience difficulty in managing and incorporating new events into the individual's present understanding (Hirsch & Mouratoglou, 1999). The study conducted by Hirsch and Mouratoglou (1999) further claimed that individuals with memory complaints can find mentally manipulating more than a few pieces of information at a time to be problematic. This research is of particular relevance to the present study because individuals who have memory complaints may have difficulty interpreting information regarding end-of-life treatments, especially larger amounts, which may impact their decisions regarding treatment preferences.

The purpose of the current study was to determine the impact that amount of information has on the life-sustaining treatment decisions of both healthy older adults and older adults with memory complaints. Keeping Prospect Theory in mind, we hypothesized that individuals who were given little information, as with the Life-Support Preferences Questionnaire (Bookwala et al., 2001), and had no memory complaints would typically opt for life-sustaining treatment as a decision of perceived highest objective gain. In contrast, we hypothesized that individuals who were given more information that explained the success of potential life-sustaining treatments for the end stage of their illness, as well as alternatives, risks, and benefits, would choose to forego life-sustaining treatment as a decision of highest objective gain. However, for individuals with memory complaints, we predicted there was little difference, if any, for opting either to have or forego life-sustaining treatment, regardless of amount of information given.

Method

Overview

This exploratory study used a two group (more information; less information) between-subjects design. Participants were interviewed individually to measure what effect the amount of life-sustaining treatment information given has on older adults' end-of-life decision making. Measures were administered in a randomized order. Effects of subjective memory complaint, as well as depression, were also assessed as covariates to determine how they relate to choices regarding life-sustaining treatment.

Participants

A community sample of eight adults, aged sixty or older, were recruited from assisted living facilities and senior citizen groups around the University of Alabama community. Volunteers were excluded if they did not meet the minimum age requirement of sixty years and if they did not speak fluent English. Participants who did not meet the minimum criteria on a cognitive screening test (Telephone Interview for Cognitive Status-modified, minimum score of 20) were excluded from the study. Participants received a \$10.00 honorarium for participation.

The average age of the experimental group ($n = 4$) was 74.75 and the average age of the control group ($n = 4$) was 75.25. The average number of years of education for the experimental group was 13.75 and 11.50 years for the control group. The experimental group was comprised of fifty percent female and fifty percent male and the control group was mostly female, which made up seventy-five percent, and twenty-five percent male. Seventy-five percent of the experimental group was of African American ethnicity and twenty-five percent was of Caucasian ethnicity. In the control group fifty percent was of African American ethnicity and fifty percent was of Caucasian ethnicity.

Health was measured on three scales. A four point scale for overall present health with 1 indicating excellent and 4 indicating poor, a three point scale for health in the past with 1 indicating better and 3 indicating not as good, and finally, a three point scale for relation of health problems to desired activities with 1 indicating not at all and 3 indicating a great deal. Participants in the control group indicated better subjective health than the experimental group. The experimental group reported 3.25 (0.50) regarding overall present health, 2.25 (0.50) regarding how their health was in the past, and 2.75 (0.50) regarding how health problems related to desired activities. The control group however, indicated better health with scores of: 2.5 (0.58), 1.75 (0.96), and 2.0 (0.82). It is important to note that although the control group had lower scores, they had greater variability than the experimental group.

Measures and Materials

Demographics. Participants' demographic information was collected through a self-report by telephone interview that asked for age, gender, race, marital status, and years of education.

Subjective health (Levy-Cushman & Abeles, 1998). Three questions were asked via telephone to assess participants' subjective health. The questions were as follows: (1) "How would you rate your overall health at

the present time?” (1 = excellent, 2 = good, 3 = fair, 4 = poor); (2) “Is your health now: better, about the same, or not as good as it was three years ago?” (1 = better, 2 = the same, 3 = not as good); and (3) “Do your health problems stand in the way of doing things you want to do?” (1 = not at all, 2 = a little, 3 = a great deal).

