

Chapter 1

Introduction

With advances in health care, including the rapid development of new medical procedures and technologies, older adults may find themselves in situations where they, or someone they entrust, must decide on implementing life-enhancing, life-sustaining, or life-ending treatments. Advance directives, a legal instructive document that expresses the choices of competent adults (e.g., durable power of attorney for health care, living wills, do-not-resuscitate orders) serve to identify treatment preferences prior to illness or injury in order to extend patients' wishes during periods of decisional incapacity. When unable to communicate health care preferences, an advance directive serves to safeguard the patients' wishes by enhancing the ability of relatives and other surrogate decision makers to enact the treatment choices patients would make for themselves if they were competent to do so (Abbott, Sago, Breen, Abernethy & Tulsky, 2001; Fagerlin, Ditto, Danks, Houts & Smucker, 2001; Larson & Tobin, 2000; McCann, Chodosh, Frankel, Katz, Naumburg & Tulsky, et al., 1998).

Basic to the decision-making process and the intended use of advance directives are three assumptions relevant to the current study. The first assumption is that competent older adults have adequate information from which to base a decision and act to formulate their decisions based on a set of values or beliefs developed over the course of their lifespan (Beck, Brown, Boles & Barrett, 2002; Cicirelli, 1998; McCann, 1998; Mathesis-Kraft & Roberto, 1997; Rosenfield, Wenger & Kagawa-Singer, 2000; Siegler & Levin, 2000). Similarly, family members and other surrogates must also exercise the decision-making privilege based upon an accurate understanding of the

proposed treatment options and the understood wishes of the older adults (Fagerlin et al., 2001; Mathesis-Kraft & Roberto, 1997). Close attention by the surrogate to the wishes of older adults, based upon expressed values, observation of life commitments, known religious beliefs, and demonstrated lifestyle, help to ensure that proxy decisions support what the older adult would want in a given clinical situation (Drane, 1995).

Secondly, the assumption is that medical decisions are not made independent of values and beliefs, which have been operationalized throughout the lives of older adults. This supposition is central to the concept of substituted judgment in that surrogates must understand the fundamental value system of older adults accurately in order to formulate decisions as if they were the patient themselves. Past research has identified numerous values and beliefs such as respect, dignity, quality of life, and independence that appear to be important in the decision-making process of older adults (Atchley, 1997; Doukas & McCullough, 1991, Rokeach & Ball-Rokeach, 1989). Collectively, these values and beliefs serve as the foundation from which older adults think about and formulate opinions about accepting or rejecting medical treatment options.

Values contribute to one's attitude, which in turn influences one's behavior (Homer & Kahle, 1988). They are the prototypes of our thinking and doing. Paolucci, Hall, and Arinn (1977) suggested that values come into play throughout the entire decision-making process. Just as one's values affect everyday decision-making, they play a central role in critical health care decision-making. Therefore, it is imperative that surrogates and health care providers concern themselves with assessing and understanding how values and beliefs drive the decision-making process (Astrow, Puchalski & Sulmasy, 2001; Doukas & McCullough, 1991). By doing so, all involved will

be better able to respect the wishes of older adults pertaining to treatment options when they are least able to articulate those wishes and more reliably manage uncertainties surrounding advanced directives (Gibson, 1990).

Among the values and beliefs found to be specifically influential in the decision-making process of older adults are religion and spirituality (Carmel & Mutran, 1997; Ejaz, 2000; Leichtentritt & Rettig, 1999; Lo, Ruston, Kates, Arnold, Cohen & Faber-Langendoen et al., 2002; Mahoney & Graci, 1999). Older adults, who experience more health-related problems and who more readily than younger individuals acknowledge their own mortality, often draw sustenance and a sense of continuing purpose from their religious beliefs (O'Connell, 1994). O'Connell (1994) suggested that religious coping adds perspective and moral resources as older adults struggle with health-related decisions, whether they involve refusing medical treatment, withdrawing life-support systems, coping with a disabling illness, choosing to move to a nursing home or even something as simple as refusing expensive brand-name drugs in favor of less expensive generic drugs. Although recent public opinion polls show that a majority of adults (65%-69%) aged 45 and older view religion as very important to the most important entity in their everyday life (Princeton Survey Research Associates, 2000, 2001), researchers involved in the area of decision-making have not focused on religious values and beliefs as factors influencing treatment decisions.

The final assumption is that preferences for medical treatment and the value system driving those decisions remain stable over time and across changes in health. If treatment preferences and influencing values change over time then decisions made from advanced directives formulated months or years earlier may not accurately reflect

the current wishes of older adults. Consequently, surrogate decision making would be complicated by outdated, potentially erroneous advanced directives (Gready, Ditto, Danks, Coppola, Lockhart, & Smucker, 2000).

Researchers measuring stability of the health care decision-making process of older adults over relatively short time periods (1 to 30 months) report moderately high stability rates (Danis, Garrett, Harris, & Patrick, 1994; Everhart & Pearlman, 1990; Gready et al., 2000; Houts, Smucker, Jacobson, Ditto, & Danks, 2002; Lockhart, Ditto, Danks, Coppola, & Smucker, 2001; Patrick, Perlman, Starks, Cain, Cole, & Uhlmann, 1997). The standard protocol for these studies is to have participants respond to hypothetical health scenarios, each varying in prognosis and health state (e.g., hydration/nutrition in current state of health or when permanently confused). For example, in a small sample of 30 intensive care patients, Everhart and Pearlman (1990) found that decisions regarding life-sustaining treatment did not change over a one month period of time despite significant, often improved health status and mood of the participants. In two later studies involving larger samples, similar findings resulted over a period of two years. Emanuel and colleagues (1994) interviewed 495 HIV and oncology outpatients and 102 adults from the general public 3 times over 24 months with regard to life-sustaining treatment preferences. Ninety-three percent of the participants interviewed at 24 months demonstrated stability in their treatment preferences. Participants who discussed their treatment preferences with their physician demonstrated greater stability of choices than those who did not. Similarly, Danis and colleagues' (1994) study of 2,536 individuals found greater stability of preferences among participants with a living will (86% stability) than those without (59%

stability). Over the 2-year study period, 85% of individuals who chose to forgo life-sustaining treatments did not change their preference whereas only 18% to 43% of those desiring life-sustaining treatment maintained their original choice. Collectively, these findings suggest that health care preferences remain stable over relatively short periods of time and that those individuals who have discussed their choices with health care professionals reflect greater stability of preferences than those who do not. Unfortunately, these studies incorporated older adults who ranged in age from the early sixties to late nineties making it difficult to assess the impact that age might have contributed to the variability of decision-making stability.

In perhaps the most notable values study across time and health states, Rokeach and Ball-Rokeach (1989) surveyed 1,409 participants over a 13 year period of time. The participants, ranging in age from 11 to 90 years, were asked to rank order a group of 18 values at 4 different points in time. The researchers describe the results as having incredibly high stability with the top 6 and the bottom 6 values receiving identical priority rankings across the 13 years. While the middle six values fluctuated in their identified rank, they consistently remained in the middle zone of the results, suggesting that these values varied in their importance across time but were never identified as either most important or of lowest importance among participants (Rokeach & Ball-Rokeach, 1989). These findings suggest that surrogates who are familiar with the operative value system of older adults will have a better foundation from which to make decisions when the need arises as values remain constant over time. Unlike the research on decision-making stability, it would appear that values stability is not age dependent in that the sample age range was quite large, yet continued to demonstrate

high statistical stability in values choices over time. However, the sample did not include individuals in the old-old category of life leaving one to wonder if values stability remains constant as one faces the end-of-life.

Appendix A contains an expanded literature review. Specifically, it includes research findings related to the stability of health care preferences and values and the conceptual frameworks guiding this study.

Purpose of the Study

Missing from research is a clear understanding of whether preferences for medical treatment and the values or beliefs that drive those decisions remain stable over time among older adults late in life. Currently, there is no legally mandated renewal recommendation for advance directives and it is unclear as to the accuracy of decisions made on health care preferences beyond three years. The purpose of the study is to examine the stability of health care decision-making and values over time and to identify and understand the values that influence the decisions of the older adults in late life. The study employed complimentary methods of quantitative and qualitative inquiry that blended two fundamental languages of human communication: words and numbers (Polit & Beck, 2004). By doing so, the data contained rich explanatory descriptions of the decision-making process and the central values that influence health care decisions of older adults.

Research Questions

Basic to the study was the assumption that older adults are knowledgeable and reliable informants about their health care decision-making processes and the values that influence decisions. It was also assumed that surrogates chosen by the older

adults to share the decision-making responsibilities are well versed in the values, beliefs, and wishes inherent in the decisions.

The following research questions were addressed:

1. Do the health care treatment preferences of older adults late in life change over a seven-year period?
2. Do values identified by older adults as influential factors in the decision-making process change over a seven-year period?
3. How do older adults late in life assign meaning to the role of values selected in the decision-making process (e.g., quality of life, burden)?
4. What role does religiosity or spirituality play in the lives of older adults in late life and the health care decision-making process?

Operational Definitions of Terms and Concepts

The term *value* has been defined as “an enduring prescriptive or proscriptive belief that a specific mode of behavior or end-state of existence is preferred to an opposite mode of behavior or end-state” (Rokeach, 1973, p. 5). Rokeach (1973) further described a value as a “standard that guides, determines action, attitudes toward objects and situations, ideology, presentation of self to others, evaluations, judgments, justifications, comparisons of self with others, and attempts to influence others” (p. 216). Collectively, values are a learned organization of principles and rules that help individuals choose between alternatives, resolve conflict, and make decisions. In this study, the term *value* refers to a set of pre-described, common indicators from which older adults ascribed meaning and importance in relation to their own life and experience.

Surrogate or *proxy* refers to an individual, likely a family member, who speaks on behalf of older adults when they are incapable of communicating or acting on their own behalf (Schulmeister, 1998). In this study, the term *surrogate* refers to the individual(s) that are directly involved in the decision-making process of the older adult. The majority of these individuals are family members of the older adult.

The terms *religious* and *spirituality* are used in the discussion of values clarification throughout the in-depth interviews with the older adults and surrogates. Together, they reflect an individual's belief in and relationship with a higher power that gives life purpose, meaning, and direction (Johnson, 1989; Koenig, 1994; McFadden, 1995; Moberg, 1989). More specifically, *religion*, *religious* or *religiosity* are terms used interchangeably throughout this document to refer to organized practice or rituals of religion that individuals may indicate are important such as church attendance, visits from clergy, ceremonial practice (i.e., communion) (Eliason, 2000). *Spirituality* refers to internalization of the individuals' religious beliefs expressed as peace with God, comfort, thoughts of the after-life, prayer, or hope. Eliason (2000) stated that spirituality points to self-transcendence, self-actualization, and the existential search for meaning, but most importantly, to the phenomenological experience of relationship.

Chapter 2

Methodology

A mixed-method approach was used to blend the strengths of both quantitative and qualitative inquiry. Forced choice items were used to elicit older adults' preferences for medical and life-sustaining treatments and to determine stability of their responses over time. Qualitative data were used to illuminate the meaning of the relationship between the preferences in each healthcare scenario and the rationale for the preferences to enhance the analyses and give guidance to the interpretation of results. Utilizing Van Manen's (1990) method of descriptive and interpretive phenomenology, the holistic approach allowed me to view the text as a whole and then to try to capture its meaning. Selected themes were gleaned from the transcripts of each interview, which allowed for an understanding of values and healthcare preferences in the older adults. Data were collected at two interview points over a seven-year period of time.

Sample

The original study sample consisted of 62 older adults living in Colorado. Participants were recruited from three organizations in two counties: (a) Weld County Retired and Senior Volunteer Program, (b) McKee Medical Center in Larimer County, and (c) Larimer County Retired and Senior Volunteer Program. The participants ranged in age from 75 to 95 ($M=80.3$; $SD=4.3$). Forty-two women and 20 men participated in the study. The sample represented a 3:1 female to male ratio that was representative of the general population of older adults over the age of 75 (U.S. Bureau of the Census, 1990). Ninety-five percent (59) of the older adults were Caucasian. All of the older adults lived in their own homes or apartments and had lived at their place of residence

an average of 17 years ($SD = 14.7$). Seventy four percent of the participants indicated that they were Protestant, 13% were Catholic, 7% reported other religious affiliation (e.g., Jewish, Mormon), and 7% said they did not affiliate with any particular religious denomination.

The original data were collected from 1995 to 1997 (Mathesis-Kraft & Roberto, 1997). At the end of the two-year period, three study participants had died, leaving 59 potential participants for the seven-year follow-up interview. An electronic search of death records revealed that 26 of the 59 participants had died since 1997. Nine participants were could not be located. Of the 24 older adults contacted, two individuals were unable to participate due to declining health and current hospitalization and one person refused to participate; thus, the 2004 sample consisted of 21 older adults capable of making their own decisions.

The T2 participants ranged in age from 83 to 101 ($M=88.0$; $SD=3.8$). Seventeen (81%) of the participants were women and all participants identified themselves as Caucasian except for one man who was Native American. The majority of the participants were widowed (57%, 1 man and 11 women) with the remaining either married (28.6%, 3 men and 3 women) or divorced (9.5%, 2 women). Seventeen (81%) of the participants lived in their own home or apartment; the others were lived in assisted living facilities. All of the participants currently had living wills, medical power of attorney or CPR directives. Of the 18 participants who provided income information, five participants (23.8%) indicated that they earned greater than \$2,500 per month, five (23.8%) earned between \$1,601 and \$2,499, seven (33.3%) earned between \$701 and

\$1,600 and the remaining participant (4.8%) indicated that their gross monthly income was \$700 or less.

Data Collection Procedures

The original interviews (T1) were conducted face-to-face in the participants' homes. The one-year follow-up interview was not analyzed in the current study as there were no changes in preferences and values from the initial interview (Roberto, 1999). The seven-year interview (T2) was conducted via telephone and took 30 to 45 minutes to complete. Participants at T2 were sent packets of information that included a cover letter (Appendix B), the telephone script for verbal permission (Appendix C), and a copy of the data collection instrument (Appendix D) to provide them the benefit of following along with the interviewer throughout the telephone conversation. Each participant was contacted by telephone, requesting permission to conduct the interview at that time. If the time was not convenient, an appointment was made to conduct the interview at a more appropriate time. At the beginning of each interview, participants were read the telephone script in order to review the risks, benefits, and confidentiality agreement for the interview. Participants were then asked to retrieve the copy of the instrument so that they could follow along as the interview progressed. However, only 5 of the 21 participants kept the packet and had it available upon interview. Thank you notes and Wal-Mart gift cards will be sent after the successful defense of the research and presentation of the dissertation. Copies of the resulting manuscripts will also be sent to several participants who requested a summary of study findings.

From a list of 24 values indicators, participants were asked to choose the five that were most influential on their health care decisions. These were not rank ordered

but randomly identified by the participants at T1 and T2. Each participant was then asked to indicate how each of the five values influenced their preferences for health care procedures and treatments. This was done to lend context to the importance of each value in the decision-making process for each participant.

Participants responded to the same series of hypothetical scenarios relating to common health care procedures and life-sustaining treatments at both T1 and T2. The health care procedures consisted of by-pass surgery, hip replacement, antibiotics for pneumonia, mastectomy/prostatectomy, and cataract surgery. Each procedure was presented under two different health states: current health and permanently confused. Each health state was also presented under three different prognoses: less than 50% chance of recovery, 50%/50% chance of recovery, and greater than 50% chance of recovery. The life-sustaining treatment scenarios consisted of resuscitation for cardiac arrest, respirator for permanent inability to breathe on one's own, dialysis for kidney failure, tube feeding for permanent inability to eat, and chemotherapy for cancer. In these scenarios, the health states were current health or permanently confused; no prognoses percentages were given for the life-sustaining treatments. Participants were asked to respond to each scenario by indicating whether they would or would not consent to the various procedures and treatments. With each response, participants were asked to explain the reasons they would or would not consent to the procedure or treatment being discussed. Participants were asked to elaborate on the reasons for consenting or refusing treatments through the use of open-ended questions such as, "What is it about your _____ (e.g., religious beliefs, independence, quality of life, etc.) that helped you to choose (or not choose) _____ (e.g., bypass at 50/50%, etc.)?"

Due to the potential tedious nature of the questioning for approximately 50 different choices, often the participants indicated that the same answer applied to several scenarios that were just discussed, rather than repeating them individually. As a safeguard to the integrity of the data, the interviewer clarified the rationales and the scenarios to insure that the transcripts revealed correct information.

