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Does End Of Life Terminology Influence Decisional Conflict In Surrogate Decision Makers?

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by

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Abstract

DOES END OF LIFE TERMINOLOGY INFLUENCEDECISIONAL CONFLICT IN SURROGATE DECISION MAKERS?

by
Dawn Fairlie

Adviser: Professor Marianne Jeffreys

This study investigated the relationship between end of life terminologies and decisional conflict in surrogate decision makers using a convenience sample of 234 adults age 50 and older at active adult communities, and senior centers in New Jersey. Participants were randomized into two groups, and each received a vignette that was personalized. The vignettes varied only in the use of the words “Do Not Resuscitate (DNR)” and “Allow Natural Death (AND)”. The Decisional Conflict Scale (DCS) was administered.

There was no difference in total DCS score based on AND and DNR versions. However, AND respondents perceived their decision as a good decision, and were eight times more likely to sign the document than DNR participants, indicating that framing influences surrogate decision making at the end of life. Those who frequently attended religious services were twice as likely as those who rarely attend religious services of implementing their decision; whether the decision is to sign or not to sign the AND or DNR.

Experienced decision makers (EDMs) evolved as a discreet group. They had lower mean total DCS scores and lower mean subscores, indicating that prior experience is an important aspect of end of life decision making. Additionally, AND and EDM participants were more likely to perceive their decision as good and were more likely to be to be sure of their decision, indicating that experienced decision makers respond more favorably to the words Allow Natural Death. The term AND lead to increased likelihood of actually making a decision. Respondents to the DNR version were likely to not sign or postpone signing. Finally, participants were more likely to withdraw from the study when the term DNR was used.

Recommendations for end of life educational enhancements of nursing faculty, students, registered nurses, and all health care professionals are presented. Policy changes to increase public awareness and create a surrogate data base are recommended. The I am Prepared™ program is introduced. Future research is needed to improve adoption of advance directives and assist communication to help the dying and the surrogate decision makers that they leave behind.

Key words: do not resuscitate; allow natural death; surrogate decision maker; experienced decision maker, framing; end of life communication; I am Prepared™

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Table of Contents

List of Tables and Figure

Chapter 1: The Problem

The Patient Self Determination Act (PSDA) was enacted in 1991 in the wake of Cruzan vs. Missouri Department of Health. This law states that individuals have the right to make decisions regarding their medical care. This includes the right to accept or refuse treatment and the right to make an advance directive. The law also stipulates that health care facilities must discuss advance health care directives upon entering their system, (American Bar Association Division for Public Education, 2009, 2013). Since its passage, many policy mandates and countless institutional guidelines have been created. Nonetheless, a study by Schickedanz et al. (2009), found that 40% of older adult participants did not contemplate Advance Care Planning (ACP), 46% did not discuss ACP with family or friends, 80% did not discuss ACP with their doctor, and 90% did not document ACP wishes. Additionally, the discussion of advance care preferences is difficult for patients and many do not want to have this discussion with their physician (Downar and Hawryluck, 2010).

In the absence of ACP or an advance directive (AD); family members are often asked to act as surrogate decision makers on behalf of patients who are no longer able to direct their own care. These surrogate decision makers are called upon to use substituted judgment, the decision that the patient would make if he or she were able. Every day in hospitals across the United States, individuals are asked to act as surrogate decision makers and must make stressful decisions surrounding the course of care for critically ill and dying loved ones. Family members who are asked to make these pivotal decisions may experience strife and discontent lasting for years. Meeker and Jezewski (2005), found that surrogate decision makers typically face great moral, emotional, and cognitive demands and that surrogate decision makers experienced long term physical and psychological ramifications after making end of life decisions. Additionally, while bereaved individuals experience distress, surrogate decision makers are vulnerable to extended psychological morbidity (Webb & Guarino, 2011). Vig, Starks, Taylor, Hopley, and Fryer-Edwards (2007), reported that having a seriously ill family member is a stressful situation for surrogates and that the majority of end of life medical decisions are made by surrogate decision makers who have varying degrees of preparation and comfort with their role. Additionally surrogate decision makers are faced with the moral, ethical, legal, and financial costs of futile treatments as well as painful procedures in the increasingly technology dominated health care system. Furthermore, Levin et al. (2008), found a delay in palliative care related to most cancer patients or their surrogates signing the directive on the day of death. These issues support the need for research aimed at improving end of life decision making.

Although the circumstances surrounding end of life decisions are as diverse as the individuals involved in them, the words used by health care providers are few: "Allow Natural Death (AND)" and "Do Not Resuscitate (DNR)". Meyer (1998), the hospital chaplain who initiated the AND terminology proposed that AND is both gentler and more definitive. Although AND terminology has been accepted in the field of palliative care since its introduction; there are few studies comparing AND and DNR terminology in the literature and no repeated analyses of its ethical implications (Chessa, 2004). Venneman, Narnor-Harris, Perish, and Hamilton, (2008, p. 2), propose that "DNR orders elicit negative reactions from stakeholders that may decrease appropriate end of life care." The semantic significance of the phrases has led to a proposed replacement of DNR with AND.

DNR is the predominant terminology used in today's health care system to address end of life decisions. Do not resuscitate has a specific meaning but the very nature of the term may suggest stopping or withholding of treatment. Indeed, DNR often heralds the realization that the goal has changed from curative to palliative. Making this decision can precipitate guilt feelings and the sense that the decision maker is abandoning the loved one by withholding treatment. "End of life issues generate feelings of guilt, tension, and conflict within families" and the health care team's presentation of options can make a difference (Cohen, 2004, p. 49), and this decision is value laden (Jezewski et al., 2005).

There has been an increased momentum in advocacy for the terminology Allow Natural Death. The New Jersey State Nursing Association (NJSNA, 2008, p. 4), passed a resolution in support of interdisciplinary dialog regarding language change from DNR to AND. NJSNA stated that "by using the term AND, clinicians are acknowledging that the person is dying and that everything is being done for the patient, that would allow the dying process to occur as comfortably as possible." AND also encourages surrogate decision makers to acknowledge that the goal of care is palliative and not curative and may actually assist in the process of letting go by affirming that the focus has changed to allowing death to occur.

This terminology might be considered less threatening to individuals due to its inference of an expected progression and positive perspective implying a gain. However, it could also be argued that AND with its inclusion of the word death, often perceived as the ultimate loss, might invoke a strong emotional response at this vulnerable time. According to Schwartz (2007), researchers are identifying many ways in which language can influence decision making. Additionally, Tversky and Kahneman (1984) found that individuals have different responses when presented with options that are framed as losses than they do to those that are framed as gains. This finding was supported by De Martino, Kumaran, Seymour, and Dolan (2006), who found that choices may be influenced by framing effects or the manner in which options were presented. Framing effects may also play a role in the end of life terminologies causing differing degrees of decisional conflict

The intervention phase of the Study to Understand Prognosis and Preferences for Outcome and Risk of Treatment (SUPPORT, Hiltunen, Medich, Chase, Peterson, & Forrow, 1999), trial recorded nurse's descriptions of individual cases that were coded and analyzed. Recurring themes of decisional conflict were identified. Murray, Miller, Fiset, O'Connor, and Jacobsen (2004), reported that there is a relationship between high decisional conflict and decision delay. Thus, the words used at the time of end of life decision making may influence decisional conflict resulting in decision delay that can lead to futile and unnecessary treatment as well as painful life-prolonging procedures.

Problem Statement

The terminology used at the time of end of life decision making may lead to decisional conflict and that conflict can lead to decision delay. This decision delay can cause unwanted prolongation of the dying process, painful death, and feelings of guilt for family members that can last for years. Decision delay can also influence the use of limited resources in an already overtaxed health care system. This study's problem statement is: surrogate decision makers' decisional conflict may be affected by the terminology used at the time of end of life decision making. Decisional conflict and decision delay at the end of life often result in painful, futile, and costly care.

Need for the Study

Prior to the work of Venneman et al. (2008), no scientific papers addressed the impact of Allow Natural Death versus Do Not Resuscitate. Venneman et al. tested the hypothesis that simply replacing title of a DNR to AND would influence approval of stakeholders. A sample of

687 study participants was split into three groups: nurses, nursing students and control lay persons. The study concluded that simply changing the title from DNR to AND increased participant acceptance and the authors posited that family members, who are often most reluctant to sign a DNR, are most likely to endorse the order if the name was changed to AND. Further research to examine difficulties in interpretation as a result of the framing effects of the negative, do not, and negative semantic reactions was recommended.

A second study Jones et al. (2008), investigated the attitudes and beliefs of 190 healthcare providers in a pediatric palliative care setting regarding the use of AND as opposed to DNR to assist in uncovering the ways each term might influence family responses to end of life treatment options. The researchers concluded that the use of term AND, which reflects the sensitive nature of end of life decisions has the potential to improve clear communication while promoting a family centered approach and recommended additional research with patients and their families.

Chen and Younger (2008) critiqued the Venneman et al. (2008) study arguing that a change of terms was simply changing words and that change would not assist health care providers in discussions of end of life care. They posited that AND would add to the confusion surrounding end of life therapies and interventions. Finally, they recommended methodology and sampling procedures which included physicians.

In response, a third study by Wittmann-Price and Cella (2010), replicated the Venneman et al study with physicians, nurses, and health care students using the tool developed by Venneman et al. and a convenience sample. They found that majority of health care professionals who were surveyed reported that they were likely to consent to AND for a dying loved one. These results supported Venneman et al. They concluded that changing terminology would be an initial step to eliminating dehumanization from caring for the dying. Recommendation of studies with patients and families was again recommended.

Bernato and Arnold, (2013) conducted a 5 x 2 between-subject randomized factorial study that investigated the effect of emotional state and physician communication of AND versus DNR with surrogate decision makers. Four physician communication behaviors were investigated: emotion handling [yes/no], framing the decision maker [patient/surrogate], framing the default [no cardiopulmonary resuscitation (CPR)/CPR], framing the alternative to CPR [allow natural death (AND)/do not resuscitate (DNR)]. The profile of mood states (POMS) and the Decisional Conflict Scale (DCS) were administered. They concluded that the experimentally induced emotional state did not influence end of life decision making; however, changes in physician communication significantly influenced this decision. Additionally, framing the social norm as not choosing CPR (versus choosing CPR) and framing the alternative to CPR as AND (versus DNR) reduced the selection of CPR as the choice. Furthermore, they concluded that framing may affect decisions by influencing the decision maker’s emotional response to the decision and may directly influence code status decisions.

Purpose of the Study

The purposes of this study are:

1) To explore the relationship between two commonly used, distinct terminologies (AND or DNR) when used at the time of end of life decision making on decisional conflict and decision delay

2) To explore the relationship of select demographic variables on decisional conflict and decision delay

3) To explore the degree to which each term predicts decision delay

4) To contribute and build on the Ottawa Decision Support Framework (ODSF)

Research Questions

The research questions of this study are:

1) Is there a difference in surrogate decision makers' decisional conflict when the terms Allow Natural Death or Do Not Resuscitate are used?

2) Is there a difference in surrogate decision makers' decision delay based upon the terminology Allow Natural Death or Do Not Resuscitate?

3) Is there a difference in surrogate decision makers' decision implementation based upon the terminology Allow Natural Death or Do Not Resuscitate?

4) Is there a difference in surrogate decision makers' end of life decision making based upon the terminology Allow Natural Death or Do Not Resuscitate?

5) What is the relationship between select demographic variables and decisional conflict among surrogate decision makers?

6) What is the relationship between select demographic variables and decision delay among surrogate decision makers?

7) What is the relationship between select demographic variables and decision implementation among surrogate decision makers?

8) What is the relationship between select demographic variables and end of life decision making among surrogate decision makers?

Definition of Terms

For the purpose of this study, the following definitions were used:

Allow Natural Death (AND) is a medical order to ensure that only comfort measures are rendered, while acknowledging that the person is dying. Everything done for the patient facilitates the dying process, making the patient as comfortable as possible, (Meyer, 1998).