Telephone Interview for Cognitive Status-modified (TICS-m; Breitner, Welsh, & Magruder-Habib, 1990). The TICS-m is a cognitive assessment tool that is used via telephone. It was used to screen for cognitive deficits in participants. Some items from the questionnaire ask: “Without looking at a calendar or watch, what is today’s date?”, “Please subtract 7 from 100 and then subtract 7 from that number until I tell you to stop,” and “What do you call the kind of prickly plant that lives in the desert?” Participants scoring less than 20 out of a possible score of 50 were excluded. A score that is lower than 20 has been indicated to be a sign of cognitive decline (de Jager, Budge, & Clarke, 2003). The typical cut-off score is 30, but for the purposes of the current study a cut-off of 20 was used in order to include participants with mild cognitive impairment. Normative samples have a mean TICS-m score of 32.3 with a standard deviation of 2.1 (Welsh, Breitner, & Magruder-Habib, 1993).

Center for Epidemiological Studies Depression scale (CES-D; Radloff, 1977). The CES-D is a 20-item measure of the frequency of depressive symptoms within the past week. It was administered in person. The scale is comprised of four subscales that measure depressed mood, psychomotor retardation, lack of well-being, and interpersonal difficulties (Schein & Koenig, 1997). Some questions ask participants: “I was bothered by things that usually don’t bother me,” “I felt that everything I did was an effort,” and “I felt that I was just as good as other people.” Responses for items range from 0-3 (0 = rarely or none of the time, 1 = some or a little of the time, 2 = moderately or much of the time, 3 = most or almost all of the time) and were used to determine the participants’ level of depression. Scores can range from 0 to 60 with higher scores being an indication of increased symptomatology (Radloff, 1977). A high degree of internal consistency has been found with older adults as reflected by Cronbach’s alpha scores between 0.86 and 0.89 (Schein & Koenig, 1997). If participants scored greater than or equal to 28, the researcher alerted the faculty advisor (a licensed clinical psychologist) to provide feedback to the participant and assess for suicidal ideation.

Metamemory in Adulthood Questionnaire (MIA; Dixon & Hultsch, 1984). The MIA is a 108-item questionnaire that measures subjective memory complaint. The current study used a 58-item subset of the 108-item questionnaire. The scale is multidimensional in that it is comprised of

four subscales that measure capacity, anxiety, stability, and locus of control. The scale asks questions such as: “I am good at remembering names,” “I get upset when I cannot remember something,” “Compared to 10 years ago, I am much worse at remembering titles of books, films, or plays,” and “If I were to work on my memory I could improve it.” Participants rate each question in relation to their understanding of memory performance and processes on a 5-point Likert scale that ranges from “agree strongly” to “disagree strongly.” Internal consistency reliabilities have been reported ranging from .74 to .93 (Hertzog, Hultsch, & Dixon, 1989).

Decisional Conflict Scale (DCS; O’Connor, 1993). The DCS is a questionnaire that measures participants’ perceptions of their own personal uncertainty in choosing options and factors contributing to uncertainty such as lack of information, lack of clarity regarding personal values, and lack of support in decision making. For the purposes of the current study the 10-item, with three response categories, format was used. This format is recommended for those who may have low literacy or response levels. Two additional items developed from another format of the DCS (O’Connor, 1993) were included to measure decisional effectiveness. These items are: “Do you expect to stick with your decision?” and “Are you satisfied with your decision?” with response options of “yes, no, or, unsure.” The DCS also measures personal perceptions on factors contributing to effective decision making such as feeling informed, making choices that are value-based, and the likelihood that the participant was satisfied with his/her choice. Test-retest reliability has been found to have a coefficient of 0.81 and internal consistency to be high, with a range of 0.78 to 0.92 (O’Connor, 1995).