Measures

Extensive demographic information was collected from each participant at T1 including age, sex, income, race, level of education, health perceptions, interference with ADLs, advanced directives. At T2, the demographic information collected was narrowed to age, income, health perceptions, health conditions, current living arrangements, and possession of advance directives. An overall health score was calculated by combining the health variables for the first two questions of the questionnaire (e.g., overall health rating, health now compared to 7 years ago). The minimum score that could be obtained was 0 and the maximum score was 2. Health was also measured by summing the existence of nine health conditions (e.g., arthritis, osteoporosis, high blood pressure) to create a health condition score. Because there were no significant changes noted in the health scores of the participants from T1 to T2, health status was not viewed as an intervening variable affecting the choices made for the hypothetical medical and life-sustaining treatment preferences.

The importance of spirituality in the daily lives of the older adults was measured differently at T1 and T2. At T1, a visual 100mm line was used whereby the participants placed a slash mark on the line indicating the level of importance of spirituality in their lives. At T2, the telephone interview prevented the use of the visual scale; the question

was phrased such that the participants could choose whether they believed spirituality was not important, somewhat important or extremely important in their daily lives. At T1 scores ranged from 10-100 and were collapsed to represent similar response categories used at T2. Scores lower than 38 were considered the same as the category representing *not important*, scores between 39 and 79 were *somewhat important* and scores above 80 corresponded with *extremely important*.

A list of 24 value indicators, developed specifically for the original study, was used to assess the impact of values upon medical decision-making. The values indicators were identified from an extensive search of the literature (Cohen-Mansfield et al., 1991; Doukas & McCullough, 1991; Lambert, Gibson, Nathanson, 1990; McCollough, Wilson, Teasdale, Kolpakchi, & Skelly, 1993) and focus groups with older adults and health care providers (Mathesis-Kraft & Roberto, 1997). The values indicators were printed on light green paper to assist the older adults in recognizing the list in the packet that was mailed to them.

The *Preferences for Life-sustaining Treatment Questionnaire* (Cohen-Mansfield et al., 1991) consists of 12 potentially life-threatening medical situations across three cognitive states (current state of health, permanently confused, permanent coma). In this study, 10 of the 12 scenarios were used : cardiac bypass, hip replacement, mastectomy or prostatectomy, antibiotics for pneumonia, cataract removal, cardiopulmonary resuscitation, respirator for permanent inability to breathe, dialysis for kidney failure, tube feeding for permanent inability to eat and chemotherapy for cancer treatment. Due to the unanimous agreement among participants at T1 that no

treatment would be desired if permanently in a coma, only current state of health and permanently confused were used at T2.

Pilot

A pilot of the instrument and the telephone recording equipment was performed with one older adult outside of the sample. No changes were made to the instrument and the interview process was completed uneventfully.

Data Analysis

Quantitative analysis was completed on the secondary data set at T1 and the new data at T2 in order to address the first two research questions. Descriptive statistics were computed using the Statistical Package for the Social Sciences software. The McNemar test was used to detect significant changes in the health care preferences and values selection from T1 to T2. The McNemar test is particularly applicable to “before-after” type of designs where each participant serves as his or her own control and in which the measurements are made on either a nominal or ordinal scale (Pett, 1997). A significance level of 0.05 was used.

Qualitative data were obtained from the open-ended responses given by the participants when asked to explain the five values selected from the values inventory and the rationales behind their consent for or rejection of the various medical and life-sustaining treatment scenarios. The qualitative data were used to address the remaining two research questions and to illuminate the human experience of the participants. Upon completion of the interviews at T1, the transcripts were read multiple times by two independent coders to generate a comprehensive understanding of patterns of responses and emerging themes found in the data (Bogdan & Bilken, 1998).

A visual tree diagram was developed which represented the identified themes and aided in the coding of the transcripts. Each transcript was read and coded independently by the two coders. Codes were compared and any discrepancies between the coders were resolved through discussion. At T1, the codes were entered into Non-numerical Unstructured Data Indexing Searching and Theorizing (NUD*IST) software to organize the data. At T2, the transcripts were read several times by the interviewer to determine if any new themes emerged from the data. The themes remained constant and the visual tree diagram was again used to assist with coding the responses. The codes were compared in the same fashion as in T1 with discrepancies resolved through discussion. NUD*IST was not used at T2 as the data for a smaller sample were manageable through the use of created Word documents.

Chapter 3

Results

The study findings are presented in the form of two manuscripts prepared for submission to scholarly journals. The first article, “Stability of Values and Health Care Preferences of Older Adults,” will be submitted to *The Journal of Gerontological Nursing*. The second article, “Values that Influence Health Care Preferences of Older Adults,” will be submitted to *The Journal of Aging Studies*. Manuscript format and submission guidelines for both journals are provided in Appendix E.

Running head: Stability of Values and Preferences

Stability of Values and Health Care Preferences of Older Adults in Late Life

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Stability of Values and Health Care Preferences of Older Adults in Late Life

Abstract

This study examined the stability of health care decisions and the influencing values of competent older adults in late life ($N=21$) over a seven-year period of time. Each participant was presented with a list of value indicators from which they were asked to identify the five that most influenced their health care decision-making process. They were also instructed to make decisions regarding five health care treatment scenarios and five life-sustaining treatment scenarios across two health states and three different levels of prognosis. Face-to-face interviews were conducted initially followed by taped, telephone interviews seven years later. No significant change in healthcare decisions was found for life-sustaining treatments over the seven-year period in older adults in late life. The only significant change noted for the health care treatments was an increase in those not consenting to hip replacement surgery at T2 regardless of health state or prognosis. Similarly, change occurred between T1 and T2 with more participants refusing cataract surgery with a prognosis of 50/50 chance of recovery. Stability was also noted in the values selected by participants. Four out of the top five values selected at the initial interview were also selected seven years later.

Stability of Values and Health Care Preferences of Older Adults in Late Life

With advances in health care, including the rapid development of new medical procedures and technologies, older adults in late life may find themselves in situations where they, or someone they entrust, must decide on implementing life-enhancing, life-sustaining, or life-ending treatments. Advance directives, a legal instructive document that expresses the choices of competent adults (e.g., durable power of attorney for health care, living wills, do-not-resuscitate orders) serve to identify treatment preferences prior to illness or injury in order to extend patients' wishes during periods of decisional incapacity. When unable to communicate health care preferences, an advance directive serves to safeguard the patients' wishes by enhancing the ability of relatives and other surrogate decision makers to enact the treatment choices patients would make for themselves if they were competent to do so (Abbott, Sago, Breen, Abernethy & Tulsky, 2001; Fagerlin, Ditto, Danks, Houts & Smucker, 2001; Larson & Tobin, 2000; McCann, Chodosh, Frankel, Katz, Naumburg, & Tulsky, et al., 1998).

Nurses, better than any other health team member, can facilitate discussions of health care choices among older adults and their family members. The time usually committed to giving direct care giving and the opportunity for relationship building with families are assets upon which nurses can capitalize to encourage communication of healthcare wishes. It is imperative not only that advanced directives are acknowledged, but also that nurses familiarize themselves with the content of the document so that wishes of the patients will dictate care that is rendered during illness. When prior discussions of wishes have not occurred, nurses must encourage family members to

draw upon their knowledge of the values and beliefs that the older adult held throughout life to inform their decision-making process.

Missing from nursing research is a clear understanding of whether preferences for medical treatment and the values or beliefs that drive those decisions remain stable over extended periods of time, especially in the face of changes in health late in life. Although individuals are encouraged to revisit prior decisions and make necessary changes to ensure accuracy and currency of the document, there is no legally mandated renewal period. If decisions regarding treatment preferences and values change over time then previously documented advance directives may not accurately reflect the current wishes of the older adult who is incapacitated. Consequently, surrogate decision-making by family members and the medical team are often complicated by outdated, potentially erroneous advance directives (Gready, Ditto, Danks, Coppola, Lockart, & Smucker, 2000). The purpose of this study was to ascertain whether or not health care decisions and values of older adults in late life remain stable over time.

REVIEW OF THE LITERATURE

Stability in Treatment Preferences

Researchers measuring stability of the health care decision-making process of older adults over relatively short time periods (1 to 30 months) report moderately high stability rates (Danis, Garrett, Harris & Patrick, 1994; Everhart, & Pearlman, 1990; Gready et al., 2000; Houts, Smucker, Jacobson, Ditto, & Danks, 2002; Lockhart, Ditto, Danks, Coppola, & Smucker, 2001; Patrick, Perlman, Starks, Cain, Cole, & Uhlmann, 1997). The standard protocol for these studies is to have participants respond to

hypothetical health scenarios, each varying in prognosis and health state (e.g., hydration/nutrition in current state of health or when permanently confused). For example, in a small sample of 30 intensive care patients, Everhart and Pearlman (1990) found that decisions regarding life-sustaining treatment did not change over a one-month period of time despite significant, often improved health status and mood of the participants. In two later studies utilizing larger samples, similar findings resulted over a period of two years. Emanuel and colleagues (1994) interviewed 495 HIV and oncology outpatients and 102 adults from the general public 3 times over 24 months with regard to life-sustaining treatment preferences. Ninety-three percent of the participants interviewed at 24 months demonstrated stability in their treatment preferences. Participants who discussed their treatment preferences with their physicians showed greater stability of choices than those who had not had such discussions. Similarly, Danis and colleagues' (1994) study of 2,536 individuals found greater stability of preferences among participants with a living will (86% stability) than those without (59% stability). Over the 2-year study period, 85% of individuals who chose to forgo life-sustaining treatments did not change their preference, whereas only 18% to 43% of those desiring life-sustaining treatment maintained their original choice. Collectively, these findings suggest that health care preferences remain stable over relatively short periods of time and that those individuals who have discussed their choices with health care professionals exhibit greater stability of preferences than those who do not. Moreover, these studies included older adults who ranged in age from the early sixties to late nineties making it difficult to assess the impact that age might have contributed to the variability of decision-making stability.

Stability of Values

Etzioni (1988), in his Normative-Affective Model for decision-making, postulates that values commitment and emotional factors significantly shape decision making. These factors influence the process that takes place, the type of information that is gathered and analyzed, the inferences that are drawn, the options that are considered and the options that are finally chosen. He proposed that normative-affective factors determine the real-life sources from which individuals draw information, how they interpret what they see, and what they think they should infer from what they have learned about the situation at hand. Emotion drives the decision-making process and values serve to regulate the decisional response (Etzioni, 1993).

When applying the Normative-Affective framework to the study of health care decision-making, it can be argued that preferences for care develop from individually defined sets of values and beliefs which have been operationalized throughout the older person's life. This implies that preferences for health care should remain fairly consistent if driven by deeply embedded, life-long values and beliefs. By clarifying values prospectively, surrogate decision-makers are able to make principled choices with greater confidence that they reflect the incapacitated person's values and preferences (Doukas & McCullough, 1991).

Among the values and beliefs found to be specifically influential in the decision-making process of older adults are religion and spirituality (Carmel & Mutran, 1997; Ejaz, 2000; Leichtentritt & Rettig, 1999; Lo, Ruston, Kates, Arnold, Cohen & Faber-Langendoen, et al., 2002; Mahoney & Graci, 1999). Older adults, who experience more health-related problems and who more readily than younger individuals acknowledge

their own mortality, often draw sustenance and a sense of continuing purpose from their religious beliefs (O'Connell, 1994). O'Connell (1994) suggested that religious coping adds perspective and moral resources as older adults struggle with health-related decisions, whether they involve refusing medical treatment, withdrawing life-support systems, coping with a disabling illness, choosing to move to a nursing home, or even an option as simple as refusing expensive brand-name drugs in favor of less expensive, generic drugs.

Numerous other values and beliefs, including respect, dignity, quality of life, and independence, also appear important in the decision-making process of older adults (Atchley, 1997; Doukas & McCullough, 1991, Rokeach & Ball-Rokeach, 1989). Collectively, these values serve as the foundation from which older adults think about and formulate opinions about accepting or rejecting medical treatment options (Astrow, Puchalski & Sulmasy, 2001; Doukas & McCullough, 1991; Homer & Kahle, 1988). In perhaps the most notable values study across time and health states, Rokeach and Ball-Rokeach (1989) surveyed 1,409 participants over a 13-year period of time. The participants, ranging in age from 11 to 90 years, were asked to rank order a group of 18 values at 4 different points in time. The researchers described the results as incredibly stable with the top 6 and the bottom 6 values receiving identical priority rankings across the 13 years. Even though the middle 6 values fluctuated in their identified rank, they consistently remained in the middle zone of the results, suggesting that these values varied in their importance across time but were never identified as either most important or least important among participants (Rokeach & Ball-Rokeach, 1989). These findings suggest that surrogates who are familiar with the operative value system of the older

adult will have a solid foundation from which to make decisions when the need arises. Unlike the research on decision-making stability, it would appear that values stability is not age dependent in that the sample age range reported by Rokeach and Ball-Rokeach (1989) was quite large yet continued to demonstrate high statistical stability in values choices over time. However, the sample did not include individuals in the old-old category of life leaving one to wonder if values stability remains constant as one faces the end-of-life.

To summarize, the literature indicates moderate to high stability of health care preferences and values indicated over a 12- to 30-month period of time throughout adulthood and early late life. The only study to date to employ a time frame longer than 24 months found only moderate stability of health care preferences 30 months after the initial interview (Patrick et al., 1997). Therefore, whether health care preferences, in particular, remain stable for longer periods of time and with older adults in the late stages of life, are not known. This study addresses the issue of stability of both health care references and the values influencing these preferences over a period of seven years among older adults in late life. Preferences for medical and life-sustaining treatments were measured for five common medical conditions and five end-of-life scenarios. Values were measured using an established list of 24 value indicators whereby participants narrowed their selections to the five most influential values in their health care decision-making process. Comparison between the initial findings and a 1-year follow-up interview suggested that the older adults in this sample identified a strong link between values commitment, emotion, and the decision-making processes. They

did not change their health care preferences or values that year (Roberto, 1999; Roberto, Weeks, & Matheis-Kraft, 2001).

The current phase of the study examined the stability of health care preferences and values of older adults in late life over seven years. Given the change reflected in the literature, from high stability to moderate stability after 24 to 30 months, it was hypothesized that there would be significant variability in the treatment preferences from year one to year seven. Conversely, it was hypothesized that there would be significant stability with the values that the participants selected as influential in their decision-making process.

METHODS

Sample

The original study sample consisted of 62 older adults living in Colorado (Roberto, 1999). Participants were recruited from three organizations in two counties: (a) Weld County Retired and Senior Volunteer Program, (b) McKee Medical Center in Larimar County, and (c) Larimer County Retired and Senior Volunteer Program. The participants ranged in age from 75 to 95 ($M=80.3$; $SD=4.3$). Forty-two women and 20 men participated in the study. The sample included a 3:1 female to male ratio that represented the general population of older adults over the age of 75 (U.S. Bureau of the Census, 1990). Ninety-five percent (59) of the older adults were Caucasian. Time 1 data were collected from 1995 to 1997.

At the end of the two-year data collection period, three study participants had died, leaving 59 potential participants for the seven year follow-up interview. An electronic search of death records revealed that 26 of the original participants had died

since 1997. It was not possible to locate nine participants. Of the 24 older adults contacted, 2 individuals were unable to participate due to declining health and current hospitalization and 1 person refused to participate; thus, the 2004 sample consisted of 21 older adults capable of making their own decisions.

Procedures

The original interviews (T1) were conducted face-to-face in the participants' homes. The one year follow-up interview data were not analyzed in the current study as there was no change in preferences and values from the initial interview (Roberto, 1999). The seven-year interview (T2) was conducted via telephone and took approximately 30 to 45 minutes to complete. Participants at T2 were sent packets of information that included a cover letter and a copy of the data collection instrument to provide them the benefit of following along with the interviewer throughout the telephone conversation. However, only 5 of the 21 participants kept the packet and had it available during the interview.

From a list of 24 values indicators, participants were asked to choose the five that were most influential on their health care decisions. These were not rank ordered but randomly identified by the participants at T1 and T2. Participants were then asked to indicate how each of the five values influenced their preferences for health care procedures and treatments. This was done to lend context to the importance of each value in the decision-making process for each participant (could cite second manuscript here).