Decision delay is the condition in which people do not decide but defer or avoid decisions (Nijstad & Handgraaf, 2008) due to higher levels of decisional conflict as indicated by a score greater than 37.5 on the DCS (O'Connor, 2010).

Decision implementation refers to individuals making a decision and suggests little to no decisional conflict as indicated by a score of less than 24 on the DCS (O'Connor, 2010).

Decisional conflict is a state of uncertainty about what actions should be taken when actions involve risk, loss, regret, or challenge an individual's personal life values, ranging from 0 (no decisional conflict) to 100 (extremely high decisional conflict) as measured by the Decisional Conflict Scale (DCS) total score. Decisional conflict involves several components: certainty about best choice, feeling informed, personal values clarity, support in decision making, and effectiveness of decision and is measured by five corresponding subscores (uncertainty, informed, values clarity, support and effect decision) ranging from 0 to 100 on the DCS (O'Connor, 1995; 2010).

Do Not Resuscitate (DNR) is a medical order to provide no resuscitation to individuals for whom resuscitation is unwarranted (Cleveland Clinic, 2009).

End of life includes components such as the presence of chronic disease or symptoms or functional impairments that persist but may also fluctuate; and symptoms or impairments resulting from the underlying irreversible disease that can lead to death (Medline Plus, 2009).

End of life decision making refers to a surrogate decision makers' decision to decline or request cardiopulmonary resuscitation (CPR) in the event that a named, hospitalized loved one is unconscious, in a poor health situation and proclaimed by the physician to be near death. End of life decision making will be measured by Part A of the DCS whereby respondents following a vignette indicate a decision to sign a document declining CPR: yes, no, or unsure.

Message framing refers to presenting a message in terms of expected gains or losses associated with a specific behavior, where a gain framed implication supports helpful outcomes or minimizes undesirable outcomes related to performing the action implied in the message, and a loss framed implication supports undesirable outcomes or the absence of helpful outcomes associated with not performing the action implied, (Broemer, 2002).

Patient decision aids (PtDAs) help to prepare people in making complex decisions that involve weighing benefits, harms, and uncertainty. They differ from usual health education materials because of their personalized focus on options and outcomes as an adjunct for decision making preparation (Bekker et al., 1999; Estabrooks et al., 2000; O'Connor et al., 1999a; O'Connor et al., 1997).

Surrogate decision maker is a person who makes a treatment decision using substituted judgment. This person makes the decision that the patient would make if he or she were able (The Center for Bioethics and Human Dignity, 2009).

Unspecified (U) refers to individuals scoring between 25 and 37.5 on the DCS.

Vignettes are hypothetical situations compiled from a variety of situations, sources, and research findings to study attitudes, beliefs, and perceptions (Hughes, 2001).

Assumptions

This research was guided by several assumptions. First, participants were representative of the general population and participants were immersing themselves in the vignette and answering honestly. In using the vignette approach, it was assumed that subjects comprehended the specific situation even though it may have been an unfamiliar experience of which they had no prior knowledge. Goldenberg (1996) found that study subjects did not need a clear understanding of the topic under investigation to apply the vignette and answer questions about it. Furthermore, vignettes assumed that respondents gave the same answers for the vignette as if the situation actually applied to them (Martin and Polivka, 1995) and that respondents take the quality of a person's relationships and personal motivations into account when they make their decisions. Additionally, it was assumed that the responses to the vignettes and the instruments were honest and representative of reactions that surrogate decision makers would experience in actual life experiences. Finally, all research is culture bound and knowledge is relative to the context in which it is generated (Gordon, Miller, & Rollock, 1990). Therefore the knowledge constructed in this study was influenced by the ideas, assumptions, and cultural norms of the participants (Banks & Banks, 1995).

Limitations

There were several limitations that were acknowledged and addressed regarding the present study. The first limitation of this study was that of internal validity. Internal validity was impacted by the use of a vignette that introduced the possibility of discrepancy between responses in a simulated versus an actual situation. Vignettes controlled for the situation, they did not control for individual interpretation of the hypothetical experience, and the personal decision making characteristics of the participants. Lastly, the use of a vignette in lieu of actual experiences limited the social context under which end of life decisions are actually made. Due to the nature of the study, it was unethical to conduct the study under real life circumstances, therefore the benefits of the knowledge gained from doing the study with a vignette provided valuable information to fill in the gaps in research and help guide practice and policy protocols. The use of a vignette was a necessary limitation given the sensitive nature of the topic. Additionally, external validity, or the generalizability of the study was limited due to unknown sample variables and the use of a convenience sample of participants over the age of 50 who are present and willing to participate in the study on the day the instrument is administered.

Significance

This study explored the possibility that two commonly used and distinct terminologies used at the time of end of life decision making would impact decisional conflict, decision making, and decision delay. Presently most DNRs are signed within three to five days of death (Helft, Qi, Brown, Drabiak, & Morrell, 2007), resulting in unwanted prolongation of life as a result of unnecessary procedures. Unwanted prolonging of death is psychologically, physically, financially, and professionally costly.

Family members are often called upon to act as surrogate decision makers for the large number of individuals who have not prepared an advance directive or have not made their preferences clear. Family members often struggle with these decisions causing delays in decision making. It was thought that a change of semantics by substituting three new words, Allow Natural Death, to this crucial, and difficult decision might help families in their decision making process. Implications of the proposed study have the potential to guide the development of strategies and policies in end of life care; improve provider/patient/family communication; advance professional education of students and licensed health providers; enhance the quality of life of the dying and their families; and reduce the costs of dying. In culmination, society will benefit as each individual is helped regarding this crucial decision. Potential societal implications are tremendous because every person may hypothetically be faced with end of life decisions for self and/or one or more family members or significant others. Furthermore, the first goal of Healthy People 2010 aimed to help individuals of all ages increase life expectancy and improve their quality of life, which reflects a personal sense of physical and mental health and the ability to react to factors in the physical and social environments (Healthy People 2010, 2000). Healthy People 2020 focuses on interactions between individuals and their environments, both physical and social, which impact health, functioning, and quality of life outcomes; as well as effects of intervention strategies over time, effects on survival and quality of life (Healthy People 2010, 2020).

Steinhauser et al. (2000), found that participants value psychosocial and spiritual issues as well as physiologic concerns at the end of life and that patients felt empowered by participating in treatment decisions. In addition, Healthy People 2010 set clear goals for increasing the proportion of persons reporting that their health care providers have satisfactory communication skills (Healthy People 2010). Healthy People 2020 encourages measures and interventions that build on current health communication and mobilize the implementation of Healthy People 2020, building on current health literacy and health communication efforts. Indeed, Steinhauser et al. (2000) noted that quality of life issues surrounding fear of pain and inadequate symptom management could be reduced through communication and clear decision making with physicians.

Additionally, Healthy People 2020 continues to support the need for appropriate communication strategies and shared decision making between patients and providers to improve population health outcomes and health care quality, and to achieve health equity by delivering accurate, accessible, and actionable health information that is targeted or tailored (Healthy People 2020, 2010). Unwanted prolongation of life is considered by some to be costly in terms of dollars spent in futility in a time of shrinking financial resources and it contributes to the depletion of an already deficient number of practicing registered professional nurses.

Many nurses experience burnout syndrome (BOS) as a consequence of working under conditions that many consider to be morally and ethically wrong. BOS secondary to stress has been identified in health care professionals in various specialties. In a study of intensive care unit (ICU) nurses, Poncet et al. (2007), found that one-third had severe BOS and the areas for improvement identified in the study included better management of end of life factors such as caring for a dying patient (p=0.02), and number of decisions to forego life sustaining treatments in the last week (p=0.04).

Projected Outcomes and Contributions

One quantitative study (Venneman et al., 2008) and one qualitative study (Jones et al., 2008) were identified that compare AND and DNR. Another study examined decisional conflict in surrogate decision makers in relationship to nursing home placement, (Chang, Kicis, & Sangha, 2007). Bernato and Arnold, (2013) conducted a between subject randomized factorial study that investigated the effect of emotional state and physician communication of AND versus DNR with surrogate decision makers. They concluded that changes in physician communication significantly influenced this decision, resulting in fewer surrogates choosing cardiopulmonary resuscitation when framed as allow natural death rather than do not resuscitate (49% versus 61%, odds ratio, 0.58 [95% CI, 0.35–0.96]).

The findings of this study will address a severe gap in care of the dying and their families, and assist in end of life communication. It is proposed that this study will also add to the Ottawa Decision Support Framework (ODSF) and add a dimension to the development of Patient Decision Aids (PtDAs).

Chapter Summary

The Patient Self Determination Act assisted in removing barriers to patient autonomy via advance directives. In spite of this legislation, many individuals do not prepare advance directives and when they do, they often do not adequately communicate that their wishes be honored. Surrogate decision makers are often called upon to make end of life decisions in which decisional conflict occurs when values and expected outcomes are discordant. Modifying end of life terminologies may be a useful method for decreasing decisional conflict and decreasing decision delay. This chapter introduced the background of the problem: surrogate decision makers' decisional conflict may be influenced by the terminology used at the time of end of life decision making; and decisional conflict and decision delay at the end of life often result in painful, futile, and costly care. The purpose of this study was identified: to explore the relationship between two commonly used, distinct terminologies used at the time of end of life decision making on decisional conflict, decision making, and decision delay. The lack of prior research supports the need for this study.

The research question was formally stated: Does end of life terminology influence decisional conflict in surrogate decision makers? Conceptual and operational terms were defined and the assumptions of the study as well as the limitations and delimitations were discussed. Finally the significance and general projected outcomes of the study were explored as well as anticipated contributions to research, practice, education and society.

Chapter 2: Review of the Literature

This chapter discusses the interrelationship of the Ottawa Decision Support Framework (ODSF), Patient Decision Aids, and the Decisional Conflict Scale (DCS). The application of The Ottawa Decision Support Framework is presented as well as the relevance of its use in this study. The current state of development of Patient Decision Aids is explored and the end of life studies that used the Decisional Conflict Scale are introduced. Applicable literature supports the concepts of the study and the independent variables; AND and DNR (two commonly used but different end of life (EOL) terminologies); and the dependent variable of decisional conflict.