Life-Support Preferences/Predictions Questionnaire-modified (LSPQ-m; Bookwala et al., 2001). The LSPQ is a questionnaire that expresses nine hypothetical illness scenarios. A large scope of illness conditions that vary on amount of pain, illness acuteness, and prognosis are covered in the questionnaire. For the purposes of the current study three of the nine scenarios used in the lab’s previous research (Schmid, 2006) were included: (1) patients with Alzheimer’s disease, (2) cancer patients with constant pain, and (3) patients with emphysema. Participants rate their responses on a continuous 5-point Likert scale (1 = definitely do not want to 5 = definitely do want) after being given a detailed description of treatment options (Bookwala et al., 2001). Scenarios read as follows:

“SCENARIO 1: You have been living with a diagnosis of Alzheimer’s disease for several years. The disease has advanced to the point that you have trouble remembering things and thinking clearly. You cannot always rec-

ognize people you know. You need someone to look after you because you are no longer able to do tasks such as cooking, paying bills, or driving. It is expected that over the next several years you will continue to gradually decline mentally and physically, and will ultimately die of Alzheimer's disease."

"SCENARIO 2: You have emphysema. You have constant shortness of breath and are unable to climb stairs or walk more than a few feet. Your medical condition cannot improve. The condition may get worse very quickly or slowly decline over several years. Your ability to think, reason, and remember are not affected."

"SCENARIO 3: You have colon cancer which has spread to the liver. You are tired and weak, requiring some help with household chores. Your thinking and memory are not affected. You have pain that requires the constant use of medication. In the opinion of the doctor, there is no chance of recovery. The doctor says that you have about six months to live." (Bookwala et al., 2001).

Medical Information Stimuli. An information set developed by the authors was administered to half of the participants. This information included definitions of advance directives and detailed descriptions of life-sustaining treatment options. The descriptions consisted of specific treatment options for each LSPQ scenario, risks of the treatment, benefits of the treatment, and alternatives for each treatment. The appendix contains a sample item from the Medical Information Stimuli.

Procedure

Participants were contacted by telephone by the researcher to administer the cognitive screen in order to verify that participants met the minimum entry criteria. Informed consent for this process was obtained and audio recorded over the telephone. Participants were also asked to answer a few questions regarding demographics and subjective health (Levy-Cushman & Abeles, 1998).

Upon meeting the minimum entry criteria, the participant was scheduled a time to meet with the researcher for an interview. The interview lasted approximately ninety minutes. Volunteers who did not meet the

minimum entry criteria on the cognitive screen were excluded from the study and were referred to their primary physician and given referral information for additional cognitive assessment if desired.

Data were collected by interviewing the participants in a location that was convenient to them, which was typically their place of residence or local community center. Participants began by first reading and signing a written informed consent statement. Next, participants were presented three vignettes in one of two sets. Half the participants ($n = 4$) were given the abbreviated version of the LSPQ for each of the three scenarios and treatment options without any additional information. The other half of the participants ($n = 4$) received the additional information developed by the authors that explained advanced directives, as well as an explanation of the specific treatment option for each scenario, risks of the treatment, benefits, and alternatives. Participants were randomly assigned to groups.

Following the vignettes, participants completed the Decisional Conflict Scale (DCS) (O'Connor, 1993). Upon completing the DCS, participants were asked to complete the Center for Epidemiological Studies-Depression (CES-D) scale (Radloff, 1977) and the Metamemory in Adulthood (MIA) questionnaire (Dixon & Hultsch, 1984). Participants were given a copy of the questions so that they could follow along throughout the interview. Once these assessments had been completed, a debriefing session was conducted in order to answer any questions and respond to any concerns that the participants may have had in relation to the current study.