Participants responded to the same series of hypothetical scenarios relating to common health care procedures and life-sustaining treatments at both T1 and T2. The

health care procedures consisted of by-pass surgery, hip replacement, antibiotics for pneumonia, mastectomy/prostatectomy, and cataract surgery. Each procedure was presented under two different health states: current health and permanently confused. Each health state was also presented under three different prognoses: less than 50% chance of recovery, 50%/50% chance of recovery, and greater than 50% chance of recovery. The life-sustaining treatment scenarios consisted of resuscitation for cardiac arrest, respirator for permanent inability to breathe on one's own, dialysis for kidney failure, tube feeding for permanent inability to eat, and chemotherapy for cancer. In these scenarios, the health states were current health or permanently confused; no prognoses percentages were given for the life-sustaining treatments. Participants were asked to respond to each scenario by indicating if they would or would not consent to the various procedures and treatments. With each response, participants were asked to explain the reasons they would or would not consent to the procedure or treatment being discussed.

Measures

Extensive demographic information was collected from each participant at T1 including age, sex, income, race, level of education, health perceptions, interference with ADLs and possession of advanced directives. At T2, the demographic information collected was narrowed to age, income, health perceptions, health conditions, current living arrangements, and possession of advance directives. To address the relevance of religion or spirituality upon medical decision-making, each participant was asked, "What role does spirituality, religion, faith, or belief in a higher being, play in your life and healthcare decision-making?" Response options were plays no part in my life, is

somewhat important, or is extremely important. If the response was either somewhat or extremely important, additional probing questions were asked to further explore the importance of spirituality in their daily lives.

A list of 24 value indicators, developed specifically for the original study, was used to assess the impact of values upon medical decision-making. The value indicators were identified from an extensive search of the literature (Cohen-Mansfield, et al., 1991; Doukas & McCullough, 1991; Lambert, Gibson & Nathanson, 1990; McCollough, Wilson, Teasdale, Kolpakchi, & Skelly, 1993) and focus groups with older adults and health care providers (Mathesis-Kraft & Roberto, 1997).

The *Preferences for Life-sustaining Treatment Questionnaire* (Cohen-Mansfield et al., 1991) consists of 12 potentially life-threatening medical situations across three cognitive states (current state of health, permanently confused, permanent coma). In this study, 10 of the 12 scenarios were used: cardiac bypass, hip replacement, mastectomy or prostatectomy, antibiotics for pneumonia, cataract removal, cardiopulmonary resuscitation, respirator for permanent inability to breathe, dialysis for kidney failure, tube feeding for permanent inability to eat and chemotherapy for cancer treatment. Due to the unanimous agreement among participants at T1 that no treatment would be desired if permanently in a coma, only current state of health and permanently confused were used at T2.

ANALYSIS

Descriptive statistics were obtained using Statistical Package for Social Sciences software to summarize the individual characteristics of the group at T1 and T2. The McNemar test was used to detect significant changes in the proportion of older adults

refusing care from T1 and T2 and changes in their selection of values influencing their decisions. The McNemar test is particularly applicable to “before-after” type of designs where each participant serves as his or her own control and in which the measurements are made on either a nominal or ordinal scale (Pett, 1997). The interviews were transcribed and then independently read and coded by two coders. Average agreement between the individual coders for each interview exceeded 85%. Codes were compared and discrepancies between coders were resolved through discussion until 100% agreement was reached. The themes that emerged from the transcribed data were identical at T1 and T2.

RESULTS

Study Participants

The 21 participants ranged in age from 83 to 101 ($M=88.0$; $SD=3.8$). Seventeen (81%) of the participants were women and all participants identified themselves as Caucasian except for one man who was Native American. The majority of the participants were widowed (57%, 1 man and 11 women) with the remaining either married (28.6%, 3 men and 3 women) or divorced (9.5%, 2 women). Seventeen (81%) of the participants lived in their own home or apartment; the others were lived in assisted living facilities. All of the participants currently had living wills, medical powers of attorney, or CPR directives.

The participants' responses to the health questions suggested declines in self-reported health from T1 to T2. The responses to two questions, “How would you rate your overall health at the present time?” and “At the present time, is your health better, about the same or worse than it was 6 years ago?” were summed to obtain an overall

health indicator score. Scores ranged from 0 to 2 with higher scores representing more positive perceptions of current health status ($M=1.0$, $SD = .74$; $M=.8$, $SD = .76$ respectively). Participants were asked to identify whether or not they had any of nine health conditions. Participants at T1 had a mean of 2.9 conditions ($SD = 1.8$) and at T2 a mean of 3.4 conditions ($SD = 1.8$) (e.g., arthritis, osteoporosis, high blood pressure, etc.).

Frequency distribution of the values indicators revealed that *Quality of Life* (T1=85%, T2=81%) and *Independence* (T1=52.4%, T2=71.4%) were the two most commonly identified by the participants (Table 1). At T1, *Dignity* (52.4%), *Religious Beliefs* (47.6%) and *Burden to Self or Others* (33.3%) followed. Similarly, at T2, *Religious Beliefs* (57.1%) was the second most commonly selected value, followed by *Dignity* (42.9%) and *Family Wishes* (42.9%). No participant chose *Life at Any Cost* or *Fear* as being important to their medical decision-making process at either interview. Overall, no significant differences were found between the values selected by the participants at T1 and T2.

The importance of spirituality in the daily lives of the older adults was scored differently at T1 and T2. At T1, the item utilized a visual 100mm line whereby the participants place a slash mark indicating the level of importance that spirituality had in their lives. At T2, the telephone interview prevented the use of the visual scale so the question was phrased such that the participants could choose whether they believed spirituality was not important, somewhat important or extremely important in their daily lives. At T1 scores ranged from 10 to 100 ($M=73.6$, $SD = 25.7$) and were collapsed to

Table 1

Values Influencing Medical Decision-Making in Older Adults (N=21)

| Values Indicators | Time 1 | | Time 2 | |
|-------------------------------|----------|------|----------|------|
| | <i>N</i> | % | <i>N</i> | % |
| Quality of Life | 18 | 85.7 | 17 | 81.0 |
| Independence | 11 | 52.4 | 15 | 71.4 |
| Dignity | 11 | 52.4 | 9 | 42.9 |
| Religious Beliefs | 10 | 47.6 | 12 | 57.1 |
| Burden to Self or Others | 7 | 33.3 | 8 | 38.1 |
| Pleasures in Life | 6 | 28.6 | 3 | 14.3 |
| Comfort- Pain & Suffering | 6 | 28.6 | 3 | 14.3 |
| Dependency for Self Care | 6 | 28.6 | 3 | 14.3 |
| Age | 4 | 19.0 | 6 | 28.6 |
| Peace | 4 | 19.0 | 4 | 19.0 |
| Status of Living Arrangements | 4 | 19.0 | 4 | 19.0 |
| Resources To Benefits | 3 | 14.3 | 3 | 14.3 |
| Support | 3 | 14.3 | 0 | 0.0 |
| Hope | 2 | 9.5 | 4 | 19.0 |
| Outcomes – Prognosis | 2 | 9.5 | 1 | 4.8 |
| Quantity of Life | 1 | 4.8 | 1 | 4.8 |
| Self Image | 1 | 4.8 | 0 | 0.0 |
| Choices | 1 | 4.8 | 1 | 4.8 |
| Life at any Cost | 0 | 0.0 | 0 | 0.0 |
| Goals in Life | 0 | 0.0 | 1 | 4.8 |
| Control | 0 | 0.0 | 2 | 9.5 |
| Fear | 0 | 0.0 | 0 | 0.0 |

represent response categories used at T2. Four participants (19%) at T1 indicated that spirituality was not important (scores lower than 38), 5 participants (23.9%) viewed

spirituality as somewhat important (scores between 39 and 79) and 12 participants (57.1%) stated that spirituality was extremely important in their daily lives (scores 80 and higher). At T2, 2 participants (9.5%) stated that spirituality played a somewhat important role and 18 participants (85.7%) stated that it was extremely important to their daily lives. One participant did not comment.

Although the number of participants who indicated they would refuse health care treatments increased at T2 across all states of health and all prognoses, few of the changes were statistically significant (Table 2). Specifically, no significant change was found in preferences for bypass, mastectomy/prostatectomy, and use of antibiotics regardless of prognosis or state of health. When responding to the health preference scenarios, for their current state of health, there was significant change in their responses from T1 to T2 for the hip replacement scenarios regardless of prognosis and for cataract surgery with a 50/50 chance of recovery. In each case, a significant number of participants changed their responses from “consent” at T1 to “would not consent” at T2. No significant change was noted with any of the life-sustaining treatments (CPR, respirator, dialysis, feeding tube and chemotherapy) regardless of whether the state of health indicated was current or permanently confused.

After responding to a given scenario, the older adults were encouraged to discuss why they would or would not consent to the given treatment or procedure. When the response was “would not consent,” common themes identified included age, interference with quality of life, negative experiences observed from others, not wanting to burden their families, and religious beliefs. When examining specific scenarios, with a prognosis of 50/50 or less than 50%, the typical comments from the participants

Table 2

Older Adults Not Consenting to Health Care Procedures and Treatments (N = 21)

| Scenarios | Time 1 | | Time 2 | | p-values |
|---------------------------|--------|------|--------|------|----------|
| | N | % | N | % | |
| CURRENT HEALTH | | | | | |
| < 50% chance of recovery | | | | | |
| Bypass | 16 | 76.2 | 14 | 66.7 | .62 |
| Hip Replacement | 6 | 28.6 | 15 | 71.4 | .01 |
| Mastectomy/Prostatectomy | 14 | 66.7 | 15 | 71.4 | 1.00 |
| Cataract | 2 | 9.5 | 7 | 33.3 | .12 |
| Antibiotics for Pneumonia | 1 | 4.8 | 5 | 23.8 | .12 |
| 50-50 chance of recovery | | | | | |
| Bypass | 12 | 57.1 | 11 | 52.4 | 1.00 |
| Hip Replacement | 3 | 14.3 | 12 | 57.1 | .01 |
| Mastectomy/Prostatectomy | 10 | 47.6 | 15 | 71.4 | .10 |
| Cataract | 2 | 9.5 | 6 | 28.6 | .00 |
| Antibiotics for Pneumonia | 0 | 0.0 | 3 | 14.3 | .25 |
| >50% chance of recovery | | | | | |
| Bypass | 8 | 38.1 | 8 | 38.1 | 1.00 |
| Hip Replacement | 1 | 4.8 | 8 | 38.1 | .01 |
| Mastectomy/Prostatectomy | 6 | 28.6 | 12 | 57.1 | .07 |
| Cataract | 2 | 9.5 | 6 | 28.6 | .28 |
| Antibiotics for Pneumonia | 0 | 0.0 | 2 | 9.5 | .50 |

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

revealed that the treatment or procedure was not worth the risk due to the poor predicted outcome. In the scenario involving hip replacement in current state of health, regardless of prognosis, the common themes for refusal of treatment included the negative and often fatal experiences of others as well as the pain and suffering that was inherent in the surgical procedure itself. When the older adult agreed to consent to a treatment or procedure, the common themes included improved prognosis, because of family wishes, and the desire to continue to live.

DISCUSSION

Although natural attrition occurred with this sample, limiting its potential size and statistical power, the findings contribute to the existing nursing knowledge concerning the critical nature of the health care decision-making process of older adults late in life. Therefore, these findings suggest that the preferences for health care and life-sustaining treatments remain stable well beyond 30 months. Nurses, other health care professionals and surrogate decision-makers can be encouraged to know that decisions made by older adults about their health care are likely to reflect their wishes accurately for many years.

The second and perhaps most notable finding is that values that influence the health care treatment preferences of older adults in late life also remain stable over an extended period of time. The stability of these values demonstrates the powerful influence they have on health care decision-making. Of the top five values that were selected by the older adult participants, four were identical at both interview intervals. The discussions surrounding why particular choices were made regarding treatment preferences support the theoretical link among feelings, beliefs, and decisions proposed

by Etzioni (1988). For example, the older adults desired to preserve their independence, their present quality of life, and their religious beliefs and to avoid becoming a burden to their families by not consenting to procedures that were perceived as threatening to their personal values. Even when they agreed with having certain procedures, their comments continued to reflect a desire to please their families, preserve their quality and independence in life, and to honor God's authority to take them at any time regardless of their earthly choice. Therefore, if families understand the value systems that have been operant throughout older adults' lives, then the critical health care decision making process can be clearer and less guilt-ridden.

The importance of spirituality or religion in the decision-making process was quite evident in the participants' responses. Not only did it hold the third and fourth place in the top five values selected by the older adults, but also, discussions of its meaning in their everyday lives revealed its deep significance to them. When asked to describe the importance of spirituality, participants responded by saying "My faith is so strong and I believe in prayer so much....as far as decisions I make, God guides me to make those decisions....I am certainly not afraid of dying 'cause I have a better place 'awaiting....I couldn't do anything if I didn't have my Lord at my side....Pray consoles me and helps me know I'm making the right decision." O'Connell (1994) stated that through years of participating in religious traditions, older adults have witnessed the impact of beliefs on the decisions of relatives and friends and have internalized the spiritual wisdom of the religious community. Meditation, prayer, counseling, and religious reading enable older adults to formulate meaning and opinion in order to attach personal judgments to decisions about what is good or bad in the pursuit of bodily health (O'Connell, 1994).

The findings from this study underscore the critical importance that religion and spirituality may play in the lives of older adults not only to give comfort but to inform them in making critical health care decisions.

IMPLICATIONS FOR PRACTICE

Although others have suggested a need to revisit choices made in advance directives (Danis, Garrett, Harris & Patrick, 1994; Everhart, & Pearlman, 1990; Gready et al., 2000; Houts, Smucker, Jacobson, Ditto, & Danks, 2002; Lockhart, Ditto, Danks, Coppola, & Smucker, 2001; Patrick, Perlman, Starks, Cain, Cole, & Uhlmann, 1997), the results of this study suggest that renewing advance directives may not be as critical for certain groups of individuals. At the initiation of this study, all participants were all over the age of 75. Perhaps their age and their late stage of life served as stabilizing factors with respect to their health care preferences. If advance directives are made at a younger age, when the realities of poor health consequences are distant, then revisiting decisions periodically may be important to ensure that the documents remain accurate reflections of the person's preferences.

Knowledge of the driving force of values behind health care decisions of older adults is central to nursing practice and clinical care. This understanding will enable nurses to advocate effectively for their patients and plan care that is client-focused and cost effective. Since older adults are the greatest users of inpatient hospital resources and pharmaceuticals (Miller, 2004), honoring their preferences regarding life-sustaining treatments and end of life care will provide a clear, ethical care trajectory for health care providers.

Nurses are poised to aid in the decision-making process of older adults and their family members or surrogates. Nurses must understand that facilitating discussions regarding advance directives has a purpose beyond filling out a form. Rather, such discussions involve taking the necessary time to explain treatments and procedures about which older adults and surrogates must make choices. Terminology related to prognosis and recovery must be explained along with the implications of each choice that can be made. While hospital nurses are appropriately engaged in these conversations, they are most effective if they occur outside of a potential crisis time that often surrounds hospitalization. Therefore, nurses who practice in long-term care facilities, physicians' offices, and home health nurses agencies should routinely encourage discussions of advanced directives among older adults and their family members. In doing so, nurses can feel confident that they are meeting the older adults' wishes for quality care and ending the emotional, turbulent feelings and last minute decision-making by family members.

In the absence of advance directives or familiarity with the wishes of an older adult, families should be encouraged to consider values and beliefs that were evident throughout the life of the older adult. This information will enable family members to focus on what is important to the older adult, feel more confident that they have the necessary information to support their decisions, relieve themselves of some of the burden of making agonizing decisions, and reduce the guilt that often follows such decisions (Roberto, Weeks & Matheis-Kraft, 2001).

Additionally, knowing that there is stability in health care preferences will ease the moral distress nurses often feel at end-of-life when aggressive care is ordered, often

against the wishes of the older adult. As advocates for patients in their care, nurses can be confident that the prior decisions made by the older adult are accurate and reflect a life-long set of values that were important to the decision-making process. By minimizing unwanted heroic measures, patients, their families, and healthcare resources can be eased during end-of-life care.

Additional longitudinal nursing research should be conducted in order to give a clearer picture of when or whether stability of treatment preferences becomes problematic. Similarly, research involving larger samples with culturally and socioeconomically diverse groups of participants is critical to the understanding of healthcare decision and values stability. Such research efforts can reaffirm the accuracy of advance directives over longer periods of time and evaluate whether legally mandated updates of advance directives would serve any useful purpose in society.