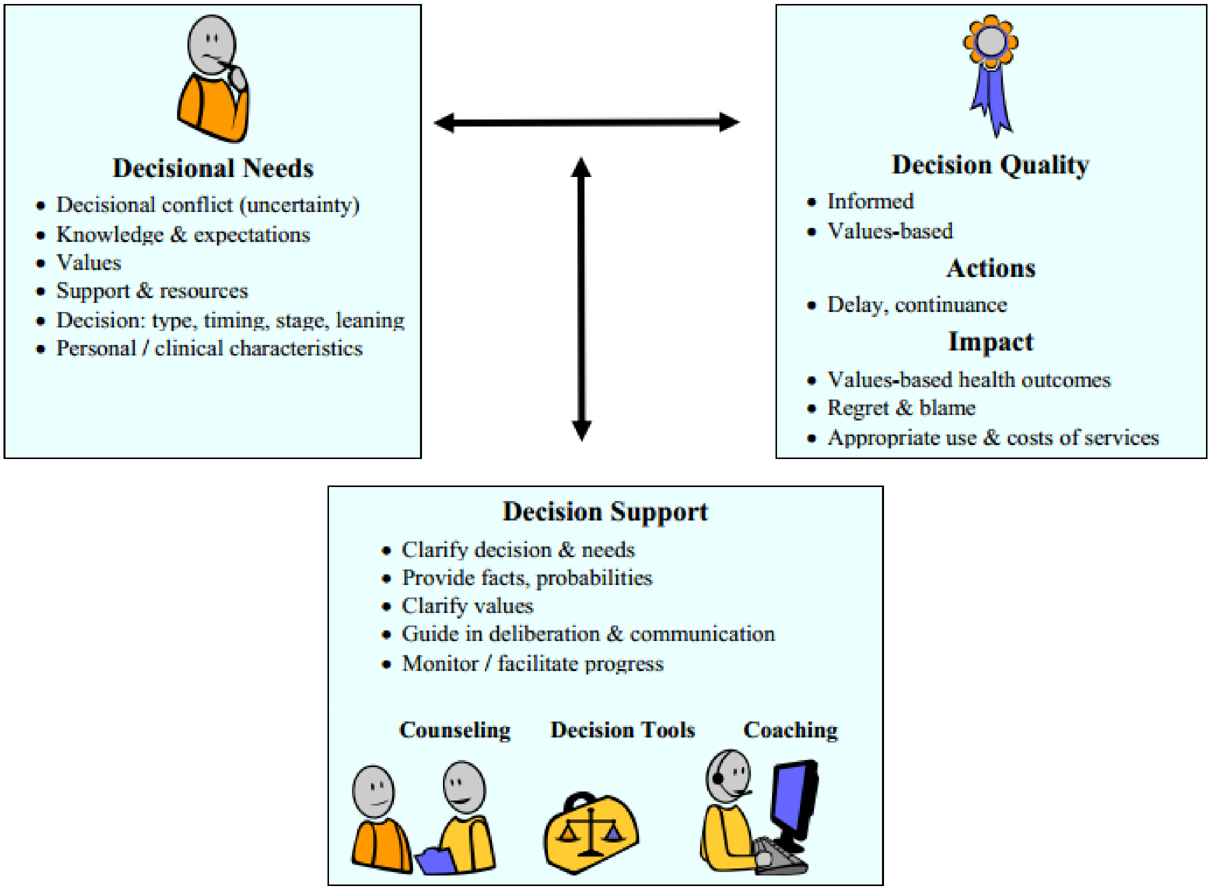
Ottawa Decision Support Framework

O'Connor et al. (1998) developed the Ottawa Decision Support Framework and the DCS (O'Connor, 1995; 2010). The two complement each other. In the domain associated with health decisions, this conceptual framework positions itself uniquely by operationalizing decisional conflict (Legare et al., 2003).

The 16 item Decisional Conflict Scale (DCS) uses a 5 point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree). The scale consists of the following subscales: uncertainty (Items 1-3); the main modifiable factors contributing to uncertainty (Items 4-6); feeling unclear about one's values (Items 7-9); feeling unsupported in the decision making (Items 10-12); and the perception of the effectiveness of the decision making after the decision is made. The DCS and its psychometric properties will be discussed in detail in Chapter 3. The ODSF (Figure 1) is an evidence based midrange theory that describes how to facilitate the decision making process (O'Connor et al, 1998; Murray et al., 2004). The ODSF is conceptualized as a guide for interventions, as a preparation for shared decision making (O'Connor et al., 1998). The ODSF is organized into four major categories: a) the elements of decisions; b) interventions that support decisions; c) evaluation of the decision support's outcome related to the decision; and d) the decision process quality. The ODSF hypothesizes that improved decision making quality will have a positive influence on patients' outcomes, (Legare et al., 2003). It applies to individuals involved in the decision making process and posits that decisional needs will influence informed values-based choices; that in turn influence actions and behaviors such as decision delay, outcomes, emotions (such as regret and blame); in addition

Figure 1

Ottawa Decision Support Framework



Credit: http://decisionaid.ohri.ca © 1998, 2006-2011 by AM O'Connor. Reproduced by permission of AM O'Connor.

to the appropriate use of health services (Ottawa Health Research Institute (OHRI), 2013). The creators of the ODSF assert that uncertainty, knowledge deficits, values clarity, and support influence decision quality; adding that decision support that addresses these decisional needs has the potential to improve decision quality.

The ODSF looks at health decisions that fall into following categories: the decision is necessitated by a new situation, diagnosis, or life transition; where careful deliberation is fundamental based on the value laden nature of the risk and/or benefits; and greater effort is required during the consideration phase than during the actual implementation of the decision (Ottawa Health Research Institute (OHRI), 2013). The ODSF provides an approach for supporting patients and their families in the decision making process with a goal of minimizing decisional conflict, decision delay, and decision regret.

Rationale for Using the Ottawa Decision Support Framework

One of the ODSF's primary contributions is that it identifies decisional conflict as an essential factor in decision making. Identification of decisional conflict is a crucial skill that is taught to health care providers learning about shared decision making (O'Connor, Llewellyn-Thomas & Flood, 2004). Conflict can be assessed using the Decisional Conflict Scale (O'Connor, 1995, 2010); a tool that facilitates identification of decisional conflict in individuals. Decisional conflict is one of the key concepts in the field of shared decision making, (Legare et al., 2007). The DCS can be used to examine the character of the decision making process, and the impact of decision support interventions.

The ODSF includes three main categories; Decision Needs, Decision Quality, and Decision Support. Each category contains several variables. Decision needs encompasses decisional conflict; knowledge and expectations; values; and support and resources. Decision needs are influenced by the type of decision in itself; the timing of the decision; the decision maker's stage in the decision making process; and their tendency to lean toward a specific decision. The individual characteristics of the decision maker also influence Decisional needs.

Decision quality is related to the decision maker being informed and taking action that is congruent with personal values. When actions are either delayed or continued, decision quality is affected. This can result in regret, blame, and inappropriate use of services and resources.

Decision support assists in clarifying decisions, providing facts and probabilities, clarifying values and guiding and coaching to support decision making skills and then monitoring and facilitating progress. Clinical knowledge, use of decision tools and coaching are methods used. The ODSF considers decision needs and decision quality to mutually influence each other; and together influenced by and influencing decision support.

Decisional Conflict

Decisional conflict is expressed as a state of uncertainty about what actions should be taken when actions involve risk, loss, regret, or challenge an individual's personal life values. Decisional conflict includes several major identifying characteristics, including verbalization of uncertainty, questioning of personal values and beliefs, vacillation between choices, and delayed decision making (O'Connor, 1995; 2010). For example, the intervention phase of the SUPPORT study (Hiltunen et al., 1999) implemented physicians suggestions that communication could improve if a registered nurse provided timely and reliable prognostic information; helped to carry out the needed discussions; convened the meetings; and uncovered relevant information. Recurring themes of decisional conflict; in which family decision makers recognize a dilemma, struggle with the decision, move toward a turning point, and then toward letting go. Family members indicated that information, discussion and facilitation of the process enhanced the chance of coming to the turning point where the decision was made.

Decisional conflict as measured by the DCS within the framework of the ODSF has been studied in individuals making end of life decisions regarding place of care (Murray, O’Connor, Fiset, & Viola, 2003); and in studying surrogate decision makers’ decisional conflict surrounding nursing home placement (Chang et al., 2007). Additionally, the DCS itself has been validated for end of life decision making (Song & Sareika, 2006); however, little is known about decisional conflict during end of life decision making for surrogate decision makers and only one study has evaluated the effect of terminologies on decisional conflict used at the time of these decisions (Bernato & Arnold, 2013).

Patient Decision Aids

The use of patient decision aids (PtDAs), as a tool to support individuals with decision making needs is well researched. In a recent review of randomized control trials (*N*=55) PtDAs were found to improve decision quality and measures of feeling informed and clear about values (O'Connor et al., 2007). Five additional systematic reviews have examined outcomes and limitations of PtDAs (Feldman-Stewart, Brundage, Siemens, & Skarsgard, 2006; Whelan, McKinley, Boulet, Macrae & Kamholz, 2001; O'Connor. et al., 2003; O'Connor et al., 2009; Coulter & Ellins, 2007), finding improved patient knowledge and understanding of their condition. A compilation of reviews found that overall, PtDAs lead to increased agreement between patient preference and choice (Coulter & Ellins, 2007). One review outlined deficiencies in the completeness, balance and accuracy of information presented in PtDAs assessed (Feldman-Stewart et al., 2006). In response to this deficit, a recent international collaboration established standards to assess PtDA quality (Elwyn et al., 2006). No studies were found that address the terminologies used in PtDAs as a potential source of decisional conflict. The objective of this study was to conduct a systematic review and meta-analysis of randomized controlled trials evaluating the efficacy of different decision aid tools compared to regular care for women facing several options in the specific field of obstetric care (Dugas, Shorten, Dube, Wasser, Bujold, &Chaillet, 2012). The Decision Analysis Tools and the Computer-based Information tool were associated with a reduction in levels of decisional conflict. The Decision Analysis Tool was the only tool that presented evidence of an impact on the final choice and final outcome. Decision aid tools can assist health professionals to provide information and counseling about choices during pregnancy and support women in shared decision making. The choice of a specific tool should depend on resources available to support their use as well as the specific decisions being faced by women, their health care setting and providers.

In addition to providing patient education in the traditional sense, PtDAs explicitly describe available options, while providing estimates of risks and benefits associated with the options. PtDAs adapt information to support patients' needs and provide a context for patients to consider their options while considering their values and preferences (O'Connor et al., 1999c; Levine & Whelan, 2001). PtDAs are intended to serve as an adjunct to decision support counseling.

In a randomized controlled trial with two years of follow up, Sculpher, Coulter, Dwyer, Rees, Abrams, et al., (2002) studied 894 women with uncomplicated menorrhagia recruited from six hospitals in England. Women were randomly assigned to the control group, the information alone group (information), or to the information plus interview group (interview). Women in the intervention groups received an information pack six weeks before their gynecological consultation. Immediately prior to their consultation, women in the interview group received a structured interview, to clarify and elicit their preferences. The main outcome was improved self-reported health status, and secondary outcomes surrounded cost of care. The interventions failed to demonstrate consistent effect on health status. Hysterectomy rates were lower for women in the interview group (38%, adjusted odds ratio [OR], 0.60; 95% confidence interval [CI], 0.38-0.96) than in the control group (48%) and women who received the information alone (48%), (adjusted [OR], 0.52; 95% [CI], 0.33-0.82). The interview group had lower mean costs ($1566) than the control group ($2751), (mean difference, $1184; 95% [CI], $684-$2110) and the information group $2026 (mean difference, $461; 95% [CI], $236-$696). The researchers concluded that using a PtDA in conjunction with one to one counseling improved patient satisfaction and demonstrated a net reduction in health care costs accrued in managing menorrhagia when compared to compared to a PtDA alone or standard care alone.

Patient decision aids are endorsed as tools to help professionals participate in shared and/or patient-centered care. The International Patient Decision Aids Standards (IPDAS) domains were informed by experts' estimations of best practice. Decision scientists analyze how individuals make decisions, what biases their choices, and how to optimally support decisions. There is debate in the decision science community about which constituent elements are the components that help people make decisions. Bekker (2010) performed a conceptual review integrating the science behind individuals' decision making with the demands of designing complex healthcare interventions; and stated that using the IPDAS collaboration checklist as a benchmark to evaluate interventions' quality is premature and potentially harmful to the validity of resources intended to help patients make treatment choices. Bekker concluded that interventions that help patients make choices have different purposes, component parts, and outcomes to those facilitating professional to patient communications. It was proposed that the

IPDAS checklist will be modified to respond to new evidence from the decision sciences and that adhering uncritically to the IPDAS checklist may reduce practice variation but is not sufficient to ensure interventions enable good patient decision making; concluding that developers must be encouraged to use sound reason about the IPDAS checklist to identify any component parts that do or do not meet their intervention's purpose.

Miller, (2011) looked at 264 low literacy patients aged 50–74 years and overdue for colorectal (CRC) screening. Participants were randomized to the web-based decision aid or a control program seen immediately before a scheduled primary care appointment to determine if a web-based multimedia CRC screening patient decision aid, developed for a mixed-literacy audience, could increase CRC screening. Findings were that the web-based decision aid increased patients' ability to form a test preference and their intent to receive screening, regardless of literacy level; concluding that further study should examine ways the decision aid can be combined with additional system changes to increase CRC screening.

Elwyn et al. (2009) assessed the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPDASi). They performed a scale development study using construct; item and scale development; and validation and reliability testing to describe the development; validation and inter-rater reliability of an instrument to measure the quality of patient decision support technologies (decision aids). Twenty-five researcher members of the International Patient Decision Aid Standards Collaboration worked together to develop the instrument (IPDASi) and eight raters evaluated thirty randomly selected decision support technologies. They concluded that IPDASi has the ability to assess the quality of decision support technologies and will be used as a tool to provide formative advice to researchers.