Data Analysis

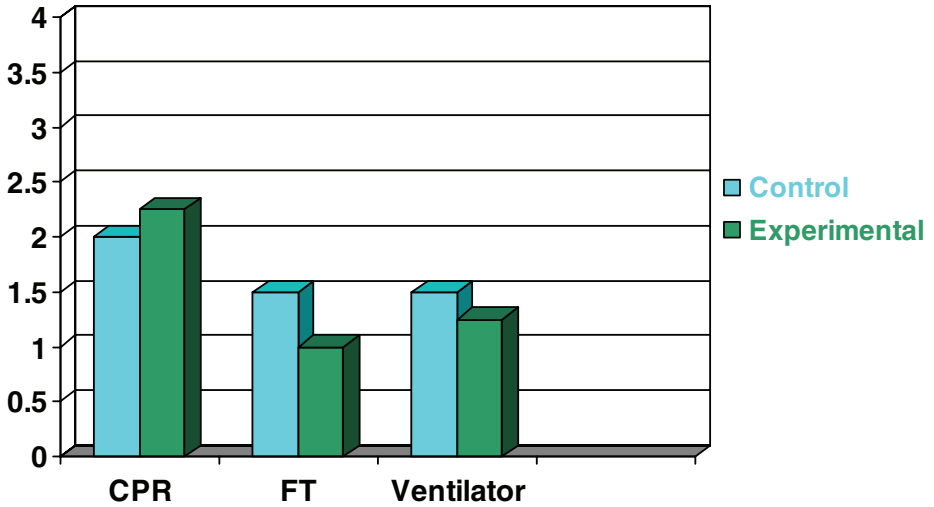
Because this is a pilot of the EDMAC project that included only eight participants, we present our results descriptively and include case examples when appropriate and illustrative. Our primary outcome variables were tendency to endorse or reject various life-sustaining treatment options on the LSPQ: CPR, mechanical ventilation, and feeding tube. We used a two group between-subjects design in which one group was provided with information regarding various life-sustaining medical treatments and the comparison group was not provided with any additional information. We also examined the correlations between memory complaint, decisional conflict, depression, and subjective health and our primary outcomes.

There was no difference between experimental and control participants in cognitive status ($TICS-m = 28.75$ experimental; $TICS-m = 29.00$ control). However, experimental participants reported fewer symptoms of depression ($CESD = 7.00$) than did control participants ($TICS-m = 13.00$).

Life-sustaining treatment choices are consistent across illness scenarios for both the control and the experimental group. Reported findings also

indicated that feeding tube decisions were in the direction of the second hypothesis (see Figure 1).

Figure 1. Participants' LSPQ ratings in Alzheimer's disease scenario



In other words, individuals receiving more information were less likely to choose to initiate tube feedings in comparison with individuals provided usual information. Mechanical ventilation as well as CPR, however, did not show any consistent pattern of results across experimental and control groups (see Figures 2 and 3).