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Running head: Values and Preferences of Health Care Decisions

Values that Influence Health Care Preferences of Older Adults in Late Life

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Values that Influence Health Care Preferences of Older Adults in Late Life

Abstract

The purpose of this study was to explore the meanings given to values influencing health care decisions of competent older adults ($N=21$). Face-to-face interviews were conducted initially (T1) followed by telephone interviews seven years later (T2). Participants were asked to make hypothetical decisions regarding five health care treatment and five life-sustaining treatment scenarios across two health states and three different levels of prognosis. Using open ended questions, participants described why they would or would not consent to medical or life-sustaining treatments. Four themes emerged from the data representing the values that influenced health care decisions. They included factors that were external to the participant, those that were internal, age, and state of health (i.e., permanent confusion). Analyses of data from the interview transcripts revealed congruence between values and medical or life-sustaining treatments at T1 and T2.

Values that Influence Health Care Preferences of Older Adults in Late Life

Because of changes in their personal health trajectory, older adults may find themselves in complex situations where they, or someone they entrust, must decide on implementing life-enhancing, life-sustaining, or life-ending treatments. Since the 1980s, older adults have been encouraged to implement advance directives that serve prospectively to identify treatment preferences to extend their wishes during periods of decisional incapacity (Abbott, Sago, Breen, Abernethy & Tulsky 2001; Fagerlin, Ditto, Danks, Houts & Smucker 2001; Larson & Tobin 2000; McCann, Chodosh, Frankel, Katz, Naumburg, & Tulsky, et al 1998). These legal instructive documents represent the expressed choices of competent adults (e.g., durable powers of attorney for health care, living wills, do-not-resuscitate orders) and are central mechanisms used by families and health care professionals to direct care for persons who become incapacitated and not able to participate actively in the decision making process.

In situations where advance directives are not available, surrogate decision-makers must find direction from other sources. Prior to becoming incapacitated and unable to facilitate the decision-making process, older adults can provide information to guide their surrogates when making difficult health care decisions. Decision-making is a life-long process; one which is heavily influenced by long-held values and beliefs. It is through the appreciation and understanding of these values and beliefs that current decision-making can be augmented.

Homer and Kahle (1988) suggested that values contribute to one's attitude, which in turn influences one's behavior and therefore one's decisions. Similarly, Roberto (1999) suggested that just as everyday decisions are influenced by one's

values, medical decisions are also influenced by values that have developed throughout a person's life. This assumption is crucial to the concept of substituted judgment, where surrogates are expected to attempt to represent the preferences of older adults accurately as if they were making those decisions for themselves (Seckler, Meier, Mulvihill, & Paris 1991).

Values important in the decision-making process of older adults include quality of life, independence, religious beliefs, and maintaining dignity (Doukas & McCullough 1991). Collectively, these values serve as the foundation from which older adults think about and formulate opinions about accepting or rejecting medical treatments. However, values do not hold universal meaning for everyone; rather they are individually defined and may influence decisions differently as situations or circumstances vary over one's life time. Therefore, it is imperative that surrogates and health care providers concern themselves with assessing and understanding the individual meaning of the values older adults hold and how they influence health care decisions specifically (Astrow, Puchalski & Sulmasy 2001; Doukas & McCullough 1991). By doing so, those involved in the care of the older adult will be better able to respect their wishes for treatment options when they are least able to articulate those wishes. They will also be able to manage uncertainties surrounding advance directives more reliably (Gibson 1990). The purpose of this study is to identify the values of older adults in late life and to examine how each value is operationalized as they formulate critical health care decisions. Concurrently, the investigation will explore the stability of the values over a seven year period.

LITERATURE REVIEW

Values and Decision-making

There appears to be a crucial link between values, emotions and the decision-making process. Etzioni (1988), in his Normative-Affective Model for decision-making, postulated that commitment to one's values and emotion significantly shape decision making. Values and emotion influence the process that takes place, the type of information that is gathered and analyzed, the inferences that are drawn, the options that are considered, and the final decisions that are made. He suggested that values are not stagnant nor are they universally defined. Although value labels remain constant and generally understood by most people (e.g., love, loyalty, trust, respect), individuals ascribe personal meaning to their values. In the same way, value meanings also reflect an individual's perceptions of societal and cultural norms, history and familial experiences. Similarly, individuals incorporate many values into their lives, however, those of greatest personal importance are the ones that most influence decision-making (Etzioni 1988).

Likewise, emotions serve as motivating factors to affect change. The greater the emotional charge surrounding a given situation, the greater the impetus to arrive at an acceptable solution. Hence, emotions drive the decision-making process and values serve to regulate the decisional response (Etzioni, 1993). Berelson and Steiner (1964), contended that the greater the influence of emotion on values and beliefs, the harder it is to influence an alternative perspective by argument, propaganda, or an appeal to intelligence. The driving assumption is that although it appears that individuals utilize normative-affective factors in a calculated fashion to influence decision-making, these

factors are actually internalized and absorbed by individuals to shape their inner selves. Etzioni (1988) presumed that these factors would be modified by an individual and when the modification process was complete, the values, behavior, attitudes, and emotions shape what the individual believes, feels, prefers, and seeks. Therefore, when the decision-making process is tested over time, the normative-affective model suggests that the choice made would remain fairly consistent if driven by deeply embedded, life-long values and beliefs. Thus, it can be argued that preferences for health care develop from an individually defined set of values and beliefs that have been operationalized throughout a person's life and should remain fairly consistent over time. By clarifying values prospectively, surrogate decision-makers are able to make principled choices that reflect the incapacitated individual's values and preferences with greater confidence (Doukas & McCullough 1991).

Values and Stability

The literature suggests that values play a significant role in the decision-making process, yet values have been empirically difficult to validate and measure over time. In perhaps the most notable values study across time and health states, Rokeach and Ball-Rokeach (1989) surveyed 1,409 participants over 13 years. The participants, ranging in age from 11 to 90 years, were asked to rank order a group of 18 values at 4 different points in time. The researchers describe the results as extraordinarily stable with the top 6 and the bottom 6 values receiving identical priority rankings across the 13 years. While the middle six values fluctuated in their identified rank, they consistently remained in the middle zone of the results, suggesting that these values varied in their importance across time but were never identified as either most important or least

important among participants. Their findings suggest that surrogates who are familiar with the operative value system of the older adult will have a better foundation from which to make decisions when the need arises.

Religious values and beliefs significantly influence older adults' decision-making process. For example, Atchley (1997) reported the subjective value of religious importance and its effects upon health and morale over an extended period of time. The sample included 1,106 adults, aged 50 years and older, who were surveyed 6 times over the course of 14 years beginning in 1977 and ending in 1991. When asked to rate the importance of being a religious person, 65.5% of the 559 respondents who completed at least 3 surveys consistently reported that being a religious person was important or very important. Similarly, 16.1% of the participants consistently rated being a religious person as unimportant or very unimportant. Thus, 81.6% of respondents showed continuity in their ratings over time with almost two-thirds rating being religious as important.

In the few studies that specifically addressed the role of religion in the decision making process of older adults, researchers reported that relying on God to influence decisions and having an affiliation with a particular religious denomination differentiated between older adults who agreed and did not agree to life-sustaining treatment options. For example, Ejaz (2000) found that nursing home residents who reported relying on God to influence decisions had more favorable attitudes toward life-sustaining treatment than those who were not as religiously inclined. Blackhall and colleagues (1995) found differences in religious denominational affiliates and ethnic groups in their attitudes toward the disclosure of diagnosis and prognosis as they related to terminal disease.

European-American Protestants were more likely than non-Protestants to believe that a patient should be told about a terminal prognosis (81% vs. 61%) and were more likely to believe that the patient should be the primary decision maker (73% vs. 59%). Jewish individuals were less likely than non-Jewish individuals to believe in telling the truth about the prognosis (52% vs. 75%). In the Korean-American group, Buddhists were less likely to believe that the patient should be told the prognosis (27% vs. 41%). In cases such as these, surrogate decision making would be augmented by the knowledge and understanding of the importance of religion in the lives of the older adult for whom the surrogate is requested to substitute judgment.

Central to the discussion of the values of older adults is whether or not values remain consistent in meaning and in use over time. Knowledge of the likelihood of stability will provide greater confidence in surrogate decisions that are based upon the fundamental values articulated by older adults earlier in life. Therefore, this study focused on the strength of values commitment to the decision-making process, the individual meanings that were ascribed to identified values, and the stability of values over time.

METHODOLOGY

A phenomenological approach was used to explore the personal meaning of values in the everyday lives of older adults (Polit & Beck 2004). Utilizing Van Manen's (1990) method of descriptive and interpretive phenomenology, the holistic approach supported viewing the text as a whole in order to capture its meaning. Selected themes were gleaned from the transcripts of each interview that allowed for an understanding of

values and healthcare preferences among the older adults. Data were collected at two interview points over a seven year period of time.

Sample

The original study sample consisted of 62 older adults living in Colorado (Roberto, 1999). Participants were recruited from three organizations in two counties: (a) Weld County Retired and Senior Volunteer Program, (b) McKee Medical Center in Larimar County, and (c) Larimer County Retired and Senior Volunteer Program. The participants ranged in age from 75 to 95 ($M=80.3$; $SD=4.3$). Forty-two women and 20 men participated in the study. The sample represented a 3:1 female to male ratio that reflected the general population of older adults over the age of 75 (U.S. Bureau of the Census, 1990). Ninety-five percent (59) of the older adults were Caucasian. Time 1 data were collected on this sample from 1995 to 1997.

At the end of the 2 year data collection period, 3 study participants had died leaving 59 potential participants for the 7-year follow-up interview (T2). An electronic search of death records revealed that 26 of the original participants had died since 1997. Nine participants could not be located. Of the 24 participants contacted, 2 individuals were unable to participate due to declining health and hospitalization and 1 person refused to participate; thus, the 2004 sample consisted of 21 older adults capable of making their own decisions. Sample differences were analyzed in order to determine if any significant variability was noted between individuals who participated in the study at T1 only and those who participated at both T1 and T2. No significant differences were noted in race, age, income, or educational level.

Procedures

The original interviews (T1) were conducted face-to-face in the participants' homes. The one year follow-up interview data were not analyzed in the current study as there were no changes in preferences and values from the initial interview (Roberto 1999). The seven-year interview (T2) was conducted via telephone and took approximately 30 to 45 minutes to complete. Participants at T2 were sent packets of information that included a cover letter and a copy of the data collection instrument to provide them the benefit of following along with the interviewer throughout the telephone conversation. However, only 5 of the 21 participants kept the packet and had it available during the interview.

Participants responded to the same series of hypothetical scenarios relating to common health care procedures and life-sustaining treatments at both T1 and T2. The health care procedures consisted of by-pass surgery, hip replacement, antibiotics for pneumonia, mastectomy/prostatectomy, and cataract surgery. Each procedure was presented under two different health states: current health and permanently confused. Each health state was also presented with three different prognoses: less than 50% chance of recovery, 50/50 chance of recovery, and greater than 50% chance of recovery. The life-sustaining treatment scenarios consisted of resuscitation for cardiac arrest, respirator for permanent inability to breathe on ones own, dialysis for kidney failure, tube feeding for permanent inability to eat, and chemotherapy for cancer. In these scenarios, the health states were current health or permanently confused; no prognoses percentages were given for the life-sustaining treatments. Participants were asked to respond to each scenario by indicating if they would or would not consent to

the various procedures or treatments. With each response, participants were asked to explain the reasons they would or would not consent to the procedure or treatment being discussed.

Measures

Demographic information was collected from each participant at T1 and T2 including age, sex, income, race, level of education, health perceptions, interference with ADLs, and possession of advance directives. Ten of the 12 scenarios presented in the *Preferences for Life-sustaining Treatment Questionnaire* (Cohen-Mansfield et al. 1991) were presented to study participants: cardiac bypass, hip replacement, mastectomy or prostatectomy, antibiotics for pneumonia, cataract removal, cardiopulmonary resuscitation, respirator for permanent inability to breathe, dialysis for kidney failure, tube feeding for permanent inability to eat and chemotherapy for cancer treatment. For each scenario, participants were instructed to consent or decline to the medical or life-sustaining treatments when in two states of health (current or permanently confused) and with three different prognoses (less than 50%, 50/50, or greater than 50% chance of recovery). Qualitative data were gathered to illustrate the meaning of the relationship between the preferences in each health care scenario and the rationale for the preferences. With each preference identified, participants were asked to elaborate on *why* they decided to accept or reject the treatment or procedure by using open-ended questions such as, "What is it about your _____ (e.g., religious beliefs, independence, quality of life, etc.) that helped you to choose (or not choose) _____ (e.g., bypass at 50/50%, etc.)?"

Data Analysis

At T1, a coding system was developed that identified the main criteria or values that were used in making each healthcare decision. At T2, each transcript was read and re-read by the interviewer (first author) to determine whether there were any new criteria or values identified in responses that had not been found at T2. No different criteria or values were identified at T2; therefore the original coding scheme was used for both T1 and T2 data. The transcripts from both interview intervals were independently reviewed by two coders. The codes were compared and any discrepancies between coders were resolved through discussion.

RESULTS

The demographic data from time 1 and time 2 are presented in Table 1. 1

Table 1.1

Demographic Information (N=21)

| Characteristics | Time 1 | Time 2 |
|-------------------------|------------|------------|
| Mean Age (SD) | 80.0 (4.3) | 88.3 (3.8) |
| Race. (%) | | |
| -White | 20 (95.2) | 20 (95.2) |
| -Native American | 1 (4.8) | 1 (4.8) |
| Income (%) | | |
| -\$700 or less | -- | 1 (4.8) |
| -\$701-\$1600 | -- | 7 (33.3) |
| -\$1601-\$2400 | -- | 5 (23.8) |
| -≥ \$2500 | -- | 5 (23.8) |
| -Missing Data | -- | 3 (14.3) |
| Living Arrangements (%) | | |
| -Own home/apartment | 21 (100) | 17 (81) |
| -Assisted living | 0 | 3 (14.3) |

| | | | | | | | | |
|----------------------|----|------|----|------|----|------|---|------|
| -Quality of Life | 2 | 9.5 | 2 | 9.5 | 1 | 4.7 | 1 | 4.7 |
| -Religious Beliefs | 0 | 0 | 0 | 0 | 1 | 4.7 | 2 | 9.5 |
| -Experiences of Self | 16 | 76.1 | 10 | 47.6 | 6 | 28.5 | 8 | 38.0 |
| -Age | 2 | 9.5 | 0 | 0 | 11 | 52.3 | 9 | 42.8 |

50/50Chance of Recovery

External

-Medical Influences

| | | | | | | | | |
|------------------------|----|------|----|------|---|------|----|------|
| -Physicians | 1 | 4.7 | 3 | 14.2 | 1 | 4.7 | 0 | 0 |
| -Medical Progress | 1 | 4.7 | 0 | 0 | 1 | 4.7 | 1 | 4.7 |
| -Invasiveness | 0 | 0 | 0 | 0 | 4 | 19.0 | 2 | 9.5 |
| -Prognosis | 16 | 76.1 | 16 | 76.1 | 8 | 38.0 | 11 | 52.3 |
| -Cost | 0 | 0 | 0 | 0 | 1 | 4.7 | 0 | 0 |
| -Experiences of Others | 3 | 14.2 | 1 | 4.7 | 3 | 14.2 | 1 | 4.7 |

Internal

| | | | | | | | | |
|----------------------|---|------|---|------|---|------|---|------|
| -Health Functioning | 7 | 33.3 | 2 | 9.5 | 4 | 19.0 | 3 | 14.2 |
| -Pain | 0 | 0 | 0 | 0 | 2 | 9.5 | 1 | 4.7 |
| -Burden | 0 | 0 | 0 | 0 | 1 | 4.7 | 0 | 0 |
| -Quality of Life | 2 | 9.5 | 3 | 14.2 | 1 | 4.7 | 1 | 4.7 |
| -Religious Beliefs | 0 | 0 | 1 | 4.7 | 1 | 4.7 | 1 | 4.7 |
| -Experiences of Self | 6 | 28.5 | 5 | 23.8 | 2 | 9.5 | 4 | 19.0 |
| -Age | 1 | 4.7 | 1 | 4.7 | 6 | 28.5 | 6 | 28.5 |