Stacey et al. (2012) reviewed 86 studies where patients used decision aids and found that decision aids were improved with explicit values clarification exercises and consequently improve informed values-based choices. They concluded that patients are assisted in developing more accurate expectations of potential benefits and harms; that their choices that are more harmonious with informed values; and they participate more in decision making. They found that decision aids have a variable effect on actual choices but they reduce the choice of elective surgery when patients consider other options. Additionally, patients using decision aids, reported a positive effect on communication with their health practitioner, and a variable effect on the time required for this consultation. Finally, they reported an improvement with more detailed decision aids compared to simpler decision aids, but the amount of improvement is smaller than that seen when decision aids are compared to usual care. Furthermore, there are no apparent adverse effects on health outcomes or satisfaction; however, more research is needed to evaluate adherence with the chosen option, patient-practitioner communication, and the associated costs.

A search of the A-Z Inventory of Patient Decision Aids maintained by the Ottawa Health Research Institute (OHRI, 2013), revealed one proprietary PtDA related to end of life preferences for CPR, one 12 page decision aid related to CPR and mechanical ventilation, and one generic PtDA: The Ottawa Patient Decision Guide ([OPDG], OHRI, 2013). The OPDG has been used as a template for more than 35 PtDAs evaluated in clinical trials (Murray, O'Connor, Stacey, & Wilson, 2008) and 86 studies were identified in which patients used decision aids (Stacey et al ; 2012). The OPDG will be used in this study.

A well-constructed decision aid has two primary merits over simply clarifying a patient’s values. One advantage is the rigorous literature search used to create a synopsis of probable outcomes (Murray, 2004). Researchers questioning the inclusiveness of the summary of probabilities can assess this literature to re-evaluate precision. Secondly, a well-constructed decision aid will offer a validated method of communicating the knowledge to patients, who may have minimal experience in quantifiable decision making. Frequently, decision aids use pictures and simple statistics to present results in terms of the percentage of individuals with certain health problems who respond positively without a specific intervention as opposed to the percentage who respond well with a specific interventions (Schunemann, 2005). A well-constructed decision aid will provide a summary of the important outcome data; however, many decision aids fail to address scientific uncertainty about related benefits and harms (Thomas, 2007).

Decision aids present an attractive strategy for ensuring that patients' values are included in the decision making process. In a systematic review conducted by O'Connor and colleagues **(**2007**)**, 34 randomized trials that used 29 unique decision aids were identified. In the trials comparing decision aids with usual care, the decision aid group had higher knowledge scores (weighted mean difference LWMDI, 19 on a 100-point scale; 95% confidence interval I [CI I], 13 to 24), more realistic expectations (relative risk IRRI, 1.4; 95% [Cl], 1.1 to 1.9), and lower decisional conflict related to feeling informed, and a higher proportion of the decision aid group was active in decision making.

Adoption of a model of shared decision making that recognizes patients' values and beliefs may decrease health care costs by helping to ensure that the effective use of resources is congruent with patients' and families' goals of care. End of life care decisions frequently involve a complex constellation of practical, emotional and informational factors. Intricate emotional and social interactions between patient, family, and health care providers have an impact on such decisions. Nurses fulfill a key role as communication agents, clarifiers, advocates, and mediators (Stacey, 2006). Furthermore, by using decision support interventions nurses can assist patients and families to make sense of complex issues, such as the impact of technology, hope, futility and the burden of decisions (Steinhauser, 2000).

Nurses need to develop decision support skills to be able to address the decisional conflict of patients and families. This support includes information, assistance, and emotional comfort in order to: enhance coping; promote feelings of empowerment; minimize stress; encourage self-care; and encourage appropriate use of health care resources.

Review of Literature

Bibliographic databases (PubMed, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), the Educational Resources Information Center (ERIC) and the Cochrane Library) were searched from 1995-2013. Key search terms used included synonyms for end of life decisions, decisional conflict, Allow Natural Death (AND), Do Not Resuscitate (DNR), surrogate decision makers, and decision framing. Because the search terms are dispersed across broad subject areas, the search was augmented by manually searching reference lists of pertinent review articles and editorials for additional studies, evaluating indexes of journals that contributed the most publications in the electronic search, and reference lists of retrieved papers. Grey literature which includes unpublished and unindexed reports that are not peer reviewed were excluded due to their minimal contributive value to literature reviews, (Cook et al., 2001).

Papers were evaluated at three levels (title, abstract, full text), then evaluated for validity, methodological rigor and topic relevance. Studies appropriate for full text review were evaluated for quality and content. The reports selected for inclusion were thematically organized and cross referenced for application to the study. An investigation was performed to evaluate the extent of knowledge development concerning end of life decision making. Publication frequency and topics of publication of authors were examined. The literature review, as presented in the subsequent sections, was organized into several categories; surrogate decision makers, communication and end of life decision making, decisional conflict, decision delay, studies comparing AND and DNR, and message framing.

Surrogate Decision Makers

The Center for Bioethics and Human Dignity (2009), defines surrogate decision makers (SDMs) as individuals who make treatment decisions that the patient would make if he or she were able through the use of substituted judgment. Buchanan and Brock (1989), introduced the concept of values to standards which ideally guide surrogate decision making; the substituted judgment standard which proposes that surrogate decision making is based on the incapacitated individual’s known preferences and values and the surrogate’s confidence that these preferences and values apply to the patient’s current condition and the prognosis. Surrogate decision makers are often confronted with unique challenges, and need to take their loved one’s values preferences, and original intentions into consideration, (Cohen, 2004). At the same time, surrogates are balancing their own values and situations, as well as family pressures (Gaugler & Zarit, 1999).

There is a dearth of research on the experiences of SDMs. Information about SDMs is not methodically noted in healthcare records and is not usually retrievable through review of electronic health records, making them a group that is difficult to identify (Webb, 2011). Surrogate decision makers often make crucial value laden decisions under circumstances of uncertainty. Additionally, findings from a study of 14 terminally ill patients examining the context end of life decision making indicate that participants values, beliefs and experiences greatly shaped their decision making (Gauthier & Swigart, 2003). When surrogates make end of life decisions for loved ones, they often find themselves considering the values of the loved one as well as considering their own values. This can make the decision making process increasingly complex. Additionally, the impact of the death of a loved one continues for many years after the death, for all groups regardless of decision maker status, or the age of the person who died (Webb, 2011).

Communication and End of Life Decision Making

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT, 1995), was a two-phase controlled clinical trial which sought to improve end of life decision making and reduce painful and prolonged dying. The phase one observation (*N* = 4301) identified communication deficiencies, occurrence of aggressive treatment, and the characteristics of death at five teaching hospitals in the United States. Less than half of the physicians (47%) knew when their patients preferred to avoid CPR; and 46% of the Do Not Resuscitate (DNR) orders written were initiated within 2 days of death. Additionally, 38% of patients who died spent a minimum of 10 days in an intensive care unit (ICU); and for half of conscious patients before their death, family members recounted moderate to severe pain at least 50% of the time. The second phase intervention by a specially trained nurse, who coordinated communication and care (n = 4804) failed to demonstrate significant improvement in physician to patient communication, with a reported 37% of control patients and 40% of intervention patients discussing CPR preferences. The five targeted outcomes included: incidence of timing of written DNR orders (adjusted ratio, 1.02; 95% confidence interval [CI], 0.90 to 1.15), physicians' knowledge of patient preferences for cardiopulmonary resuscitation (CPR, adjusted ratio, 1.22; 95% [CI], 0.99 to 1.49), days in the ICU, mechanical ventilation, or comatose prior to death (adjusted ratio, 0.97; 95% [CI], 0.87 to 1.07), or reported pain level (adjusted ratio, 1.15; 95% [CI], 1.00 to 1.33). Additionally, the Phase II intervention failed to reduce use of hospital capital (adjusted ratio, 1.05; 95% [CI], 0.99 to 1.12, JAMA, 1995).

Since the SUPPORT study, numerous studies have indicated that end of life conversations are often avoided by physicians and patients/surrogates (Cherlin, Fried, Prigerson, et al, 2005, Selman, Harding, Benyon et al, 2007; Leydon, Boulton, Moynihan et al, 2000). In the Coping with Cancer Study (CWC), a prospective, longitudinal, multi-institutional study of 603 patients with advanced cancer, only 188 (31.2%) reported having end of life conversations with physicians (Balboni et al., 2008). Many physicians fear that such conversations may cause psychological distress (Lyon, McCabe, Patel, & D’Angelo, 2004). However, physical and emotional distress may actually decrease. It is noted that end of life discussions are associated with less aggressive and futile care near death as well as more timely hospice and palliative care referrals and that aggressive care is associated with poorer quality of life and difficulties with bereavement adjustment and increased regret (Wright, Zhang, Ray, & Mack, 2009). Furthermore, physicians frequently avoid or postpone end of life conversations, use euphemisms, or maintain an optimistic persona (Mercurio, 2007; Wharton, Levine, Bulka, & Emanuel, 1996), rather than acknowledging that death is near to allow the patient, surrogate, and health care team to focus on palliative care (Quill, 2000).

A cross-sectional, stratified, random, national survey of 1,462 participants involved in end of life experiences; including nurses, social workers, chaplains, hospice volunteers, physicians, patients, and recently bereaved family members, found that that fear of pain and inadequate symptom management could be reduced through open communication and clear decision making with physicians. Additionally, patients felt empowered by participating in treatment decisions. Alternately, negative descriptions included scenarios in which treatment preferences were not made clear and left patients feeling unimportant, and family members confused while being concerned about suffering. A sense of urgency about making crucial decisions during crisis with depleted emotional reserves was also expressed (Steinhauser et al., 2000).

Finally, in a systematic review of 102 publications; Frost, Cook, Heyland, and Fowler (2011), examined which factors influence end of life decision making among patients and clinicians; concluding that both patient and clinician race, ethnicity, and nationality influence end of life care. Additionally, patients and clinicians often have different expect expectations and preferences; influenced by religion, race, culture, and geography. Consideration of these factors may raise awareness, enhance communication, and guide clinicians in end of life discussions.

Decisional Conflict

The literature reveals multiple studies documenting decisional conflict and the usefulness of various decision aids in assisting patients in their decision making process including the use of a decision aid for long term tube feedings in cognitively impaired older adults (Mitchell, Tetroe and O’Connor, 2001) and Briggs, Kirchloff, Hammes, Song et al., (2004) looked at preferences for feeding tube placement in cognitively impaired individuals. Murray et al. (2003) employed the DCS to evaluate women’s decision making needs regarding place of care at end of life and reported that there is a relationship between high decisional conflict scores and decision delay. Song and Sereika (2006), evaluated the Decisional Conflict Scale (DCS) and a decision aid intervention to measure the quality of end of life decision making while Allen, Allen, Hilgeman, and DeCoster (2008), measured decisional conflict in end of life decision making using a vignette approach to study 78 adults (aged 74.5±7.18) finding that the decision aid reduced decisional conflict (p = .049, d=0.47) for hypothetical life sustaining treatment decisions. Lyon et al. (2009) examined the effect of a patient decision aid on the congruence in adolescent/surrogate preferences for end of life care, decisional conflict, and communication quality. Families acknowledged a life threatening condition and were willing to initiate these conversations when their adolescents were medically stable. These adolescents reported feeling significantly better informed about end of life decisions and their surrogates were more likely to feel that their attitudes and wishes were known. Bernato and Arnold, (2013) conducted a between subject randomized factorial study that investigated the effect of emotional state and physician communication of AND versus DNR with surrogate decision makers. Four physician communication behaviors were investigated: emotion handling (yes/no), framing the decision maker (patient/surrogate), framing the default (no cardiopulmonary resuscitation CPR/CPR), framing the alternative to CPR (allow natural death [AND]/do not resuscitate [DNR]). The profile of mood states (POMS) and the Decisional Conflict Scale (DCS) were administered. They concluded that the experimentally induced emotional state did not influence end of life decision making; however, changes in physician communication significantly influenced this decision.