Figure 2. Participants' LSPQ ratings in emphysema scenario

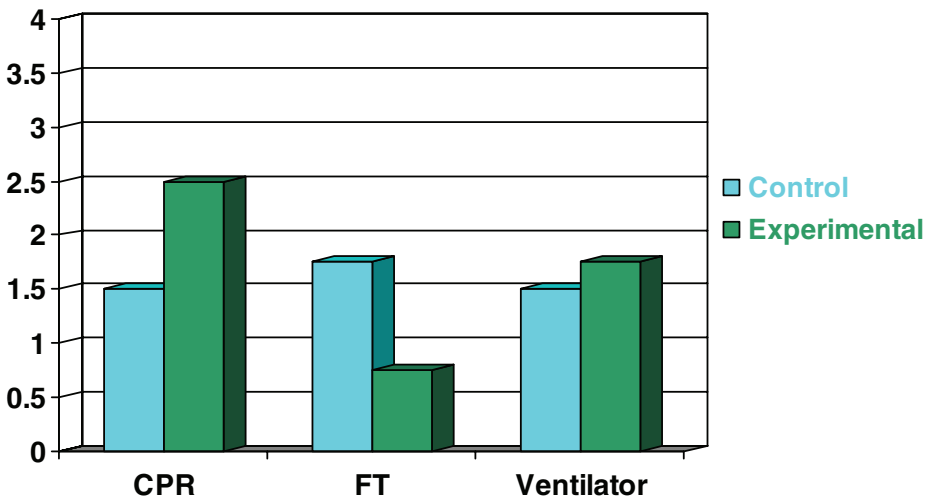
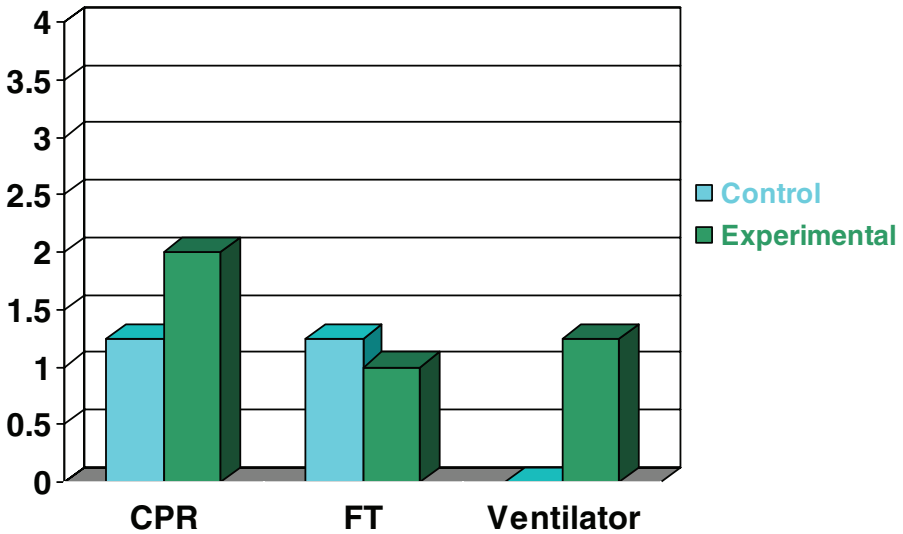


Figure 3. Participants' LSPQ ratings in cancer with pain scenario



Results indicated that there were some significant associations among study variables, even with our limited sample size in this pilot project. An exploratory analysis of memory complaint showed that there was not an association for memory complaint with life-sustaining treatment preferences or illness scenarios. There was, however, an association between total decisional conflict and preferences for any life-sustaining treatment within the context of Alzheimer's disease ($r = -.74, p = .04$) and emphysema ($r = -.80, p = .02$). Greater decisional conflict was associated with less desire for life-sustaining treatment in both illness conditions. Greater decisional conflict was also significantly associated with greater cognitive impairment ($r = -.83, p = .01$).

Additionally, there was a correlation between lack of perceived memory capacity and perceived health decline ($r = .78, p = .02$). Results indicated that perceived memory stability is associated with perceived stability of and satisfaction with life-sustaining treatment preferences ($r = .78, p = .02$). Finally, health problems showed an association with less desire for feeding tube initiation ($r = .78, p = .02$).

Discussion

Our project is one of the first to examine the impact of provision of medical information on life-sustaining treatment preferences among old-

er, community-dwelling adults. Based on our preliminary examination of data from eight participants (4 experimental and 4 control), we found that individuals are consistent in their expressed desire for life-sustaining treatments (e.g., CPR, feeding tubes, and mechanical ventilation) across illness scenarios (e.g., Alzheimer's disease, emphysema, and cancer with pain). Therefore, health care professionals can ask general values questions regarding patients' expectations of quality of life in order to obtain advance care plans for medical treatments at the end of life. Given the limited time physicians spend with patients, this consistency in treatment preference enables physicians to ask fewer questions and still enhance the probability that individual treatment preferences will be honored at the time life-sustaining treatment may be needed.