> 50% Chance of

Recovery

External

-Medical Influences

| | | | | | | | | |
|-------------------|----|------|----|------|---|------|---|------|
| -Physicians | 1 | 4.7 | 4 | 19.0 | 1 | 4.7 | 1 | 4.7 |
| -Medical Progress | 1 | 4.7 | 1 | 4.7 | 0 | 0 | 1 | 4.7 |
| -Invasiveness | 0 | 0 | 0 | 0 | 5 | 23.8 | 4 | 19.0 |
| -Prognosis | 20 | 95.2 | 12 | 57.1 | 5 | 23.8 | 2 | 9.0 |
| -Cost | 1 | 4.7 | 0 | 0 | 1 | 4.7 | 0 | 0 |

| | | | | | | | | |
|------------------------|----|------|---|------|----|------|---|------|
| -Experiences of Others | 2 | 9.5 | 1 | 4.7 | 2 | 9.0 | 1 | 4.7 |
| Internal | | | | | | | | |
| -Health Functioning | 8 | 38.0 | 4 | 19.0 | 3 | 14.2 | 0 | 0 |
| -Pain | 1 | 4.7 | 0 | 0 | 0 | 0 | 0 | 0 |
| -Burden | 0 | 0 | 0 | 0 | 1 | 4.7 | 0 | 0 |
| -Quality of Life | 1 | 4.7 | 2 | 9.5 | 1 | 4.7 | 0 | 0 |
| -Religious Beliefs | 1 | 4.7 | 1 | 4.7 | 0 | 0 | 1 | 4.7 |
| -Experiences of Self | 0 | 0 | 1 | 4.7 | 1 | 4.7 | 4 | 19.0 |
| -Age | 1 | 4.7 | 1 | 4.7 | 5 | 23.8 | 4 | 19.0 |
| Confused State | | | | | | | | |
| <50Chance of Recovery | | | | | | | | |
| External | | | | | | | | |
| -Medical Influences | | | | | | | | |
| -Physicians | 0 | 0 | 1 | 4.7 | 0 | 0 | 0 | 0 |
| -Medical Progress | 1 | 4.7 | 3 | 14.2 | 2 | 9.5 | 2 | 9.5 |
| -Invasiveness | 0 | 0 | 0 | 0 | 1 | 4.7 | 1 | 4.7 |
| -Prognosis | 4 | 19.0 | 3 | 14.2 | 2 | 9.5 | 1 | 4.7 |
| -Cost | 0 | 0 | 0 | 0 | 2 | 9.5 | 0 | 0 |
| -Experiences of Others | 0 | 0 | 1 | 4.7 | 1 | 4.7 | 0 | 0 |
| Internal | | | | | | | | |
| -Health Functioning | 11 | 52.3 | 5 | 23.8 | 1 | 4.7 | 0 | 0 |
| -Pain | 2 | 9.5 | 1 | 4.7 | 4 | 19.0 | 1 | 4.7 |
| -Burden | 0 | 0 | 0 | 0 | 2 | 9.5 | 2 | 9.5 |
| -Quality of Life | 0 | 0 | 0 | 0 | 3 | 14.2 | 2 | 9.5 |
| -Religious Beliefs | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 4.7 |
| -Experiences of Self | 1 | 4.7 | 0 | 0 | 2 | 9.5 | 1 | 4.7 |
| -Age | 0 | 0 | 0 | 0 | 3 | 14.2 | 4 | 19.0 |
| -Confusion | 0 | 0 | 0 | 0 | 12 | 57.1 | 8 | 38.0 |

50/50 Chance of
Recovery

External

| | | | | | | | | | |
|------------------------|----|------|---|------|----|------|---|------|---|
| -Medical Influences | | | | | | | | | |
| -Physicians | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| -Medical Progress | 0 | 0 | 1 | 4.7 | 0 | 0 | 0 | 0 | 0 |
| -Invasiveness | 0 | 0 | 0 | 0 | 1 | 4.7 | 1 | 4.7 | |
| -Prognosis | 11 | 52.3 | 2 | 9.5 | 2 | 9.5 | 1 | 4.7 | |
| -Cost | 0 | 0 | 0 | 0 | 2 | 9.5 | 0 | 0 | |
| -Experiences of Others | 1 | 4.7 | 0 | 0 | 1 | 4.7 | 0 | 0 | |
| Internal | | | | | | | | | |
| -Health Functioning | 4 | 19.0 | 6 | 28.5 | 1 | 4.7 | 0 | 0 | |
| -Pain | 0 | 0 | 0 | 0 | 4 | 19.0 | 1 | 4.7 | |
| -Burden | 0 | 0 | 0 | 0 | 2 | 9.5 | 2 | 9.5 | |
| -Quality of Life | 1 | 4.7 | 1 | 4.7 | 3 | 14.2 | 2 | 9.5 | |
| -Religious Beliefs | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 4.7 | |
| -Experiences of Self | 0 | 0 | 1 | 4.7 | 2 | 9.5 | 1 | 4.7 | |
| -Age | 0 | 0 | 0 | 0 | 3 | 14.2 | 4 | 19.0 | |
| -Confusion | 0 | 0 | 0 | 0 | 12 | 57.1 | 8 | 38.0 | |
| >50Chanceof Recovery | | | | | | | | | |
| External | | | | | | | | | |
| -Medical Influences | | | | | | | | | |
| -Physicians | 0 | 0 | 1 | 4.7 | 0 | 0 | 0 | 0 | |
| -Medical Progress | 1 | 4.7 | 1 | 4.7 | 0 | 0 | 0 | 0 | |
| -Invasiveness | 0 | 0 | 0 | 0 | 1 | 4.7 | 1 | 4.7 | |
| -Prognosis | 4 | 19.0 | 4 | 19.0 | 4 | 19.0 | 0 | 0 | |
| -Cost | 0 | 0 | 0 | 0 | 2 | 9.5 | 0 | 0 | |
| -Experiences of Others | 1 | 4.7 | 0 | 0 | 1 | 4.7 | 1 | 4.7 | |
| Internal | | | | | | | | | |
| -Health Functioning | 6 | 28.5 | 0 | 0 | 0 | 0 | 0 | 0 | |
| -Pain | 0 | 0 | 0 | 0 | 3 | 14.2 | 0 | 0 | |
| -Burden | 1 | 4.7 | 0 | 0 | 1 | 4.7 | 0 | 0 | |
| -Quality of Life | 2 | 9.5 | 1 | 4.7 | 0 | 0 | 0 | 0 | |
| -Religious Beliefs | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 4.7 | |

| | | | | | | | | |
|----------------------|---|---|---|---|---|------|---|------|
| -Experiences of Self | 0 | 0 | 0 | 0 | 1 | 4.7 | 0 | 0 |
| -Age | 0 | 0 | 0 | 0 | 1 | 4.7 | 2 | 9.5 |
| -Confusion | 0 | 0 | 0 | 0 | 8 | 38.0 | 8 | 38.0 |

Table 3
Reasons *Why* Older Adults Accepted or Refused Life Sustaining Treatments (N=21)

| Current Health Life Sustaining Treatments | Consent | | | | Not Consent | | | |
|---|---------|------|--------|------|-------------|------|--------|------|
| | Time 1 | | Time 2 | | Time 1 | | Time 2 | |
| | N | % | N | % | N | % | N | % |
| External | | | | | | | | |
| -Medical Influences | | | | | | | | |
| -Physicians | 0 | 0 | 1 | 4.7 | 0 | 0 | 0 | 0 |
| -Medical Progress | 1 | 4.7 | 1 | 4.7 | 0 | 0 | 0 | 0 |
| -Invasiveness | 0 | 0 | 0 | 0 | 8 | 38.0 | 1 | 4.7 |
| -Prognosis | 9 | 42.8 | 4 | 19.0 | 8 | 38.0 | 2 | 9.5 |
| -Cost | 1 | 4.7 | 0 | 0 | 3 | 14.2 | 1 | 4.7 |
| -Experiences of Others | 2 | 9.5 | 2 | 9.5 | 10 | 47.6 | 5 | 23.8 |
| Internal | | | | | | | | |
| -Health Functioning | 3 | 14.2 | 0 | 0 | 0 | 0 | 0 | 0 |
| -Pain | 0 | 0 | 0 | 0 | 3 | 14.2 | 4 | 19.0 |
| -Burden | 0 | 0 | 0 | 0 | 6 | 28.5 | 4 | 19.0 |
| -Quality of Life | 5 | 23.8 | 6 | 28.5 | 12 | 57.1 | 8 | 38.0 |
| -Religious Beliefs | 0 | 0 | 0 | 0 | 3 | 14.2 | 4 | 19.0 |
| -Experiences of Self | 1 | 4.7 | 0 | 0 | 0 | 0 | 0 | 0 |
| -Age | 0 | 0 | 0 | 0 | 6 | 28.5 | 5 | 23.8 |
| Permanent Confusion | | | | | | | | |
| Life Sustaining Treatments | | | | | | | | |
| External | | | | | | | | |
| -Medical Influences | | | | | | | | |
| -Physicians | 0 | 0 | 1 | 4.7 | 0 | 0 | 0 | 0 |

| | | | | | | | | |
|------------------------|---|-----|---|------|----|------|---|------|
| -Medical Progress | 0 | 0 | 1 | 4.7 | 0 | 0 | 0 | 0 |
| -Invasiveness | 0 | 0 | 0 | 0 | 3 | 14.2 | 1 | 4.7 |
| -Prognosis | 0 | 0 | 4 | 19.0 | 1 | 4.7 | 2 | 9.5 |
| -Cost | 0 | 0 | 0 | 0 | 1 | 4.7 | 1 | 4.7 |
| -Experiences of Others | 0 | 0 | 3 | 14.2 | 1 | 4.7 | 6 | 28.5 |
| Internal | | | | | | | | |
| -Health Functioning | 1 | 4.7 | 0 | 0 | 0 | 0 | 0 | 0 |
| -Pain | 0 | 0 | 0 | 0 | 3 | 14.2 | 4 | 19.0 |
| -Burden | 0 | 0 | 0 | 0 | 8 | 38.0 | 4 | 19.0 |
| -Quality of Life | 0 | 0 | 1 | 4.7 | 11 | 52.3 | 4 | 19.0 |
| -Religious Beliefs | 0 | 0 | 0 | 0 | 1 | 4.7 | 4 | 19.0 |
| -Experiences of Self | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| -Age | 0 | 0 | 0 | 0 | 7 | 33.3 | 5 | 23.8 |
| -Confusion | 0 | 0 | 0 | 0 | 11 | 52.3 | 9 | 42.8 |

External Factors

Among the values that influenced decision-making apart from the individual were those with medical emphasis and the awareness of past experiences of others. Medical factors such as influence from physicians, medical technology progress, degree of invasiveness, predicted prognosis or outcome, and cost of the treatment or procedure were identified as important to health care decisions.

By far, participants were influenced most by the prognosis that was assigned to each health care scenario both at T1 and T2, especially when in their current state of health. However, when the decision was to consent to various treatments or procedures, participants at T1 were more willing to rely on prognosis to affirm their decision, especially given a greater chance of recovery, than they were at T2. Similarly, more participants declined treatments, particularly when the chance of recovery

lessened, at T1 than T2. The importance of prognosis is illuminated by the assertion of one older woman who consented to cardiac bypass at both interviews by stating:

T1: (to bypass, >50%, at age 75) You bet! Well, it's possible that it would prolong my life and I could still enjoy it. I think that is reason enough!

T2: (to bypass, > 50%, at age 82) "Oh yes, I would. They work out good. They have a good success rate. Yes, I would just tell him (physician) that is was going to be. If there is hope at all, I would have it.

In contrast, a male participant declined all surgical procedures when prognosis was less than 50% chance of recovery at T1 and 50/50 or less at T2 when the scenarios were presented in current state of health, suggesting that it was more important to remain at his current level of health than to risk decline when prognosis was low. At T1 (age 79), he stated "yes, I would consent, if there was a 50/50 chance and if they guarantee me 50/50 because I would like to live. I like life, so 50/50 chance is pretty good." When asked the same questions at T2 (age 85), he responded "Well, if I had less than 50% chance, what's the use? Why go to all the expense and all that and the anguish of my family." (at 50/50) "Well, possibly, I would have to conference with the family before I made that decision, but I might try it for 50/50 chance."

Prognosis was also influential in decisions regarding life-sustaining treatments in one's current health at both T1 and T2, and seen more frequently at T1 than at T2. It became less influential when participants were informed that all decisions were being made for them as they were hypothetically in a permanently confused state of mind. However, participants at T1 were still more likely to refer to prognosis as important in their decision-making across prognosis than they were at T2.

The second most influential external factor to decision-making was an awareness of the treatment experiences of others. Positive and negative experiences of others

equally influenced the decisions made by the participants in their current state of health. Their responses were highly consistent at T1 and T2, particularly with regard to treatments with less than a 50% chance of recovery. The following are excerpts from the participant interviews that illustrate both the positive and negative impact that the experiences of others had upon their personal decisions:

I would say yes [to by-pass, <50%] to that. So many of my friends have had it and it has been successful. (female, age 85)

Can you put a zero there? See there's different types of chemo—they go aggressively and really...we lost a daughter and a granddaughter because they did that and it...chemo is what killed them. Their lungs were destroyed. And they used aggressive chemo. (male, age 83)

An almost non-existent effect was noted when participants were informed that they were in a permanently confused state or when deciding upon life-sustaining procedures.

Although the remaining external factors were less frequently identified as influential in decision-making, the explanations reflected strong opinions regarding the values. For example, when describing the effect of invasiveness of surgical procedures upon their decisions, two individuals replied: “Oh no [to respirator] that is just unnatural. I can't imagine living the rest of my life with that thing stuck down my throat. What kind of quality of life is that?” (female, age 87); and a 90-year-old gentleman emphatically stated, “At my age, I don't want any more surgeries. I don't think I would come out of it if I did. I would rather take my chances without ANY surgery.” Similarly, when speaking of the medical progress with non-surgical prostate treatments, a male

participant demonstrated the importance and relevance of medical information when he stated:

T1 (age 83): Well, I read that, you know at a certain age, you probably live just as long without the surgery. I think I would probably live a good long time, even if I did have cancer of the prostate. I do have prostate problems and I'm taking medications for it.

T2 (age 90): I'm not really sure at my age. I don't know...sometimes you can live quite a long time with prostate cancer. Why go through it? I'm going by what a doctor told me a couple of years ago.

Internal Factors

Eight factors were identified from the transcripts reflecting influences on decision-making at the individual level. These included health functioning, pain, burden on others, quality of life, religious beliefs, past experiences with the various treatments or procedures, age and confusion.

The most pervasive factor internal to the participants was health functioning which highlighted the importance of maintaining their current state of health when considering health care treatment options. Health functioning was also more frequently identified at T1 and most often when consenting to rather than when declining treatments, regardless of mental status. All participants indicated that continued health functioning influenced their willingness to consent to at least one medical treatment when in both states of health at T1. At T2, only 14 participants (67%) in their current state of health and 7 (33%) when in a permanently confused state agreed to medical treatments based upon maintaining health functioning. This finding is illustrated by the response of a female participant, age 85, who indicates her willingness to accept surgery both at T1 and T2 to maintain her health functioning: "Oh yes, I think I would consent [to a mastectomy < 50%]. You would have a chance to have a better life and

keep on living. As long as I'm physically able to think and move, why, that's all I care about." Health functioning became irrelevant to decision-making for the life-sustaining procedures at both interview times.

Past experiences of the participants was the second most influential internal factor affecting decision-making, although limited primarily to decisions made when in current health and if the prognosis was 50/50 or less. As would be expected, participants did not speak often of having any past experience with periods of confusion or with life-sustaining treatment.

Confusion was an influencing factor for eighteen individuals (86%) in deciding not to consent to medical treatment and fourteen individuals (67%) when declining life-sustaining treatments. As suggested by the responses of several of the participants, mental state (i.e., confusion) often was considered with age as they discussed their preferences for medical and life-sustaining treatments: "No to that one [mastectomy]. If I am confused, it's not going to do me much good. Well, it would be awful to try to help me through something like that." (female, age 87); "The fact that life is limited and with each year my satisfaction and freedom are slowly limiting. And at 86, I've had many good years, a wonderful family...what more could I want." [no to all life-sustaining treatments, female, age 83] "At 80 years old, I am not going to start making very many repairs! So NO to all of them!" [all medical procedures and life-sustaining treatments, female]

The remaining internal factors were discussed by several participants, but not to the degree that was suggested by the literature. Age become more frequently mentioned in T2, yet was not addressed by a majority of individuals. Similarly, burden

upon family members and quality of life were mentioned when discussing medical treatments in both their current state of health and when permanently confused, but each had a greater impact upon decision-making when discussing the life-sustaining procedures. For example, an 87-year-old woman reflects the beliefs of many of the participants when she stated:

You know, those kind of things [by-pass surgery] are so expensive and so worrisome for the family, because my husband went through all of that. That was just...oh dear, you didn't want him to die and yet we all knew he wasn't going to get any better and it was so hard to see him go through that. I wouldn't want to put my family through that again.