Decision Delay

Patients who report decisional conflict are increasingly likely to change their minds, experience decision delay, experience regret over the decision that they have made, fail a knowledge test, and shift blame to their physicians for negative outcomes (Sun, 2004; Gattellari, 2005; Stacey, Samant, & Bennett, 2008). Thus, the decision making process can become maladaptive through the use of avoidance and delay. The irrational decision maker will try to remove him/herself from an uncertain situation by ignoring, postponing or shifting the responsibility for the problem. In addition, personality and environment affect the process (Taylor, 1979).

Studies Comparing AND and DNR

Prior to the work of Venneman et al., (2008), no scientific studies addressed the effect of Allow Natural Death versus Do Not Resuscitate. Venneman et al. tested the hypothesis that simply replacing the title of a DNR order with AND would influence approval by stakeholders. A sample of 687 study participants was split into three groups: nurses, nursing students and control lay persons (representing family members). After reading a brief scenario about the impending death of a loved one, participants marked their likelihood of consenting to either a AND or DNR order on a scale of zero to one hundred percent. The authors reported that participants were statistically more likely to sign the order when it was titled AND (77.19%, *SD* = 26.59, *n* = 372) over an identical order titled DNR (69.15%, *SD* = 33.13, *n* = 315) using a One-way ANOVA (*F* = 12.434 (685, 1) *p* = 0.000). A One-way ANOVA was then applied to evaluate the influence of endorsement by nursing education level without varying the order title (*F* = 49.083 (684, 2) *p* = 0.000). A Scheffe test post hoc showed a significant difference between all three groups, *p* = 0.000 for all comparisons with working nurses (85.29%, *SD* = 23.20, *n* = 294) being most likely to endorse and controls (60.69%, *SD* = 32.46, *n* = 229) being least likely to endorse. Nursing student's endorsement was in between the two (72.29%, *SD* = 29.48, *n* = 164). A significant difference in endorsement of DNR related to nursing background was demonstrated (*F* = 24.607 (312,2) p = 0.000). A Scheffe post hoc test revealed that working nurses (83.3%, *SD* = 26.18, *n* = 127) were significantly more likely to endorse a DNR than nursing students (65.84%, *SD* = 33.49, *n* = 78) *p* = 0.000 or controls (55.80%, *SD* = 33.85, *n* = 110) *p* = 0.000, which did not significantly differ from each other p = 0.097. All groups were different when endorsing AND (*F* = 24.77 (369,2) *p* = 0.000). A Scheffe test post-hoc indicated that working nurses (86.38%, *SD* = 20.66, *n* = 167) were more likely to endorse AND than were nursing students *p* = 0.049 or controls p = 0.000; and nursing students (78.15%, *SD* = 24.05, *n* = 86) were significantly more likely to endorse than controls (65.16%, *SD* = 30.59, *n* = 119) *p* = 0.001). Across all groups, there was a higher likelihood to endorse AND with less variation than DNR.

The study concluded that simply changing the title from DNR to AND increased participant acceptance. It was noted that the nursing students and the lay group representing family members were statistically more likely to be influenced by the change. Additionally, the authors posited that family members, who are often most reluctant to sign a DNR would be more likely to endorse the order if the name was changed to AND. The researchers recommended further research to examine difficulties in interpretation as a result of the framing effects of the negative do not and negative semantic reactions.

A second study, by Jones et al. (2008), investigated the attitudes and beliefs of 190 healthcare providers in a pediatric palliative care setting regarding the use of AND as opposed to DNR to assist in uncovering the ways each term might influence family responses to end of life treatment options. Qualitative data was collected along with quantitative data for a study of confidence and comfort levels of the use of the terms AND and DNR by 118 pediatric palliative care providers in the ICU. The researchers concluded that the use of terms which reflect the sensitive nature of end of life decisions have the potential to improve clear communication while promoting a family centered approach. The researchers recommended additional research with patients and their families. Chen and Younger (2008) critiqued the Venneman et al. (2008) study arguing that a change of terms was simply changing words and that change would not assist health care providers in discussions of end-of-life care. They posited that AND would add to the confusion surrounding end-of-life therapies and interventions. They recommended methodology and sampling procedures which included physicians.

In response, a third study by Wittmann-Price and Cella (2010), replicated the Venneman et al study with physicians, nurses, and health care students using the tool developed by Venneman et al. using a convenience sample. All responses were anonymous. Eighty-seven nurses or nursing students participated with a predominant percentage (37%) of the nurse group aged 41 to 60 years. One hundred physicians or medical students responded with 78% of the physician group aged 26 to 40 years compared. The levels of education were consistent with the health care role of the participants. Of the physicians that responded, 60% reported that they were practicing medicine. The physician groups were split equally with 50% being women and 48% being men (2 unanswered). Seventy-eight percent of the nurses were women. The predominant ethnicity reported in both groups was Caucasian (nurses, 69%; physicians, 41%). Nine percent of nurses and 5% of physicians reported that they were African American. The largest reported religion for both groups was Christian, 54% of nurses and 34% of physicians. Eighty-three percent of nurses said that they should be highly likely (75% or greater) to give consent for an AND order for a loved one and 51% would be 100% likely to give the consent. Seventy-eight percent of physicians reported that they would be highly likely (75% or greater) to give consent for an AND order for a loved one and 33% would be 100% likely to give the consent. The researchers reported no significant correlations between age, religion, ethnicity, or education with likeliness to consent to an AND order.

In summary, they found that majority of health care professionals who were surveyed reported that they were likely to consent to AND for a dying loved one. These results supported Venneman et al (2008). They concluded that changing terminology would be an initial step to eliminating dehumanization from caring for the dying. Recommendation of studies with patients and families was put forward.

Bernato and Arnold, (2013) explored the effect of emotional state and physician communication behaviors on surrogates' life-sustaining treatment decisions. They found that an experimentally induced emotional state did not influence code status decisions, although small changes in physician communication behaviors substantially influenced this decision. When no cardiopulmonary resuscitation was framed as the norm, rather than cardiopulmonary resuscitation, fewer surrogates chose cardiopulmonary resuscitation. Framing the alternative to cardiopulmonary resuscitation as allow natural death rather than do not resuscitate also resulted in fewer surrogates choosing resuscitation.

Reverend Meyer, a hospital chaplain, argued that DNR terminology is harsh, insensitive, and confusing, while AND terminology is gentler, and more definitive (Meyer, 1998). Meyer suggested a phasing out of Do Not Resuscitate (DNR) terminology with a simultaneous phasing in of Allow Natural Death (AND) terminology. There is evidence that this is occurring on the Physician Orders for Life Sustaining Treatment (POLST) form which translates patient preferences into specific medical orders to be honored by physicians and other health care workers during a medical crisis. The POLST form places AND/DNR side by side as a single option, (Center for Ethics in Health Care, Oregon Health & Science University, 2008).

From the perspective of medical ethicist Cohen (2004), the most prevalent problems associated with end of life decision making involve communication and semantics. "End of life issues generate feelings of guilt, tension, and conflict within families, and how the health care team presents the medical situation and the possible responses to it make all the difference" (Cohen, 2004, p. 49). Additionally, Cohen proposes that DNR sounds impersonal and cruel, representing to the family that the health care team has given up. He continued that this may push families toward a resistive stance in signing a DNR order. Cohen concluded that Allow Natural Death sounds gentler and more consoling even though it contains the word death. AND implies that care of the loved one will continue. According to Cohen, replacing DNR with AND can change the death experience for the survivors; leaving a memory of compassion and dignity, rather than one of abandonment.

In a 2005 editorial, registered nurses, Knox and Vereb reported that often families will refuse a DNR order because they internalize it as nothing will be done for the patient. Knox and Vereb propose that the AND terminology acknowledges that the patient is dying and that everything will be done to ensure that the death occurs as comfortable as possible. The authors noted a personal communication in the editorial with nurse case manager, Diane Huber (May 29, 2005) indicating that in her experience working with allow natural death language; decision makers seem to have a better understanding of the concept. Families will spend a lifetime reflecting on the conversation and their decision; the AND directive may help them in finding peace with it. In contrast, Chessa (2004), a clinical ethicist, cautioned against changing to AND terminology citing his belief that the words aim to change decision behavior by persuasion rather than by discussion. Chessa recommended evidence based trials using substituted terminology to evaluate any change in end of life terminology.

Message Framing

Message framing was introduced as a part of Prospect Theory by Tversky and Kahneman (1984), to explain deviations in decision making behaviors that might be predicted by an expected utility theory. Prospect Theory posits that the frame of reference of a decision maker may alter an outcome. Prospect Theory includes subjective assessment as a component of a decisional outcome. This subjective piece can be influenced by the wording of information or how the message is framed. There is evidence that variations in the framing of options elicit different preferences and that choices are very likely to be influenced by the manner in which options are presented (De Martino, Kumaran, Seymour, & Dolan, 2006). DNR orders may elicit negative reactions from individuals and may decrease appropriate end of life care. Evidence indicates that the plan of care for a patient with a DNR order is often unclear and fails to define limits other than cardiopulmonary resuscitation. Furthermore physicians initiate fewer interventions when a DNR order was present versus when a DNR order was absent (Smith & O'Neill, 2008). The semantic significance of the phrase was a factor in proposing a replacement or reframing of DNR with Allow Natural Death (AND). Framing effects are well recognized, and choice theories have been further advanced to consider these effects.

Message framing has been investigated in various circumstances, with findings indicating that the same information presented in two logically equivalent but opposite frames can yield different decisional outcomes. Areas in which message framing has been explored other than psychology and economics include: oncology, public health preventative initiatives, obstetrics, and genetic testing. Chapple, Campion, and May (1997), addressed anxiety and confusion in relation to terminology in genetic counseling and found careful choice of words may prevent unnecessary anxiety experienced by patients. Bernato and Arnold, (2013) concluded that changes in physician communication significantly influenced surrogate decision makers, resulting in fewer surrogates choosing cardiopulmonary resuscitation when framed as Allow Natural Death rather than Do Not Resuscitate.

Chapter Summary

This chapter discussed the relationship of the Decisional Conflict Scale and the Ottawa Decision Support Framework and examined the rationale for its use as an underlying guide. The effective use of Patient Decision Aids was explored and the key concepts of the study were defined. Applicable literature was presented supporting the concepts of the study and the independent variables, AND and DNR, and the dependent variable of decisional conflict. The relevant literature was organized into several categories: surrogate decision makers, communication and end of life decision making, decisional conflict, decision delay, studies comparing AND and DNR, and message framing.

Chapter 3: Methods

This chapter introduces the study method comparing two commonly used end of life terminologies; Allow Natural Death and Do Not Resuscitate. First, the sample population and the description of subjects, as well as subject sources and the selection process are described. Next, the Decisional Conflict Scale (DCS), its subscales, response categories, administration and scoring procedures are examined along with the development procedures and validity. Then the patient decision aid, vignette, and rationale for their use in this study are presented. The data collection settings and procedures as well as their rationale are described in detail to facilitate study replication. Finally, protection of human subjects and the script that describes the study procedure, risks, and subject withdrawal are detailed. Data analysis techniques and parameters are identified.

Research Design

This quantitative comparative study compared two commonly used end of life terminologies (AND or DNR) employing randomized descriptive techniques that incorporated a research packet consisting of six components:

1) The information sheet (Appendix A);
2) The designated loved one page (DLO, Appendix B);
3) One of two versions of a patient decision aid: PtDA Version 1 (AND, Appendix C), or PtDA Version 2 (DNR, Appendix D);
4) One of two corresponding personalized vignettes (AND, Appendix E) or (DNR, Appendix F);
5) The Decisional Conflict Scale (DCS, both versions Appendix G);
6) The demographic data sheet (DDS, Appendix H).

The findings of this study were posited to influence end of life policy, contribute to the development of the Ottawa Decision Support Framework, and impact Patient Decision Aid development.