At this time in data collection, we have not found general support for Prospect Theory. There was no association between subjective health, health problems, or perceived health change and treatment preferences. There also was no association between memory complaint and treatment preferences. The only exception was the significant association between health problems and desire for tube feeding across illness scenarios. Notably, provision of additional medical information seems to decrease individuals' desire for tube feeding, in line with our hypothesis. It may be that continued data collection built on this pilot project will reveal the expected impact of information on treatment preferences, and support will be found for Prospect Theory. However, it may also be that Prospect Theory is dependent on individual differences in perceived severity of illness or perceived risk of treatment (i.e., feeding tubes are the most severe; Alzheimer's disease is the most severe), or prior exposure to life-sustaining treatment (i.e., individuals are more familiar with CPR and are less influenced by new information regarding treatment risks).

Interestingly, the experimental group indicated feelings of less confidence in decisions as well as lower levels of knowledge about life-sustaining treatment options than the control group. This could be because individuals who have less knowledge about treatment options, as in the control group, may be unaware of how little they know about treatment options. Perhaps increased level of knowledge caused a greater depth of thought that activates decisional conflict, whereas value-based decisions do not activate decisional conflict. Notably, greater decisional conflict was associated with less desire for treatment when presented with both the Alzheimer's disease and emphysema health scenarios.

Anecdotally, the experimenter noticed that answers on the decisional conflict scale may vary depending on whether participants were thinking only about the illnesses and treatments described in the LSPQ or were

thinking more broadly about end-of-life treatment options and illnesses. Some participants related answers to the decisional conflict scale in response to the treatment options given in the LSPQ whereas some participants answered questions about decisional conflict in relation to all possible treatment options to any given health scenario that may not have been mentioned in this study.

Some limitations of this pilot project should be noted. Because the data collection in this study is only a pilot of eight individuals, the findings are not generalizable. All participants were recruited from the Tuscaloosa, Alabama area and only represented either African American or White ethnic groups. It should be noted that this pilot study did not control for whether the information described in the Medical Information Stimuli was framed in a positive, negative, or neutral light. Future studies may be structured to examine how this may affect results. Furthermore, this study did not control for how the participants interpreted the illness scenarios or treatment choices, nor did it measure how well the participants were actually able to visualize themselves into the three debilitated health scenarios. Future studies should attempt to measure participants' understanding of illnesses and treatments.

The EDMAC project, however, is one of the first to examine the impact of information regarding medical treatments on life-sustaining treatment preferences expressed by older community-dwelling adults with or without memory complaints. It is also the first study to examine the impact of information on decisional conflict regarding end-of-life treatment options. We expect ongoing data collection to reveal support for the study's hypotheses. We anticipate that participants who are not given the Medical Information Stimuli who have no memory complaint will opt in favor of life-sustaining treatment, participants who are given the Medical Information Stimuli who do not have any memory complaint will opt to forego life-sustaining treatment, and that participants who have memory complaint, regardless of amount of information provided, will not show any difference in either opting to forego or pursue life-sustaining treatment.

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Appendix

Example of Medical Information Stimuli

TREATMENT OPTION - MECHANICAL VENTILATION

Mechanical ventilation (MV) can be used to assist you to breathe when you can no longer breathe on your own. MV can provide your brain with needed oxygen so that you can maintain your thinking skills and quality of life.

THE PROCEDURE

This procedure requires surgery called tracheotomy and a varying period of time in the hospital. A tracheotomy provides surgical access to the trachea to allow oxygen to flow into your lungs. You may have to have a tracheotomy in order to be able to use a mechanical ventilator for weeks, months, years, or even the rest of your life.

BENEFITS

1. MV can either assist you to breathe or they can take over breathing for you completely and keep you alive.
2. Your family may feel better knowing that you know that your breathing is being assisted or controlled by MV.

RISKS

1. Some types of tubes inserted may cause coughing and pain.
2. Infections (pneumonia, for example) may occur as a result of MV for patients who use MV for an extended period of time.

ALTERNATIVES

If you do not choose to have a MV, you may not be able to breathe on your own. Lack of oxygen to your brain will cause brain damage that will harm your thinking skills and make your quality of life worse. Eventually, if you do not begin to breathe on your own, you will die.