The responses of several individuals paralleled the following statements regarding the importance of quality of life, especially with life-sustaining treatments: "No! [to tube feeding] The quality of life would be gone and it's no use in prolonging life. I think you are meant to go at that stage." (male, age 83). "No to all of them! [life-sustaining, confused state] because if I was confused, the quality of life wouldn't be good. I would just be a burden to everybody." (female, age 94).

While relatively few participants cited religion as being influential in their decisions regarding medical or life-sustaining treatments, their responses were perhaps the most passionate and descriptive of all responses. The following are examples from the discussions with the participants who indicated that they would decline medical or life-sustaining treatments based upon their religious beliefs:

I don't believe in that. The good Lord put me in that position. He probably wants to talk to me up there. (male, age 83)

Put zeros in the whole column [life-sustaining, confused]...and that is the way I feel about that! I don't believe in all this life support—it's not natural. There's a reason for me to be there and the Man upstairs probably says, I'm ready. (male, age 90)

Well, I don't know. If I said no [by-pass at 50/50], that would be like saying I don't have any faith in God. No, I think I'd go ahead because I think the decision when I die should be God's, not mine. (female, age 83)

When participants were asked to rate the importance of religion in their lives, their responses revealed a great deal about themselves and the influence of religion on decision-making. Several individuals spoke of a life-long pattern of religious affiliation but stated that their faith had grown stronger with time and the various trials of their lives. The following statements illustrated the importance of religion and spirituality in the lives and decision making process of some of the respondents:

Well, I just don't see how people get along without believing. It seems like it would be nothing to look forward to. (female, age 89)

It influences everything I do actually, because, well, I think that I feel that we are here on a journey to our next life. So it's going to be affecting everything.

(female, age 82)

I don't know how to explain it but it gives me confidence, more confidence in things I do and better judgment in the things I do. (female, age 82).

I believe that God controls or has His eye on everything I do. I feel that He guides me even though sometimes it's not what I want but it's what He wants. I pray quite often and I do believe that God does help me through the rough times

and that if it doesn't seem like He is then I know it's His will, that what is happening is happening for a reason. So I depend a great deal on what God wants me to do and how He watches over me and I know He protects me.

(female, age 88)

DISCUSSION

The findings of this study suggest that the health care decision-making process is a complex interface between external and internal factors that clearly influence how older adults in late life make choices. Older adults do not simply choose one factor that guides their decisions but rather consider many as they attempt to sort through multifaceted medical decisions. The older adults made choices based upon a broad set of values, as well as indicating consideration for the effectiveness of a particular treatment. This approach reflects the basic propositions of the Normative-Affective model for decision-making (Etzioni, 1988). The older adults' decisions reflected the perceived effects of the hypothetical treatments or procedures on their personal lives and on their families, providing an interface between logic and emotion. Awareness and appreciation of the many influencing values of older adults in late life will enable families and health care providers to assume the decision-making responsibility appropriately when needed, especially when prior decisions and preferences are unknown.

The older adults' responses suggested moderate stability in the values selected early in the interview at both T1 and T2. When asked about underlying reasons for consenting or refusing to consent to various treatment options, the same values were operationalized in their preferences for medical and life-sustaining treatments. Collectively, of greatest importance to these older adults was their understanding of

prognosis for each scenario presented, their perceived personal quality of life with or without treatment, their ability to maintain their current health functioning, not being a burden to their families or society (physically or financially), and their religious values and beliefs.

Findings from this study supported the Normative-Affective Model for Decision-Making, demonstrating a strong link between emotion-laden values and preferences for health care treatments (Etzioni 1988). When the participants spoke of values, their tone of their voices reflected the depth of importance that each held for them personally and as well as the impact that each had on their families. Prognosis and personal cost (e.g., loss of independence, burden on others) were frequently discussed when declining various treatments or procedures. This was particularly true when prognosis was fair to low; the scenarios evaluated that way involved surgical procedures or life-sustaining treatments, especially when the given state of cognition was permanently confused. The responses were often an emphatic “no!” as the older adults proceeded to state that it would be illogical to consider such a treatment at their advancing age, that the care would be too much of a burden for their families, or that they would forgo treatment because the odds were not in favor of any improvement in their lives. Families can be encouraged if they realize that older adults operate from a framework of logic whereby they put thoughtful consideration into personal, family, and societal consequences of decisions that are made on their behalf.

Health functioning was also important to the older adults in this study. They desired to maintain as much normalcy as possible while being prudent with their health care decisions. This became apparent as they discussed their consent to or decline of

treatments based on prognosis. Tsevat and colleagues (1998) reported similar findings with regard to health values of older adults. In their study, hospitalized older adults, aged 80 to 98 years, preferred to continue to live as long as they could in their current state of health rather than to risk shorter but potentially healthier life. This suggests that within the old old cohort there continues to be a fairly strong will to live.

Because the older adults did not often refer to religious beliefs when asked to discuss rationales to the various health care preferences, one might conclude that, although they report that religious beliefs are very important, those beliefs are not operationalized through actual decisions. However, when viewing the interviews holistically (Van Manen, 1990), most of the responses reflect a tone of calm, resolve, peace, life satisfaction and free of fear of impending death. These attitudes are often described in the literature as being positively associated with religiosity and spirituality (Hoge, 1992; Koenig, 1994; O'Connell, 1994; Wolinsky & Stump, 1996) and may actually undergird other rationales and be indirectly inferred.

Collectively, no differences were noted in the values discussed or the tendency to accept or reject treatments or procedures based upon gender, age, socioeconomic status, or health status. Although this may have been due to the small sample size, it may represent a blurring of distinctions between the variables in very old adults that has not yet been explored to the fullest extent in research. Rosenfeld and colleagues (2000) found that age was a deterrent to end-of-life treatments by participants that represented the oldest-old (mean age 83 years), yet no differentiation was reported on other variables such as gender. Tsevat and colleagues also reported no gender or age differences in health values of older adults aged 80 to 98 years. Similarly, Bookwala

and colleagues found no significant gender or age differences among older adults (mean age of 73 years) and their preferences for end-of-life values such as religious beliefs, becoming a burden on family, pain at the end-of-life, or independence. However, they reported that older women were significantly more likely to prefer a dignified end to life than were older men. In each of the studies cited, small sample sizes were utilized to gather data. Consequently, further research is needed using larger, more heterogeneous samples to explore potential variability among older adults with respect to values and healthcare preferences. Such information will advance understanding of values and will be of considerable use in surrogate decision-making for incapacitated older adults in late life.

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Chapter 4

Discussion

The purpose of this study was to investigate the stability of health care preferences and values over seven years. It also was intended to explore the meanings of the values considered to influence the health care decisions of older adults. Although the study sample was small due to natural attrition, the findings have added to the understanding of healthcare decision-making of older adults. Three central issues are highlighted throughout the findings of the study. First, health care preferences of older adults remain stable over time. Second, value choices not only influence the health care preferences of older adults but also remain stable over time. Third, factors that influence health care decisions include both a consideration of factually presented or observed information as well as emotionally based influences.

Contrary to the literature (Danis, et al, 1994; Everhart & Pearlman, 1990; Gready, et al., 2000; Patrick, et al., 1997) where only moderate stability for up to 30-months was reported, the findings from this study suggests that health care preferences in older adults remain highly stable over a long period of time. When change occurred, older adults chose to decline rather than accept surgical treatments (e.g., hip surgery, cataract removal) at T2. These findings are important to surrogate decision-making for two distinct groups. Primarily, families and others who are involved in proxy decision-making can have confidence in advanced directives that have been completed by the older adults within the past seven years. Therefore, careful consideration of the directives can ensure that decisions are made accurately and according to the intended wishes of the older adult when they are least able to make decisions for themselves.

While decisions made on behalf of others is difficult at best, families can be relieved of the burden and guilt that often surrounds these decisions as they try to determine what is “best” for the older adult. Health care professionals also benefit from this understanding in that clinical care decisions can be made as the older adult desires, limiting the unwanted heroic and costly treatments or procedures.

Values stability was evident not only in the measured responses to the values inventory over time but also in the rich conversations illuminating why older adults decide to consent or decline various health care treatment options. Similar to the findings of Rokeach & Ball-Rokeach (1989), four of the top five values identified by the older adults were identical at T1 and T2. Equally as important is that when the older adults talked about how they arrive at the decisions made for each health care scenario, they consistently return to the fundamental values that had been identified earlier. Just as stability of health care preferences impacts the validity of long-standing advanced directives, the appreciation of the stability of values as influencing factors of decision-making is just as critical. In the absence of advance directives, or when families are engaged in disagreements with decisions that need to be made on behalf of an older adult, emphasis should be redirected toward conversations surrounding the life-long values held by their loved one. The known values can lend clarity to confusion and empower families to make informed decisions about treatments without every having discussed particular options with the older adults.

Findings from this study supported the Normative-Affective Model for Decision-Making by demonstrating a strong link between emotion-laden values and preferences for health care treatments (Etzioni, 1988). When specifically discussing values that

influenced decisions, the top five values that were consistently chosen were very personal, emotion-based values (e.g, quality of life, independence, dignity, religious beliefs and burden to family). When they spoke of the values, their tone of the participants voices reflected the depth of importance that each held for them personally and as well as the impact that each had on their families. When the participants were asked to explain further what each value meant to them as an instrument of decision-making, a tone of disbelief would resound as if to question why I would even need to ask about something that seemed to be so obvious to them. Etzioni (1988) notes, however, that decisions are not solely based upon emotion but rather a blending of emotion and fact. This was again apparent in the findings. Although few participants chose age, prognosis, or cost as top priority values, these were frequently discussed when declining various treatments or procedures. This was particularly true when prognosis was fair to low; the scenarios involved surgical procedures or involved life-sustaining treatments and especially when the given state of health was permanently confused. The responses were often an emphatic "No!" as the older adults proceeded to imply that it would be illogical to consider such a treatment at their advancing age, that these would cost too much money and add such a financial burden to the government and their families, or that they would forgo treatment because the odds were not in favor of any improvement in their lives. Families can be encouraged that older adults operate from a framework of logic whereby they put thoughtful consideration into personal, family and societal consequences of decisions that are made on their behalf. And yet, they are deeply concerned that their personal values are

respected and that they are able to be as autonomous and productive as possible until the end of their life.

Among the values that were considered to be very important to the older adults were their religious beliefs. The findings highlighted not only the importance of these beliefs in their everyday lives but as being instrumental in their health care decision-making process. Rich conversations were enjoyed with these participants as they described very personal beliefs and the meaning that these beliefs held for them. Several participants revealed that while they had always incorporated these beliefs into their lives, the dependency upon God and their faith had grown stronger as they grew older and faced varied challenges throughout. These findings support Koenig's (1994) Theory of Faith Development in that individuals who are able to integrate their faith into everyday events are able to experience new ways of living, reacting and interacting with other. Koenig (1994) proposes that this enables older adults to transcend negative life events, maintain a sense of meaning, hope and purpose even in the most dismal of circumstances and function at the highest level possible given the available resources. Interestingly, the older adults did not often refer to religious beliefs when asked to discuss rationales to the various health care preferences. Therefore, one might conclude that while they say that religious beliefs are very important, those beliefs are not operationalized through actual decisions. However, when viewing the interviews holistically (Van Manen, 1990), most of the responses reflects a tone of calm, resolve, peace, life satisfaction and free of fear of impending death. These attitudes are often described in the literature as being positively associated with religiosity and spirituality

(Hoge, 1992; Koenig, 1994; O'Connell, 1994; Wolinsky & Stump, 1996) and may actually under gird other rationales and be indirectly inferred.

Finally, from a methodological perspective the interviews were conducted in such a manner that participants were encouraged to relax and enjoy the process. Humor and personal anecdotes from the interviewer were interjected appropriately throughout the interview which added to the comfort level of the participants and their freedom to express their values and beliefs unencumbered. Whereas face to face interviews are most desirable, telephone interviews can be equally as rich and informative if the process is approached both professionally to safe guard against bias yet warmly and inviting to encourage depth in the discussions, especially with sensitive, personal topics. The older adults often expressed honor at being able to assist with the development of new knowledge through the research project.

Research and Implications

This study is among the first to examine explicit values underlying critical health care preferences as well as life-sustaining treatment and to determine the stability of those preferences over an extended period of time. Future studies need to examine more fully stability of health care preferences over time with larger, more representative samples of participants in order to fully appreciate the long-term validity of advance directives. Similarly, additional emphasis must be placed upon qualitative studies of values selection, meanings ascribed to values and how these are operationalized in active and passive health care decision-making of older adults.

The results of this and other research clearly demonstrates that older adults are willing and able to address critical health care decisions while they are ill (Leichtentritt &

Rettig, 1999; Pearlman, et al, 1993) and before decisions are required (Roberto, 1999). Therefore, it is imperative that health care professionals initiate such discussions between older adults and their families. Such an advance discussion will enable families to address important issues surrounding health care treatment options and consequences associated with the various choices. Furthermore, families can feel confident that the expressed wishes of the older adult have not only been heard but will assist in the trajectory of care when or if hospitalization is required.

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Appendix A
Expanded Literature Review

Expanded Literature Review

The following includes a discussion of the theoretical frameworks guiding the study: the normative-affective decision-making model and the religious faith development model. Discussion of empirical findings regarding the stability of health care decision-making and values over time will be highlighted.

Theoretical Frameworks

Normative-Affective Decision-Making Model

Early investigations of the decision-making process have heavily promoted analyses supportive of rational choice or logical-empirical methods of decision-making. These view the individual as antecedent to and independent of group influences, as being self-interested acting only out of rationality, and engaging in decision-making that is value-neutral (Zey, 1992). Critics of these propositions contend that they are counterintuitive to the reality of everyday life with the many multidimensional factors that drive even the most basic decision-making processes. By the late 1970s, scholars began placing greater emphasis on alternative propositions that suggested more deliberate recognition of affect and values as important influences on the decision-making process.

To date, the health care decision-making literature lacks a strong theoretical foundation relative to either the logic-laden or values-laden paradigms. Etzioni (1988) proposed a normative-affective model for decision-making that helps to explain the process by which older adults make critical health care decisions and the values that drive the process. He postulated that normative (values commitment) and affective (emotional) factors significantly shape decision making. These factors determine the

type of information that is gathered and processed, the inferences that are drawn, the options that are considered and the options that are finally chosen. Rather than being grounded in logical-factual-rational endeavors, cognition, inference and judgment are dominantly rooted in normative-affective (noncognitive) factors. Etzioni (1993) proposed that normative-affective factors determine the real-life sources from which individuals draw information, how they interpret what they see and what they think they should infer from what they have learned about any given situation. The normative-affective theory describes logical-empirical factors as playing a role in decision making but only within the framework of normative-affective factors.

The normative-affective model encompasses a continuum process which may include *exclusion* of the role of logical-empirical considerations whereby choices are made exclusively on normative-affective grounds; in other situations, by *infusion* of logical-empirical factors in a limited way to normative-affective factors; and in still other situations, normative-affective factors play a less significant role in the process referred to as *indifference zones*. Katona (1975) suggested that “there is hardly any knowledge lacking affective connotations” implying that no decision is made void of emotion. Likewise, historical findings of individuals across time and culture reflect that the *indifference zones* dominated by logical-empirical factors are utilized less in decision-making and that decisions made by *exclusion* of logical-empirical factors is most frequently utilized (Etzioni, 1988).

The current study focused on the strength of emotion and values commitment to the decision-making process. Although decisions may occur spontaneously at one point in time, most involve a process; a series of steps and required repeated steps

before a decision is considered final. However, the greater the influence of emotion on values and beliefs, the harder it is to influence an alternative perspective by argument, propaganda or an appeal to intelligence (Berelson & Steiner, 1964). Therefore the driving assumption of this theory is that while it would appear that individuals utilize normative-affective factors in a calculated fashion to influence decision-making, these factors are actually internalized and absorbed by individuals to shape their inner selves. Etzioni (1988) presumed that these factors would be modified by an individual and when the modification process was complete, the values, behavior, attitudes, and emotions shape what the individual believes, feels, prefers, and seeks. Therefore, when the decision-making process is tested over time, the normative-affective model suggests that the choice made would remain fairly consistent if driven by deeply embedded, life-long values and beliefs.