Sample Population and Eligibility Criteria

The study included a convenience sample of adults living in New Jersey, age 50 or over, and capable of reading English at the eighth grade reading level. Demographic data were gathered for analysis. Subjects at active adult communities, and senior centers in New Jersey were surveyed at the respective meeting sites.

Sample Size Determination

Aggregate data was analyzed using Cohen's power analysis and confirmed by consulting with a nurse researcher with psychometric expertise. A sample size of 150 was determined appropriate. In addition to providing adequate power, the sample size *(N*=150) was adequate to protect against outliers and skewness (Munro, 2005; Waltz, Strickland & Lenz, 2005).

Human Subjects Protection

Permission to conduct this study was obtained from the dissertation advisory committee, Institutional Review Board (IRB) at the City University of New York, Graduate Center (GC/CUNY, Appendix I) and the City University of New York, College of Staten Island (CSI/CUNY), and at the administration sites as indicated. An IRB approved information sheet that indicated tacit consent to protect participant confidentiality was used to inform participants of their rights (Appendix A). The identities of participants remained anonymous. Data was collected and protected in a locked file cabinet in the investigator's office. Only the investigator had access to the dedicated file cabinet.

Instrument

The Decisional Conflict Scale

After obtaining permission from O'Connor, (Appendix J), the Decisional Conflict Scale (DCS) was used in this study. The 16 item DCS uses a 5 point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree). The scale consists of the following subscales: uncertainty (Items 1-3); the main modifiable factors contributing to uncertainty (Items 4-6); feeling unclear about one's values (Items 7-9); feeling unsupported in the decision making (Items 10-12); and the perception of the effectiveness of the decision making after the decision is made. The score calculation methods were calculated as instructed in the User Manual-Decisional Conflict Scale. The total score was calculated by that the responses of 16 items were summed, then divided by 16 and multiplied by 25. Totals scores can range from zero (no decisional conflict) to 100 (extremely high decisional conflict). Scores lower than 25 are considered to indicate little difficulty in decision making and associated with implementation. Scores greater than 37.5, are considered to indicate feeling unsure about implementation; and associated with decision delay (O'Connor, 2010). The DCS is written at the eighth grade reading level and has been used to study various low literacy populations worldwide. It has been used been used in more than 40 studies, and takes approximately 5-10 minutes to complete.

Items were developed from the construct of decisional conflict and validated by a panel of decision making experts. The DCS was initially evaluated with 909 participants who were asked to make decisions about influenza immunization and breast cancer screening; a subsample of participants was retested two weeks later. The test-retest correlation for the DCS and the uncertainty subscale was 0.81; the uncertainty subscale internal consistency coefficient was determined to be 0.78-0.92, ($p = 0.001$); effective decision making subscale 0.77-.084, (p =

0.001); and the factors contributing to uncertainty subscale 0.58-0.70; with an overall internal consistency coefficient range from 0.78 to 0.92 (p = 0.001), Bunn & ‘Connor, 1996).

The DCS demonstrated significant ability to discriminate between participants who had strong intentions to accept or decline immunizations or screenings and those who were uncertain of their intentions ($p<0.0002$). There was also significant discrimination between those who accepted or rejected immunization and participants who delayed the decision to be immunized. Construct validity demonstrated discrimination between groups who make and groups who delay decisions, with effect sizes ranging from 0.4 to 1.2 for the total scale. A weak inverse correlation was noted between the DCS and knowledge test scores ($r = -0.16$, $p < 0.05$), (O’Connor, 1995; 2010).

Results of a meta-analysis of the DCS demonstrated that the correlation between total DCS score and decision delay was very high (Sun, 2004). Increased total DCS scores were significantly correlated with decision delay with a point-biserial correlation coefficient ranging from 0.29 to 0.62 ($p < 0.0001$). Sun (2004), concluded that the DCS is a statistically significant predictor of decision delay according to study specific logistic regression models and reported odds ratio given by the random effects model of 23.81 (95% CI 4.66-121.51, $p < 0.004$)), indicating a 24-fold increase in decision delay for every one unit increase of the total DCS score.

Song and Sareika, (2006) examined the reliability and validity of the DCS for end of life decision making. They used combined data from two independent samples in which 59 outpatients with life threatening illness and their surrogate decision makers were compared using a decision aid intervention. The DCS demonstrated convergent, construct, and discriminant validity based on total scale scores and high internal consistency in the end of life decision making context. An examination of the correlation among the DCS subscales was weak

($r = 0.24$) and statistically insignificant in this sample ($n = 59$, p=0.001). A moderate correlation was revealed in perception of modifiable factors and the effectiveness of decision making ($r = 0.52$, $p<0.001$). The DCS evaluated intervention and control group patients using total and subscale scores and the individual items. The difference between the intervention and the control group was significant ($p = 0.001$). There was no significant difference in perceptions about modifiable factors contributing to uncertainty between groups; however the intervention group's perceptions concerning modifiable factors contributing to uncertainty and decision quality were statistically higher than the control group ($p = 0.001$) in both instances and internal consistency reliability Cronbach's alpha coefficient of .81 for the DCS total score. The weakest item to total correlations include the uncertainty subscale items ($.22 < r < 0.33$) and one modifiable factor contributing item (Item 12, $r = 0.23$). Chronbach alpha improved to .84 when the three uncertainty questions were eliminated. Chronbach alphas for the subscales of uncertainty, modifiable contributing factors, and effectiveness of decision making were 0.45, 0.80, and 0.92 respectively and correlations of the subscales to the DCS were 0.50, 0.87, and 0.73 (for each r, $p<0.001$). The authors concluded that the DCS appears to be a viable instrument for measuring the quality of end of life decisions and noted that the uncertainty subscale was weak in ability to discriminate and a lack of relationship with modifiable factors leading to uncertainty and effectiveness of decision making. The authors admit that previous studies show that uncertainty scores were highest among the subscales and did not significantly decline after a decision aid intervention. They cite their limited sample size and cautiously recommend the elimination of the uncertainty subscale in end of life decision making (Song and Sereika, 2006).

The DCS in End of Life Decision Making

Six studies have used the DCS to evaluate end of life decision making. In one study, patients with chronic obstructive pulmonary disease (COPD) confirmed preferences regarding mechanical ventilation and intubation, (Mitchell, Tetroe, and O'Connor, 2001); a second study examined preferences for feeding tube placement among cognitively impaired older individuals, (Briggs, Kirchhoff, Hammes, Song & Colvin, 2004); a third study evaluated women's preferences for end of life place of care, (Murray et al., 2003). In all cases, it appeared to be useful in measuring the impact of decision support interventions on patients making end of life choices surrounding possible treatments.

In a fourth study, Allen, Allen, Hilgeman, and DeCoster (2008), measured decisional conflict in end of life decision making using a vignette approach to study 78 adults (aged 74.5 ± 7.18). Measures included the Life Support Preferences/Predictions Questionnaire modified (LSPQ-m) and the Decisional Conflict Scale. A patient decision aid that included detailed descriptions of life sustaining treatment options for each LSPQ-m illness scenario, risks of the treatment, benefits of the treatment, and alternatives for each treatment (called medical information stimuli) was employed. Their findings showed that the decision aid reduced decisional conflict ($p = 0.049$) for hypothetical life sustaining treatment decisions. A mixed analysis of variance with group and race as between-subjects variables and illness and treatment as within-subjects variables revealed significant main effects of race, illness, and treatment, as well as a significant race-by-illness-by-group interaction (Λ=0.923, $F(2, 73)=3.05$, $p = 0.05$, partial $\eta^2 = 0.08$). Additionally, they reported ethnic differences in patterns of desire for life sustaining treatments for African Americans and Caucasians; where the patient decision aid resulted in less desire for life-sustaining treatments in African Americans but slightly greater desire for life sustaining treatments in Caucasians.

The fifth study, (Lyon et al., 2009) examined the effect of a patient decision aid on the congruence in adolescent/surrogate preferences for end of life care, decisional conflict, and communication quality. Families acknowledged a life threatening condition and were willing to initiate end of life conversations when their adolescents were medically stable. Significantly increased congruence for testing the difference of the two kappa values for the two conditions was reported for intervention versus control dyads. Intervention adolescents reported feeling significantly better informed about end of life decisions. Intervention adolescents and all of the surrogates were more likely to feel that their attitudes and wishes were known.

In a sixth study, Bernato and Arnold, (2013) investigated the effect of emotional state and physician communication of AND versus DNR with 256 surrogate decision makers using a 5 × 2 between-subject randomized factorial experiment. They implemented a web-based simulated interactive video meeting with an intensivist to discuss code status. They found that the experimentally induced emotional state did not influence end of life decision making. Additionally, framing no cardiopulmonary resuscitation as the norm rather than cardiopulmonary resuscitation resulted in fewer surrogates choosing cardiopulmonary resuscitation. The researchers concluded that changes in physician communication significantly influenced this decision.

Patient Decision Aids

Patient decision aids prepare and help people making complex decisions that involve weighing benefits, harms, and uncertainty, (Bekker et al., 1999; Estabrooks et al., 2000; O'Connor et al., 1999b; O'Connor et al., 1997). They differ from usual health education materials because of their personalized focus on options and outcomes as an adjunct for decision making preparation. According to the International Patient Decision Aids Standards Collaboration (Elwyn, 2006), patient decision aids are designed to prepare individuals to participate in making choices among healthcare options. PtDAs include evidence based information about a health condition; as well as the options; and potential benefits and harms. They help patients to identify their values in relation to the decision and to clarify the value they place on the specific benefits and harms. PtDAs usually describe the options in sufficient detail to provide an experience of the physical, emotional, and social effects of the decision itself; then guide individuals in considering which benefits and harms are most important to them, (Leatherman & Warrick, 2008).

This current study adapted CPR and DNR definitions and information developed by the American Academy of Family Physicians (2009), and used by Venneman et al (2008), in their study. The words Allow Natural Death and Do Not Resuscitate were equally substituted in the PtDAs to compare decisional conflict elicited by the different terms.

Vignette

Vignettes are hypothetical situations compiled from a variety of situations, sources, and research findings to study attitudes, beliefs, and perceptions (Hughes, 2001). Vignettes are used in research to prompt responses to study questions, when study of actual situations is impractical or unethical. Attitudes, perceptions and values surrounding end of life decision making are difficult to measure ((Denk, Benson, Fletcher, & Reigel, 1997); and vignette research provides a less threatening way to investigate emotionally difficult topics (Barter and Renold, 1999). Participants were asked to personalize the vignette so that they may envision the actual event as realistically as possible.

The vignette used in this study, was developed by the study researcher under the direction of O'Connor during a personal meeting. It describes an end of life scenario that is personalized by the reader. Subsequent review by a group of six nursing doctoral candidates provided evidence of face validity

The content validity index (CVI) for the vignette was calculated using the ratings of two doctorally prepared nurses with expertise in end of life issues and/or ethics, (Appendix K). The CVI was 1.00 for the vignette indicating that the doctorally prepared nurses found the items highly relevant and representative of the domain. Their comments were appraised by the nurse researcher and no items required modification.

Demographic Data Sheet

The demographic data sheet (DDS) was designed by the investigator to ascertain the characteristics of the sample and face validity was established by a panel of six nursing doctoral candidates. The DDS consists of a twelve item multiple selection survey that queries respondents regarding previous surrogate decision making experience, personal ownership of an Advance Directives (AD) or Health Care Proxy (HCP), age, sex, marital status, education, employment in the health care field, race, religious affiliation, religious attendance, and income. Questions were grouped by topic and arranged from general to specific. Demographic questions were included as indicated in a review of the literature. Demographic parameters were then evaluated by the panel of six nursing doctoral candidates for appropriateness and thoroughness in the collection of specific data that will be important to identify and analyze for the study participants. The two content validity experts were invited to provide comments about the DDS. Experts' comments were appraised by the nurse researcher and no items required modification.

Settings

Active adult communities and senior centers in New Jersey were used to gather data from voluntary participants.

Procedure

After obtaining Institutional Review Board (IRB) approval, participants were randomized into two groups, each received a one of two formats of a research packet. The packets were identical except for the use of the words Allow Natural Death and Do Not Resuscitate. Envelopes containing sealed packets and an information sheet were distributed. Participants were instructed to read the information sheet that indicated that completion of the survey is indicative of tacit consent. Participants were then asked to remove the packet and complete the cover sheet prior to breaking the packet seal. The cover sheet directed the participant to write the first name of a living adult loved one (excluding their child), and their relationship to the loved one in the spaces provided. The question, Does your loved one have a living will, health care proxy, or advance directive?, directed respondents to check no, yes, or not sure. Next, the research assistant instructed participants to open the packet to the first page and follow the directions. The research assistant then left the room while surveys were completed.

Participants were directed to read the decision aid and then insert the name of the named loved one (from the cover sheet of the test packet) into the blank spaces of the vignette (called the Case in the test packet). The vignette was scripted at the eighth grade reading level and described an end of life scenario of the loved one. Each participant was randomly assigned to receive one of two versions of the decision aid and vignette; V1 (AND) or V2 (DNR). V1 used the words Allow Natural Death and V2 used the words Do Not Resuscitate. The scripts were otherwise identical. After participants read the vignette, they were directed to complete the Decisional Conflict Scale (DCS) followed by a short demographic survey.

Instructions at the end of the packet indicated that they may leave when they are finished and directed participants to place their completed packets back into the envelope, seal it, and deposit the envelope in the designated box upon exiting the room.

Data Collection Procedure

Following dissertation proposal committee approval, the researcher contacted data collection site administrators and obtained letters of acknowledgement for participation in the study. Letters were submitted to the IRB as part of the approval process. IRB approval was obtained, with the provision that additional sites would be added after appropriate letters of acknowledgement were submitted to the IRB. Additional sites were identified and the required letters were submitted to the IRB (Appendix L). Site liaisons were contacted to invite their group members' participation in the study and to schedule survey dates. Consenting data collection site liaisons were asked to identify a designated area at the test site for participants and non-participants. At the time of the data collection event, the group liaison introduced the researcher and research assistant. The researcher thanked those who opted to participate in the study and introduced the research assistant before leaving the test room. The research assistant was trained by the researcher and completed the necessary training protocols for IRB clearance.

Guided by the script (Appendix M), the research assistant asked individuals who preferred not to participate in the nursing research study to relocate to the designated area. Once non-participants exited and volunteer participants were seated, the research assistant thanked them for their participation, provided instruction to guide participants, and distributed pencils that participants were directed to keep as an incentive/token of thanks for completing the survey.

Packets that contained either version of the PtDA randomly mixed into a single stack were distributed so that participants were unaware that they were receiving different versions. The participants were directed to read the consent form and participant questions were solicited. Participants were instructed that they should leave the room when finished and completed surveys were placed face down in the box at the room exit when they left. Participants were guided by the research assistant to complete the Designated Loved One (DLO) page and to follow the directions on the survey that advised them to turn the page and quietly complete the survey. The research assistant informed the participants that she would be seated outside the room until all participants were finished.

Data Analysis

The data were scored and coded and analyzed using SPSS version 21 software (SPSS, Inc., Chicago, IL). Variables were examined for accuracy of data entry and missing values. Group differences in decisional conflict with each terminology were explored using independent sample *t*-tests. A mixed analysis of variance (ANOVA) was applied to explore the effects of selected variables and possible interactions on surrogates desire or refusal of CPR. A statistician was consulted for guidance in data analyses, procedures, missing data, and accuracy of interpretation.

Chapter Summary

This chapter introduced the research design and discussed the design rationale. The minimal sample size (150) was determined and a convenience sample population consisting of adults age 50 and over living in New Jersey was selected. The sampling technique, subject sources, and selection process were explained. The Decisional Conflict Scale (DCS) was described in detail with the rationale for its use. The patient decision aid (PtDA) and the vignette were also described. Data collection settings: active adult communities and senior centers were identified. To facilitate study replication, the procedures with rationale were specified. Protection of human subjects and the script that describes the study procedure, risks, and subject withdrawal were presented, and data analysis techniques and parameters identified.

Chapter 4: The Results

This descriptive study compared two commonly used end of life terminologies. The influence of Allow Natural Death (AND) and Do Not Resuscitate (DNR) terminologies on surrogate decision makers' decisional conflict is examined through use of a vignette. This chapter will present the results of the study. Descriptive statistics, used to describe data from the Demographic Data Sheet (DDS) and the Decisional Conflict Scale (DCS) will be addressed first. Presentation of the inferential statistics for the independent and dependent variables will follow in the order of each research question. A concise summary of the results will conclude the chapter.

Sample Demographics

A convenience sample was selected for this study. The sample was drawn from a population of adults age 50 or older attending one of five selected senior centers in Morris County, New Jersey or one of two active adult communities in Monmouth County, New Jersey. Participation was voluntary and consent was tacit. Three hundred and sixty (360) research packets were distributed using randomized techniques between AND version (n=182) and DNR version (n=178). Remaining unaware of the two versions, participants were instructed by the trained research assistant (RA) to: a) complete the Designated Loved One page; b) quietly follow the survey directions for completion and return to a designated box Thirty-three participants (9.2%) completed the designated loved one page, opened the booklet and did not complete the remainder of the survey (AND version *n*=9 [2.5%]; DNR version *n*=24 [6.7%]). An additional 93 (25.8%) participants withdrew and anonymously returned the survey booklet unopened. One hundred twenty (120) adults (33.3%) completed the AND version and 114 adults (31.7) completed the DNR version for a total response rate of 65%. Site specific response rates ranged from 12% to 40%, (Table 1). Final sample size was *N*=234.

Table 1

Questionnaire Packet Distribution and Completion

	Distributed	Withdrew Unopened	Opened and Not Competed	Completed	Response Rate
Site 1					
AND	20	5	1	14	70%
DNR	20	8	2	10	50%
Total	40	13	3	24	60%
Site 2					
AND	18	8	6	4	22%
DNR	18	7	5	6	33%
Total	36	15	11	10	28%
Site 3					
AND	15	13	1	1	7%
DNR	15	6	3	6	40%
Total	30	19	4	7	23%
Site 4					
AND	14	3	1	10	71%
DNR	13	1	2	10	77%
Total	27	4	3	20	74%
Site 5					
AND	30	3	0	27	90%
DNR	29	10	4	15	52%
Total	59	13	4	42	71%
Site 6					
AND	40	13	0	27	68%
DNR	39	1	6	32	82%
Total	79	14	6	59	75%
Site 7					
AND	45	8	0	37	82%
DNR	44	7	2	35	80%
Total	89	15	2	72	81%
Grand Total	360	93	33	234	65%

Participant Demographics

The DDS was used to gather the demographics of the study participants (Table 2). Of the 234 respondents, age ranged from 50 to over 90, with the greatest percentage (31%) falling in the

Table 2

Demographics

Age		Highest education completed	
50-54	1%	Some high school	2%
55-59	5%	High school	35%
60-64	15%	Trade school	6%
65-69	31%	Some college	18%
70-74	18%	Associate degree	9%
75-79	16%	Bachelor's degree	12%
80-84	7%	Graduate degree	18%
85-89	6%	Ethnic/racial category	
90 & +	1%	African American or Black	1%
Sex		American Indian or Alaska Native	0%
Female	56%	Asian	2%
Male	44%	Hispanic or Latino	1%
Marital status		Native Hawaiian or Other Pacific Islander	0%
Single	1%	White, non-Hispanic	95%
With partner	2%	Other	0.4%
Married	76%	Yearly household Income	
Separated	0.4%	less than $50,000	36%
Divorced	3%	between $50,000 and $99,999	44%
Widowed	17%	between $100,000 and $150,000	16%
Worked in health care		more than $150,000	5%
No	79%	Attend services	
Yes	21%	Never	7%
Religious Affiliation		Rarely (several times a year)	30%
None	3%	Sometimes (at least once a month)	18%
Buddhist	0%	Frequently (at least once a week)	45%
Christian	83%	Personally have	
Hindu	0%	Neither Advanced Directive nor Health Care Proxy	11%
Jewish	11%	Advanced Directive	18%
Muslim	0%	Health care Proxy	17%
Other	3%	Advanced Directive and Health care Proxy	55%
Made decision in real life		Site	
No	58%	1	10%
Yes	42%	2	4%
Discussed preferences with you		3	3%
No	25%	4	9%
Yes	75%	5	18%
Named you as surrogate decision maker		6	25%
No	54%	7	31%
Yes	46%		

Note: Percentage is based on the number responding and does not include missing responses

65-69 year-old range. The next most frequently represented group was the 70-74 year-old range (19%); followed by the 75-79 year-old group (16%); the 60-64 year-old group (15%); the 80-84 year-old group (7%); the 85-89 year-old group (6%); the 55-59 year-old group (5%); the 50-54 year-old group (1%); and the 90 and over group (1%). Fifty-six percent were female and 44% were male. The majority of respondents were married (76%). Seventeen percent were widowed, 3% divorced, 2% single and living with partner, 1% single, and less than 1% was separated. Highest educational preparation ranged from some high school to college graduate school degree with 35% high school diploma followed by; graduate school (18%), some college (18%), baccalaureate (12%), associate (9%), trade school certificate (7%), and some high school (2%). Seventy-nine percent reported that they had never worked in the health-care field, and the remaining 21% reported working in the health care field.

Most respondents described themselves as White, non-Hispanic (95%) with the remaining respondents self-identifying as Asian (2%), African American or Black (1%), Hispanic or Latino (1%), and other pooled groups (<1%). When queried regarding religion, the majority reported their religion as Christian (83%), followed by Jewish (11%), Atheist or Agnostic (3%), and other (3%). Forty-five percent reported frequent attendance of religious services, followed by 30% stating that they rarely attended religious services. Services were attended at least once a month by 18% and never by 7%. Annual income ranged from less than $50,000 (36%), to more than $150,000 (5%). Forty-four percent reported annual incomes between $50,000 and $99,999; with the remaining 16% between $100,000 and $150,000.

Additionally, information regarding the lived experience with making this type of decision was gathered. The majority reported having not made this type of decision in real life (58%); while 42% said that they had made this type of decision. Fifty-four percent had not previously been named by their loved one as surrogate decision maker; while 46% had been named by their loved one as surrogate decision maker. Seventy-five percent said that their loved one had discussed their preferences, and 25% said that they had not. When asked about personally having prepared documents representing their own future wishes for end of life care, 55% reported having both an advance directive and health care proxy; 18% had only an advance directive; 17% had only a health care proxy; and 11% reported having neither an advance directive nor a health care proxy.

Although AND and DNR versions were randomly distributed, chi-square analyses indicated that females completed a statistically significant higher percentage of the AND version (63%) as compared to 49% completing the DNR version (χ^2= 4.487, *df* =1, *p*=.034). In addition, respondents using the AND version had a statistically significant higher percentage (83%) of indicating that they had discussed preferences in comparison to 68% of respondents using the DNR version (χ^2= 4.074, *df* =1, *p*=0.044). No other demographic variables were statistically significant for version completion.

Decisional Conflict Scale

With the permission of O'Connor, the Traditional Decisional Conflict Scale (DCS) was used to compare surrogate decision maker's decisional conflict when two different end of life terminologies were used as part of a personalized vignette guided decision exercise. As per O'Connor's guidelines, Part A was used to appraise difficulty in making a specific decision and consisted of at least two response options plus an unsure option. For the purposes of this study, Part A asked respondents if they would sign a particular document (AND or DNR, depending on version received). Response options included yes, no, or unsure. Part B of the traditional DCS consists of 16 positively phrased statements with a five point Likert scale, ranging from Strongly

Disagree (0), Agree (1), Neither Agree (2), Disagree (3) to Strongly Disagree (4). The DCS is further divided into 5 subscales: informed (items 1-3); values clarity (items 4-6); support (items 7-9); uncertainty (items 10-12); and effective decision (items 13-16). The score calculation methods were calculated as instructed in the User Manual-Decisional Conflict Scale. The total score was calculated by that the responses of 16 items were summed, then divided by 16 and multiplied by 25. Totals scores can range from zero (no decisional conflict) to 100 (extremely high decisional conflict). Scores lower than 25 are considered to indicate little difficulty in decision making and associated with implementation. Scores greater than 37.5 are considered to indicate feeling unsure about implementation; and are associated with decision delay. Similarly, subscores for each subscale were calculated by summing the responses of a subscale, then dividing by the numbers of items in the subscale and multiplying by 25 (O’Connor, 2010).