Normative values which are innate to all individuals, such as equality, justice, and freedom, contain an affective or emotional element (Etzioni, 1988). Within the context of this framework, the emotion or affect imparts the motivating force to values. Normative values are used to curb emotions or to legitimate them. Therefore, the emotion drives the decision-making process and the values serve to regulate the response. Abelson (1976) suggested that beliefs serve many functions separate from rationality. Among other things, values and beliefs may be comforting, may protect against anxiety, may organize vague feelings, may provide a sense of identity, and may be a prerequisite for participating in a cause. Further, Etzioni (1988) maintained that these normative values not only shape the means to an end but directly guide the goal set forth in the decision-making process.

Practical application of the principles of the Normative-Affective theory has been demonstrated in the medical community through the quest for a more standard approach to assessing the values that belie the decisions involved in the process of determining advanced directives. In 1988, a National Values History project was begun whereby a standardized questionnaire was developed for use by the medical community to assess the values articulated by individuals as they voiced their treatment preferences (Gibson, 1990). The document recognizes the importance of discussing wishes concerning specific medical procedures such as organ donation, dialysis, cardiopulmonary resuscitation, artificial respiration, nutrition, and hydration. Similarly, it serves as guide to assessing the individuals' attitudes and values toward health, health care providers, relationships, independence and control, as well as attitudes toward life, illness, death, religion, finances, and the living environment (Gibson, 1990). Conclusions drawn from the use of the tool validates the importance of prospective identification of health care decisions by the patient and concurrent discussion of those decisions with family members and physicians. By clarifying values prospectively, surrogates are able to make principled choices, with greater confidence, which reflect the incapacitated person's values and preferences (Doukas & McCullough, 1991). The significance of this type of assessment is that no formal or legal commitment to a particular medical treatment is made. Instead, importance is placed upon the validation of value themes that create a memory bank to be recalled by the surrogates during times of medical necessity (Lambert, Gibson & Nathanson, 1990).

Theory of Religious Faith Development

The Theory of Religious Faith Development proposed by Koenig (1994) suggests that the content of belief is what determines attitude and behavior, which in turn, influences the emotional state. It examines the growth and maturation of faith in adulthood, especially among elders with chronic health problems. Theory application must be made in light of a pre-existing religious faith history; therefore inference cannot apply to individuals without such a history.

Developmental models imply increasing maturity from an underdeveloped, juvenile condition to a fully mature, seasoned state. Determining where an individual falls on the continuum of religious faith is more difficult to ascertain. Spiritual development points to self-transcendence, self-actualization and one's existential search for meaning, but most importantly, to the phenomenological experience of relationship (Eliason, 2000). Factors such as genetics, environment, culture and interpersonal influences make standardization of faith development difficult. Koenig (1994) cautioned scholars to recognize that members of varying religious traditions frequently express religious faith differently. Failure to recognize the value of different perspectives and faith expressions can lead to inappropriate judgment about a person's level of faith.

Koenig's theory specified stages of development from early childhood through adulthood and later life. A brief description of the early stages will follow with greater emphasis being placed upon stage five-adulthood and later life. The initial step in faith development is the recognition and belief in a high power—God. There becomes a transitional period whereby the individual begins to develop a personal, trusting

relationship in God which can wax and wane in the quality and intensity of commitment throughout the lifespan. However, as faith matures, greater stability in that personal relationship and dependency becomes evident. Individuals will often speak of nurturing the personal relationship with God through private prayer, scripture reading, public worship and other forms of devotion (Koenig, 1994).

Mature faith evolves into a trust and dependency upon God that determines how one thinks and acts toward oneself and others in daily life. At this phase of faith development, individuals may or may not be able to continue in the active participation of religion (i.e., church attendance) yet rely upon intrinsic or internal religiosity where their beliefs and commitments become motivating factors in their lives (Koenig, Hays, Larson, George, Cohen, McCullough, et al, 1999). Koenig (1994) suggested that “when religious motivations take on an intrinsic quality, mature adult faith becomes possible.” Older adults have spent many years exploring the riches of their religious tradition, witnessing the impact of belief on the decisions of relatives and friends, and internalizing the spiritual wisdom of the religious community. They have usually come to appreciate religion as a constant source of comfort and internal meaning, rather than an external force that may be invoked in times of panic or pain (O’Connell, 1994). This attitude enables a person to transcend negative life events, maintain a sense of meaning, hope, and purpose even in the most dismal of circumstances and function at the highest level possible given the available resources (Koenig, 1994). Koenig proposed further that “religious faith of this type seldom develops in the absence of hardship or suffering, and requires the personal experience of having one’s faith successfully carry one through a difficult time.” This level of faith, driven by adversity,

can be experienced at any age, however, it is often most apparent later in life when losses become more commonplace.

Stability in Religiosity

Few researchers have examined the religious experience and the change across the lifespan. Studies that have been done have focused on the practice of religion and less on the intrinsic nature of the meaning of religion across the lifespan. For example, several researchers suggest that church attendance declines after the age of 70 as functional disabilities prevent active participation. Therefore, Koenig and colleagues (1988) postulated that with the decline in church attendance, there is an increase in frequency and importance of prayer and other intrinsic religious activity, particularly evident among individuals with poor health states. Individuals who integrate their faith are able to experience new ways of living, reacting and interacting with others. Repeated experience of successful resolution of problems through the reliance on God strengthens and matures faith expression. "A first-hand experience of God, a desire to serve him, an integration of faith into other areas of life, a relationship with God that provides direction and guidance—these are the elements of mature faith" (Koenig, 1994, p. 132).

Utilizing the *Intrinsic Religious Motivation Scale* developed by Dean Hoge (1972), Koenig and colleagues have linked intrinsic religious motivation with religious coping. Findings from several studies using the *Intrinsic Religious Motivation Scale* and the *Religious Coping Index* (Koenig, 1988) indicate very strong correlations among items (Koenig, Kvale, & Ferrel, 1988; Koenig, George & Siegler, 1988; Koenig, Moberg, & Kvale, 1988). Among the ten most highly valid items of the intrinsic religious motivation

scale are three that relate to decision-making: a) one should seek God's guidance when making every important decision; b) I try hard to carry my religion over into all my other dealings in my life and c) my religious beliefs are what really lie behind my whole approach to life (Hoge, 1972). Thorson and Powell (1991) distinguished between extrinsic religiosity and intrinsic religiosity in their study conducted with adults aged 18 to 88. Respondents who were older had higher scores of intrinsic religiosity as well as lower scores for death anxiety. However, in a study of 1138 Israeli elders, Carmel and Mutran (1997) found that religiosity positively affected attitudes toward the dying process and willingness to accept life-sustaining treatments, but negatively affected attitudes toward actual death within the orthodox Jewish community. These findings support Koenigs' (1994) caution that one must not generalize the effects of religiosity without knowledge of the religious tradition of the individual.

Koenig and colleagues (1988) surveyed 106 older adults to examine the influence of religious beliefs, activities and commitment on their lives. In response to the statement, "My religious faith is the *most important* influence in my life." the majority of respondents stated that it was definitely true (55%) or tended to be true (27%). Similarly, most participants definitely agreed to (66%) or tended to agree (20%) with the statement, "One should seek God's guidance when making every important decision." Overall the majority of the older adults' responses are similarly one-sided, which underscores the depth of their commitment to their religious beliefs.

In a study of 542 hospitalized older adults, Koenig (1998) found that over half of the sample (53.4%) reported attending religious services once a week or more; 58.7% prayed or read scriptures at least daily; over 85% held intrinsic religious attitudes and

over 40% spontaneously reported that their religious faith was the most important factor in their coping with medical illness. Almost 90% of the sample indicated that religious faith involved all aspects of their lives and that God's guidance was sought in making every important decision, including decisions affecting their health and the use of health related services. O'Connell (1994) suggested that religious coping adds perspective and moral resources as older adults struggle with health-related decisions, whether they involve refusing medical treatment, withdrawing life-support systems, coping with a disabling illness, choosing to move to a nursing home or even something as simple as refusing expensive brand-name drugs in favor of less expensive, generic drugs because of a religiously inspired sense of justice.

Similarly, Bookwala and colleagues (2001) surveyed 101 older adults about their preferences for life-sustaining treatments and values that were important to their decisions about medical treatments that they wanted to receive. Over 50% of those surveyed reported that their religious beliefs were an important factor in their decisions about preferred medical treatments. Wolinsky and Stump (1996) reported that subjective religiosity and religious belief variables (life after death) contributed to a sense of control among older adults. Older adults gave "religion" as a reason for the decline of CPR as a therapy option. Respondents offered reasons such as "God should decide" or "When my time's come, its come" as they declined CPR as an option.

In a study of 133 cognitively alert nursing home residents, Ejaz (2000) utilized Berrenberg's *Belief in Personal Control Scale* to explore personal and religious attitudes that influenced decisions toward life-sustaining treatments. Residents who relied on God to influence decisions, in general, had more favorable attitudes toward life-

sustaining treatments than those who were not as religiously inclined. Ejaz proposes that perhaps such individuals rely on God to make the final decision for the while opting to everything on their own power to preserve life (Ejaz, 2000).

Finally, Cicirelli (1997) surveyed 388 older adults to determine the effects of psychosocial and background variables on attitudes toward end of life decisions. He found that higher subjective religiosity scores were related to lower end of life scores and higher maintain life scores. Significant correlations were found religiosity, ethnicity and socioeconomic status. Those who favored maintaining life not matter how dire the circumstances tended to be Black, to be of lower socioeconomic status, and to have greater subjective religiosity. Those who favored ending their lives tended to be White, to have higher socioeconomic status and to have less subjective religiosity. Cicirelli suggested that individuals may not be basing their decisions solely upon rational consequences of the decision but rather upon well-established basic values and other characteristics (e.g. socioeconomic status and religiosity) (Cicirelli, 1997).

In the few studies that specifically address the role of religion in the decision making process of older adults, researchers report that relying on God to influence decisions and having an affiliation with a particular religious denomination differentiates between older adult who agree and who do not agree to life-sustaining treatment options. For example, Ejaz (2000), found that nursing home residents who report relying on God to influence decisions had more favorable attitudes toward life sustaining treatment than those who were not as religiously inclined. Blackhall and colleagues (1995) found differences in religious denominational affiliates and ethnic groups in their attitudes toward the disclosure of diagnosis and prognosis as they relate to terminal

disease. European-American Protestants were more likely than non-Protestants to believe that a patient should be told about a terminal prognosis (81% vs. 61%) and were more likely to believe that the patient should be the primary decision maker (73% vs. 59%). Jewish individuals were less likely than non-Jewish individuals to believe in telling the truth about the prognosis (52% vs. 75%). In the Korean-American group, Buddhists were less likely to believe that the patient should be told the prognosis (27% vs. 41%). In cases such as these, surrogate decision making would be augmented by the knowledge and understanding of the importance of religion in the lives of the older adult for whom they are requested to substitute judgment. Decisions which are made void of the religious context that enabled the older adult to formulate past decisions may not accurately reflect the wishes of the older adult in the long run.

Stability of Decisions and Values Over Time

Health Decisions. Critical to the discussion of advanced directives, surrogate decision-making and personal decision-making is the concept of stability. The few studies published to date suggest that there is at least a moderately high stability rate among older adults within periods of 6 to 30 months and in several instances, actually improved stability with repeated interviews (Danis, Garrett, Harris & Patrick, 1994; Emanuel, Emanuel, Stoeckle, Hummel & Barry, 1994; Everhart & Pearlman, 1990; Houts, Smucker, Jacobson, Ditto & Danks, 2002; Lockhart, Ditto, Danks, Coppola, & Smucker, 2001; Patrick, Pearlman, Starks, Cain, Cole & Uhlmann, 1997).

It is the link between the initial decision and decisions rendered over time that provides confidence in the identified treatment choices of the older adult when proxy decision-making is warranted. This is of particular importance when the values and

beliefs of the older adult is unknown to those making the proxy decisions. Findings from previous studies suggest that there is at least moderate stability in treatment preferences over time even when illness is taken into consideration. For example, Everhart and Pearlman (1990) interviewed 30 intensive care patients regarding preferences toward life-sustaining treatments. Patients were interviewed while in the hospital and one month later. When asked to respond to preferences toward resuscitation, resuscitation with mechanical ventilation, hydration/nutrition in current state of health or with stroke or dementia, 65 to 85% of the time the choice remained stable at the second interview. Despite significant, often improved changes in health status and mood, the treatment preferences remained stable over a short period of time suggesting that treatment preferences made during periods of serious illness are reliable and useful in proxy decision-making.

In two later studies utilizing larger samples, similar findings resulted over a period of two years. Emanuel and colleagues (1994) interviewed 495 HIV and oncology outpatients and 102 members of the general public with regard to life-sustaining treatment preferences. The sample was re-interviewed at 12 months and 24 months. Ninety-three percent of the patients' interviewed a third time at 24 months consistently responded to the interview questions 85% to 100% of the time. Among the patients interviewed, stability improved with repeated interviewing. Similarly, patients who discussed the life-sustaining treatment preferences with their physicians showed greater improvement in the stability of preferences than any group. Lastly, participants with recent hospitalizations also maintained stability in their treatment preferences indicating that recent illness did not affect their pre-determined choices. Using a much larger

sample of adults (N=2,536), Danis and colleagues (1994) found that 85% of their sample that had chosen to forgo life-sustaining treatments did not change their preference two years later. Of those desiring life-sustaining treatments, only 18% to 43% answered “yes” to the same question at the two year follow-up interview indicating low to moderate stability of preferences. Several health measures were associated with stability of choice. Patients with a living will were less likely to change their preferences (14%) than those without (41%). Individuals were also more likely to want increased treatment at the second interview if they had recently experienced hospitalization, an accident, become more immobile or depressed or had less social support.

More recently, Lockhart and colleagues (2001) found that quality of life and life or death judgments were only moderately stable over a sixteen-month period of time. When presented with the most severe condition of coma, 88% of the sample made the same judgments at both interviews. Similarly, in the least severe condition, deafness, 90% of the participants had concurrent choices at both interviews. However, for the remaining five conditions representing more moderate disability (cognitive ability, communication, pain, confinement to bed, blindness), an average of 69% stability was reached. Participants who did not have a living will, did not have children, had lower perceived quality of life at follow-up interview, and had longer time between interviews had more unstable judgments (Lockhart, et al, 2001).

Finally, and perhaps most intriguing, Houts and colleagues (2002) conducted a unique longitudinal study of 400 older adults and their surrogates investigating stability and predictability of life-sustaining treatment preferences. The study was conducted over the course of two years whereby participants were interviewed at baseline and

again at 1 and 2 years later. An initial life-sustaining treatment preference model was utilized whereby fourteen scenarios were given to the older adult participants to choose between various life-sustaining treatment options. The scenarios were presented in the exact form at year one and again at year two. The preferences were predicted accurately at 0.77 after 1 year and at 0.79 after two years indicating significant stability of preferences over time. When compared to the surrogate responses, the stability of preferences for the older adults was significantly higher than for the surrogates making concurrent predictions after both year one and year two. After baseline administration, the preference scenarios were modified, eliminating scenarios where there was less than 50% agreement across the sample. Through the refinement of the preference tool, accuracies in prediction were increasingly significant with the older adult sample to a level of 0.81 and the surrogates at a level of 0.75. The authors concluded that preference models are useful to patients, surrogates and physicians when trying to discern life-sustaining treatment preferences, but must be updated periodically to ensure accuracy and reflect current medical treatment trends.

In sum, each of the studies reviewed suggest that decision-making stability is high to moderate for time periods of up to two years. It would also appear that higher stability is attained with decisions involving the most severe and least severe scenarios presented. Questions remain as to how long surrogates and health professionals can confidently rely on advanced directives to accurately predict decisions made on behalf of incapacitated older adults.

Values. . Rokeach and Ball-Rokeach (1989) obtained national data from the National Opinion Research Center ranking 18 values. Over a period of 13 years, adult

participants were asked to rank order the values at 4 different survey points: 1968, 1971, 1974, and 1981. The results were described highly stable with the top six and the bottom six values receiving identical priority rankings across the thirteen years. While the middle six values varied in rank order, they also remained in the middle zone of the results without exception. The implication that is critical to decision-making is that surrogates who are familiar with the operative value system of the older adult will have a better foundation from which to make decisions when the need arises especially in the absence of advanced directives.

Similarly, Atchley (1997) reported the subjective value of religious importance and its effects upon health and morale over a fourteen year period of time. The sample included 1,106 adults, aged 50 years and older, who were surveyed 6 times over the course of 14 years beginning in 1977 and ending in 1991. When asked to rate the importance of being a religious person, 65.5% of the 559 respondents who completed at least three surveys consistently reported that being a religious person was important or very important. Similarly, 16.1% of the participants consistently rated that being a religious person was unimportant or very unimportant. Thus, 81.6% of respondents showed continuity in their ratings over time with almost two-thirds rating being religious as important, which supports the general findings of the literature.

Appendix B

Cover Letter to Participants

June 7, 2004

Mrs. M. H.
2100 Happy Street
Quickstep, Colorado 00000

Dear Mrs. H.:

My name is Vicki Martin. I am a graduate student at Virginia Polytechnic Institute and State University. My colleague at the University of Northern Colorado, interviewed you several years ago about your preferences for health care treatments.

I am writing to invite you to help me with the next phase of the project. I would like to talk with you by telephone about your current health care preferences. The interview should take approximately 30 minutes. Enclosed is a packet of information that will assist us during the interview. As a small token of appreciation for assisting me with this project, you will receive a \$5.00 Wal-Mart Gift Card upon completion of the interview.

As a nurse who is pursuing a graduate degree, I greatly appreciate your help and look forward to talking with you in the next week or two.

Cordially,

Vicki C. Martin

Appendix C

Telephone Transcript for Permission to Participant in the Study

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY**Informed Consent for Participants of Investigative Projects
(Telephone Interview Script – Client)**

Title of Project: **Exploring Health Care Decision-Making of Older Adults: Consistency and Clarification of Responses Over Time**

Investigators: Vicki C. Martin, RN, MSN, PhD-C and Karen A. Roberto, Ph.D.

Script for Telephone Survey**I. Purpose of this Research**

Hello, I am Vicki Martin from the Center for Gerontology at Virginia Tech. I am calling about a letter that I sent to you a week or so ago asking for your permission to interview you about your current health care preferences. I am required to give you information about the study so you can decide whether to participate.

II. Procedures

If you agree, I will ask you questions over the phone. That will take about 30 minutes.

III. Risks

There are no foreseen risks to participating in this project.

IV. Benefits

The information you provide will help health care providers better understand health care preferences of older adults and what helps them make those decisions about health care preferences. It will also help teachers and researchers in gerontology. I am not promising any other benefits, but if you would like a summary of the findings, I can send you a copy at the end of the study.

V. Extent of Anonymity and Confidentiality

Your answers are completely confidential. Your responses will be identified only by a code number, not by your name. Your name will never be associated with comments you make. Most of the information will be combined with answers given by others in the study. Only the people working on the project will see your particular answers.

I will tape-record the telephone interview. The tapes will be identified only by code number. They will be stored in a locked cabinet at the Center for Gerontology at Virginia Tech. Only those working on this project will have access to the tapes. After we finish reviewing the data, the audiotapes will be destroyed.

VI. Compensation

I appreciate your help very much and will send you a \$5.00 Walmart Gift card as a token of appreciation for you time.

VII. Freedom to Withdraw

You do not need to answer a question if it makes you feel uncomfortable and you may end the phone call if you do not wish to continue.

VIII. Approval of Research

This research project has been approved, as required, by the Institutional Review Board for Research Involving Human Subjects at Virginia Polytechnic Institute and State University.

IX. Subject's Responsibilities

To summarize, we are asking you to spend about 30 minutes answering questions about your current health care preferences. Do you have any questions?

X. Subject's Permission

Do you agree to participate voluntarily? _____ Yes _____ No

_____ I certify that I have explained the study to this participant, answered any questions, and obtained permission to proceed with the interview.

_____ I certify that I have explained the study to this person, answered any questions, and politely terminated the telephone call when the person declined to participate.

Participant Code Number: _____

Interviewer Signature: _____ Date: _____

Vicki C. Martin, RN, MSN
5749 Houndschase Lane
Harrisonburg, VA 22801
540-433-6196
martinvc@jmu.edu

Dr. Karen A. Roberto
Professor & Director, Center for Gerontology
237 Wallace Hall (0426)
Virginia Polytechnic Institute and State University
Blacksburg, VA 24061
540-231-7657 (phone)

Appendix D
Interview Instrument

MAKING HEALTH CARE DECISIONS

Please remember that all the information you provide will be held in strict confidence. There is no right or wrong answers to any of the questions. Just give the answer that is right for you.

1. How would you rate your overall health at the present time?

- | | |
|----------------------------------|---------------------------------------|
| <input type="checkbox"/> 1. Poor | <input type="checkbox"/> 3. Good |
| <input type="checkbox"/> 2. Fair | <input type="checkbox"/> 4. Excellent |

2. At the present time, is your health better, about the same, or worse than it was 6 years ago?

1. Worse 2. About the same 3. Better

3. How much do your health problems stand in the way of your doing the things you want to do?

1. Not at all 2. A little 3. A great deal

4. Do you have any of the following conditions at the present time?

- | | | |
|-------------------------|-----------------------------|------------------------------|
| 1. Arthritis | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| 2. Osteoporosis | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| 3. High Blood Pressure | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| 4. Heart Problems | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| 5. Circulation Problems | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| 6. Respiratory Problems | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| 7. Digestive Problems | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| 8. Chronic Pain | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| 9. Diabetes | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| 10. Hearing Problems | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| 11. Eyesight Problems | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| 12. Other | <input type="checkbox"/> No | <input type="checkbox"/> Yes |

5. Where do you live?
- a. Own home or apartment _____
 - b. In the home of a family member or friend _____
 - c. Assisted Living Facility
(includes congregate housing) _____
 - d. Nursing Home _____
 - e. Other (explain) _____
6. Do you have any of the following?
- a. Living Will _____ No _____ Yes
 - b. Medical Durable Power
of Attorney _____ No _____ Yes
 - c. CardioPulmonary Resuscitation
(CPR) Directive _____ No _____ Yes
 - d. Other similar written documents _____ No _____ Yes
Describe:
7. Who have you asked to make healthcare related decisions for you if you become unable to make those decisions on your own?

| | |
|------------|--------------|
| First Name | Relationship |
|------------|--------------|

Now I am going to ask you some questions about how you feel about yourself. During the last month,....

| Question | Yes | No |
|--|-----|----|
| 1. Have you been bothered by things that usually don't bother you? | | |
| 2. Have you not feel like eating or felt like your appetite was unusually poor? | | |
| 3. Have you felt that you could not shake off the blues even with the help of your family and friends? | | |
| 4. Have you felt that you were just as good as other people? | | |
| 5. Have you had trouble keeping your mind on what you were doing? | | |
| 6. Have you felt depressed? | | |
| 7. Have you felt that everything you did was an effort? | | |
| 8. Have you felt hopeful about the future? | | |
| 9. Have you thought that your life had been a failure? | | |
| 10. Have you felt tearful? | | |
| 11. Has your sleep been restless? | | |
| 12. Have you been happy? | | |
| 13. Have you talked less than usual? | | |
| 14. Have you felt lonely? | | |
| 15. Have you felt that people were unfriendly? | | |
| 16. Have you enjoyed life? | | |
| 17. Have you had crying spells? | | |
| 18. Have you felt sad? | | |
| 19. Have you felt that people disliked you? | | |
| 20. Have you felt that you could not get "going?" | | |

1. Are you presently:
- | | |
|------------------------|-----------------------------|
| _____ 1. Never married | _____ 3. Widowed |
| _____ 2. Married | _____ 4. Divorced/separated |

2. What was your age at your last birthday? _____ years
3. Please tell me which category best describes your present gross **monthly** income?
- | | | | |
|---------|----------------|---------|-----------------|
| _____1. | \$700 or less | _____3. | \$1601 - \$2499 |
| _____2. | \$701 - \$1600 | _____4. | \$2500 + |
4. What role does spirituality (religion, faith, or beliefs in a higher being) play in your life? Of the following, please tell me which response best indicates the importance of spirituality in your life.

| | | |
|-----------------------------|--------------------------|---------------------------|
| 0 | 1 | 2 |
| Plays no part in my life | Is somewhat important | Is extremely important |

- b. If the participant indicates 1 or 2, then...
- How does (spirituality, religion, faith in a higher being) help you make decision of everyday life?

How does (spirituality, religion, faith in a higher being) help you make important decision about your health care?

Please look at the green sheet that was sent to you with your letter. Below is a list of items that some people have said are important to them when they make decisions in their life.

Look at these and then tell me the five most important items that help you make important decisions regarding you health care.

- _____ 1. Independence
- _____ 2. Personal burden to self or others
- _____ 3. Amount of resources used in relations to the benefit received
- _____ 4. Pleasures of life, such as social activities, appearance
- _____ 5. Religious beliefs (i.e., belief in afterlife, faith, God)
- _____ 6. Comfort - pain and suffering
- _____ 7. Life at any cost
- _____ 8. Quality of life
- _____ 9. Hope
- _____ 10. Quantity of life
- _____ 11. Self image
- _____ 12. Choices
- _____ 13. Support (i.e., how much is needed/available)
- _____ 14. Goals in my life
- _____ 15. Age
- _____ 16. Dependency for self-care
- _____ 17. Family wishes
- _____ 18. Control
- _____ 19. Outcomes-prognosis
- _____ 20. Dignity
- _____ 21. Fear
- _____ 22. Peace
- _____ 23. Status of my living arrangement
- _____ 24. Other

I am going to ask you about the choices you think you would about health care treatments, depending upon your state of health and chance of recovery. I will also ask you to tell me *why* you decided to accept or refuse the treatments.

Today, in your **Current State of Health** (physical and mental), would you consent to any of the following treatments/procedures if your doctor told you that your chance for recovery was **less than 50%**?

| <u>Treatments</u> | YES | NO |
|-----------------------------|------------|-----------|
| By-Pass Surgery | | |
| Hip Replacement | | |
| Mastectomy/Prostate Removal | | |
| Cataract Surgery | | |
| Antibiotics for Pneumonia | | |

Today, in your **Current State of Health** (physical and mental), would you consent to any of the following treatments/procedures if your doctor told you that your chance for recovery was **50/50**?

| <u>Treatments</u> | YES | NO |
|--------------------------|------------|-----------|
| By-Pass Surgery | | |
| Hip Replacement | | |
| | | |

| | | |
|-----------------------------|--|--|
| Mastectomy/Prostate Removal | | |
| Cataract Surgery | | |
| Antibiotics for Pneumonia | | |

Today, in your **Current State of Health** (physical and mental), would you consent to any of the following treatments/procedures if your doctor told you that your chance for recovery was **greater than 50%**?

| <u>Treatments</u> | YES | NO |
|-----------------------------|------------|-----------|
| By-Pass Surgery | | |
| Hip Replacement | | |
| Mastectomy/Prostate Removal | | |
| Cataract Surgery | | |
| Antibiotics for Pneumonia | | |

WHY did you answer yes or no to the above questions?

If you were **Permanently Confused** (not going to get better and may get worse) and were not able to make health care decisions for yourself, would you want your family members' to consent to any of the following treatments or procedures if your chance of recovery was **less than 50%**?

| <u>Treatments</u> | YES | NO |
|-----------------------------|-----|----|
| By-Pass Surgery | | |
| Hip Replacement | | |
| Mastectomy/Prostate Removal | | |
| Cataract Surgery | | |
| Antibiotics for Pneumonia | | |

If you were **Permanently Confused** (not going to get better and may get worse) and were not able to make health care decisions for yourself, would you want your family members' to consent to any of the following treatments or procedures if your chance of recovery was **50/50**?

| <u>Treatments</u> | YES | NO |
|-----------------------------|-----|----|
| By-Pass Surgery | | |
| Hip Replacement | | |
| Mastectomy/Prostate Removal | | |
| Cataract Surgery | | |

| | | |
|---------------------------|--|--|
| Antibiotics for Pneumonia | | |
|---------------------------|--|--|

If you were **Permanently Confused** (not going to get better and may get worse) and were not able to make health care decisions for yourself, would you want your family members' to consent to any of the following treatments or procedures if your chance of recovery was **greater than 50%**?

| <u>Treatments</u> | YES | NO |
|-----------------------------|-----|----|
| By-Pass Surgery | | |
| Hip Replacement | | |
| Mastectomy/Prostate Removal | | |
| Cataract Surgery | | |
| Antibiotics for Pneumonia | | |

WHY did you answer yes or no to the above questions?

Today, in your **Current State of Health** (physical and mental), would you consent to any of the following treatments/procedures?

| <u>Life-Sustaining Treatment</u> | YES | NO |
|---|-----|----|
| If your heart stopped, would you want to be resuscitated with CPR? | | |
| If you became permanently unable to breathe on your own, would you want to be placed on a breathing machine (respirator or ventilator)? | | |
| If your kidneys failed, would you want kidney dialysis? | | |
| If you were permanently unable to be fed by mouth, would you want to be fed by a tube? | | |
| If you got cancer, would you want to be treated with chemotherapy | | |

WHY did you answer yes or no to the above questions?

If you were **Permanently Confused** (not going to get better and may get worse) and were not able to make health care decisions for yourself, would you want your family members' to consent to any of the following treatments or procedures?

| <u>Life-Sustaining Treatment</u> | YES | NO |
|---|-----|----|
| If your heart stopped, would you want to be resuscitated with CPR? | | |
| If you became permanently unable to breathe on your own, would you want to be placed on a breathing machine (respirator or ventilator)? | | |
| If your kidneys failed, would you want kidney dialysis? | | |
| If you were permanently unable to be fed by mouth, would you want to be fed by a tube? | | |
| If you got cancer, would you want to be treated with chemotherapy | | |

WHY did you answer yes or no to the above questions?

Appendix E
Journal Guidelines



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Journal of Family Nursing

Editor:
Janice M. Bell University of Calgary

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Submission Manuscript Guidelines:
Peer-reviewed, the Journal of Family Nursing publishes scholarly work on nursing research, practice, education and policy issues related to families in health and illness. Appropriate articles of empirical and theoretical analyses on the subject of family health are also considered. Papers are selected for their scientific merit and creative treatment of significant issues in the field. Both family-as-context and family-as-unit are represented. The Journal of Family Nursing recognizes a strong mandate to represent cultural diversity and families across the life cycle and encourages interdisciplinary contributions. An objective of the journal is to establish a forum in which practitioners, educators and researchers in various clinical specialties and settings can extend the lively debate and begin a more critical dialogue about the family in health and illness. Submit five copies of your 15-20 page manuscript, prepared according to the guidelines in the 4th edition of the Publication Manual of the American Psychological Association, entirely double-spaced, with all art camera-ready. A copy of the final revised manuscript saved on an IBM-compatible disk should be included with the final revised hard copy. Submission to JFN implies that the manuscript has not been published elsewhere, nor is it under consideration by another journal. Manuscripts should be sent to: Janice M. Bell, Editor Journal of Family Nursing Faculty of Nursing University of Calgary 2500 University Drive, NW Calgary Alberta, T2N 1N4 Canada Tel: +1 (403) 220 4647 / Fax: +1 (403) 284 4803 / email: jmbell@ucalgary.ca



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Appendix F

IRB Approval for the Study




Institutional Review Board

Dr. David M. Moore
IRB (Human Subjects) Chair
Assistant Vice President for Research Compliance
CVM Phase II, Duckpond Dr., Blacksburg, VA 24061-0442
Office: 540/231-6991; FAX: 540/231-6033
email: dmoored@vt.edu

DATE: June 9, 2004

MEMORANDUM

TO: Karen A. Roberto Center for Gerontology 0426
Vicki C. Martin

FROM: David Moore 

SUBJECT: **IRB Expedited Approval:** "Exploring Health Care Decision-Making of Older Adults: Consistency and Clarification of Responses over Time" IRB # 04-279

This memo is regarding the above-mentioned protocol. The proposed research is eligible for expedited review according to the specifications authorized by 45 CFR 46.110 and 21 CFR 56.110. As Chair of the Virginia Tech Institutional Review Board, I have granted approval to the study for a period of 12 months, effective May 28, 2004.

cc: File
Department Reviewer Shannon Jarrott 0416