The results were examined, and after consideration of the absoluteness of end of life decisions, it was decided that data should be collapsed into three response categories. Strongly agree and agree categories were merged; neither agree nor disagree was left unaltered; and disagree and strongly disagree categories were merged; yielding the collapsed response distribution in percent (Table 3).

For all items, each of the response options were selected by some of the respondents; however responses were skewed towards strongly agree or agree across all items. Item means ranged from 0.72 (item 1) to 1.56 (item 12) with standard deviations ranging from 0.75 to 1.24. Additionally, the data were analyzed for missing responses. First, the number of missing responses for each case was calculated across the 16 survey questions. There were 22 cases with

Table 3

Collapsed Response Distribution in Percent (Sample N=234)

			Agree or Strongly Agree (0 or 1)	Neither Agree Nor Disagree (2)	Disagree or Strongly Disagree (3 or 4)
Subscale		Item	AND DNR Total	AND DNR Total	AND DNR Total
1. Informed subscale	1	I know which options are available to me	90.0 91.2 90.6	6.7 8.0 7.3	3.3 0.9 2.1
	2	I know the benefits of each option	88.3 89.4 88.8	5.8 9.7 7.7	5.8 0.9 3.4
	3	I know the risks and side effects of each option	87.4 88.4 87.9	6.7 10.7 8.7	5.9 0.9 3.5
2. Values clarity subscale	4	I am clear about which benefits matter most to me	92.4 84.1 88.3	4.2 14.2 9.1	3.4 1.8 2.6
	5	I am clear about which risks and side effects matter most	93.2 80.5 87.0	3.4 16.8 10.0	3.4 2.7 3.0
	6	I am clear about which is more important to me	88.3 79.5 84.1	9.2 17.9 13.4	2.5 2.7 2.6
3. Support subscale	7	I have enough support from others to make a decision	78.2 78.9 78.5	16.0 20.2 18.0	5.9 0.9 3.4
	8	I am choosing without pressure from others	84.7 81.6 83.2	12.7 16.7 14.7	2.5 1.8 2.2
	9	I have enough advice to make a choice	89.1 83.9 86.6	5.0 14.3 9.5	5.9 1.8 3.9
4. Uncertainty subscale	10	I am clear about the best choice for me	89.0 77.2 83.2	5.9 14.9 10.3	5.1 7.9 6.5
	11	I feel sure about what to chose	79.7	15.3	5.1

			Agree or Strongly Agree (0 or 1)	Neither Agree Nor Disagree (2)	Disagree or Strongly Disagree (3 or 4)
Subscale		Item	AND DNR Total	AND DNR Total	AND DNR Total
			75.4	14.0	10.5
			77.6	14.7	7.8
	12	This decision is easy for me to make	55.9	16.9	27.1
			51.8	23.7	24.6
			53.9	20.3	25.9
5. Effective decision subscale	13	I feel I have made an informed choice	89.9	5.9	4.2
			77.7	17.9	4.5
			84.0	11.7	4.3
	14	My decision shows what is important to me	87.4	8.4	4.2
			75.2	16.8	8.0
			81.5	12.5	6.0
	15	I expect to stick with my decision	85.8	11.7	2.5
			75.2	18.6	6.2
			80.7	15.0	4.3
	16	I am satisfied with my decision	85.7	11.8	2.5
			72.6	21.2	6.2
			79.3	16.4	4.3

missing data where 20 of these cases had two or less missing responses. Table 4 shows the frequency of the missing responses.

Table 4

Frequency of Missing Responses

# of missing responses	# of respondents	Percent
0	212	90.6
1	16	6.8
2	4	1.7
4	1	0.4
6	1	0.4
Total	234	100

The mean number of missing responses was 0.15 with a standard deviation of 0.58. The Mann Whitney U tests were used for comparing the distribution of DCS missing responses between the AND and DNR groups, and between 2-category demographic groups. The Kruskal-Wallis test (nonparametric) was used to compare the distribution of DCS missing responses across demographic groups with three or more categories, and sites. There was no significant difference in missing value between the versions, demographic groups and sites (all *p*-values are larger than 0.05); which confirmed that missing responses were random. The *p*-values are shown in the Table 5 below.

Table 5

Missing Responses between Demographic Groups

Demographic group	*p*-value
Made decision in real life	0.949
Named as surrogate	0.874
Discussed preferences	0.368
Personally have AD/HCP	0.808
Age	0.349
Sex	0.241
Marital status	0.541
Education	0.314
Worked in the health care	0.156
Race	0.878
Religious affiliation	0.649
Attend religious services	0.760
Household Income	0.446
Version	0.932
Site	0.135

For the purposes of DCS total score and subscore calculations, scores were based on valid responses. If there were two or more missing values in the calculation of subscore, the subscore would not have been calculated and would have been considered missing.

Next, a Cronbach's alpha was performed to evaluate internal consistency of the DCS, AND version, DNR version, and combined sample (Table 6). The alpha coefficient for the total instrument was .97 with subscore alpha coefficients ranging from .84 to .97 for both versions and the combined data. A minimum reliability coefficient of .80 is considered adequate for well-established instruments (Nunnally & Bernstein, 1994).

Table 6

Internal consistency of DCS: AND version, DNR version, and combined (Chronbach Alpha)

	AND	DNR	Total
Total DCS Score	.97	.97	.97
Informed Subscore	.96	.97	.96
Value Clarity Subscore	.96	.94	.95
Support Subscore	.85	.91	.87
Uncertainty Subscore	.84	.84	.84
Effective Decision Subscore	.96	.95	.96

For clarification, the following pertinent definitions are now restated and then results of paired research questions are discussed. First, statistical methods will be presented. Second, descriptive statistics, bivariate analyses, and additional analyses will be described. Finally, results and conclusions will be reported.

Decisional conflict is a state of uncertainty about what actions should be taken when actions involve risk, loss, regret, or challenge an individual's personal life values, ranging from 0 (no decisional conflict) to 100 (extremely high decisional conflict) as measured by the Decisional Conflict Scale (DCS) total score. Decisional conflict involves several components: certainty about best choice, feeling informed, personal values clarity, support in decision making, and effectiveness of decision and is measured by five corresponding subscores (uncertainty, informed, values clarity, support and effect decision) ranging from 0 to 100 on the DCS (O'Connor, 1995; 2010).

Decision delay and decision implementation are depicted in Table 7. Decision delay is the condition in which people do not decide but defer or avoid decisions (Nijstad & Handgraaf, 2008) due to higher levels of decisional conflict as indicated by a score greater than 37.5 on the DCS (O'Connor, 2010). Decision implementation refers to individuals making a decision and suggests little to no decisional conflict as indicated by a score of less than 24 on the DCS (O'Connor, 2010).

Table 7

Decision delay and decision implementation

Term	Definition	DCS Score
Decision delay	the condition in which people do not decide but defer or avoid decisions due to higher levels of decisional conflict	>37.5
Decision implementation	individuals making a decision and suggests little to no decisional conflict	<25

Research Questions One and Two

The first pair of research questions is:

1) Is there a difference in surrogate decision makers' decisional conflict when the terms Allow Natural Death or Do Not Resuscitate are used?

2) What is the relationship between select demographic variables and decisional conflict among surrogate decision makers?

Statistical Method

The version and select demographic variables were assessed to evaluate any relationship with the DCS total score, informed subscore, value clarity subscore, support subscore, uncertainty subscore and effective decision subscore. Modeling was conducted using a two-step approach. First, bivariate (single factor) analyses using independent sample *t-test*s or One-way ANOVA were conducted to identify individual predictors (version and select demographics) separately for the dependent variables (total score and each subscore). The version and select demographic variables that were significant (*p*<0.05) in the first step were included in the N-way ANOVA. The model included main effects and all possible two way interactions.

Descriptive Statistics and Bivariate Analyses

Descriptive statistics including the sample size, mean, standard deviation of total score, informed subscore, value clarity subscore, support subscore, uncertainty subscore, and effective decision subscore were calculated for the AND version and the DNR version, and demographic groups. The descriptive statistics and *p*-values for the bivariate analyses for total score, informed subscore, value clarity subscore, support subscore, uncertainty subscore and effective decision subscore are shown in Appendix N.

Results

The bivariate analyses showed that the version is not associated with the total score, informed subscore, value clarity subscore, support subscore and uncertainty subscore, but it is associated with effective decision subscore. The mean scores for AND version and DNR version are shown in Table 8.

The bivariate analyses also showed that the made decision in real life, surrogate decision maker, and discuss preference variables are associated with the total score. Additionally, the made decision in real life and surrogate decision maker variables are associated with the informed subscore. Surrogate decision maker, and discussed preference variables are associated with the value clarity subscore. The made decision in real life, surrogate decision maker, and discussed preference variables, are associated with support subscore. The discussed

Table 8

Differences in Mean Scores between AND Version and DNR Version

	AND		DNR				
	Mean	*SD*	Mean	*SD*	*df*	*t*	*p*
Total DCS	20.85	17.19	24.19	17.04	232	-1.493	0.137
Subscores							
Uncertainty	26.35	22.05	31.21	23.12	232	-1.646	0.101
Informed	19.72	20.12	18.66	16.86	231	0.436	0.663
Values Clarity	18.45	17.66	21.67	18.64	231	-1.355	0.177
Support	20.2	18.96	22.51	17.49	231	-0.966	0.335
Effective Decision	19.95	18.61	26.33	20.79	232	-2.479	0.014*

*statistically significant at 0.05 significance level

preference variable is associated with the uncertainty subscore. Finally; the version, living will, surrogate decision maker, and discussed preference variables are associated with the effective decision subscore, (Table 9).

Data Analyses Results Using N-way ANOVA

A multi-factor ANOVA was performed in this analysis. The total score, informed subscore, value clarity subscore, support subscore, uncertainty subscore, or effective decision subscore is the dependent variable. The version and select demographics variables that were significant ($p<0.05$) from bivariate analyses were the independent variables, excluding the discussed preference variable; since the discussed preference question was only answered by those respondents who indicated yes to the question of surrogate decision maker. The sample size would have been greatly reduced for the N-way ANOVA if the discussed preference variable was included. All possible 2-way interactions were included in the models and none of them was significant. The *p*-values from the N-way ANOVA for total score, informed subscore, value clarity subscore, support subscore, uncertainty subscore and effective decision subscore are shown in Appendix O.

Table 9

Version and significant demographic variables for DCS total score and subscores

Question	P-value
DCS total score	
Version	0.137
Made the decision in real life	0.032*
Surrogate decision maker	0.006*
Discuss preferences	0.004*
Informed subscore	
Version	0.663
Made the decision in real life	0.047*
Surrogate decision maker	0.031*
Value clarity subscore	
Version	0.177
Surrogate decision maker	0.007*
Discuss preferences	0.003*
Support subscore	
Version	0.335
Made the decision in real life	0.027*
Surrogate decision maker	0.013*
Discuss preferences	0.041*
Uncertainty subscore	
Version	0.101
Discuss preferences	0.002*
Effective decision subscore	
Version	0.014*
Living Will	0.032*
Surrogate decision maker	0.003*
Discuss preferences	0.003*

*statistically significant at 0.05 significance level

Conclusions

Analyses revealed that there is no significant difference in surrogate decision makers' decisional conflict (total score) when the terms Allow Natural Death or Do Not Resuscitate are used (*p*=0.085). There is however a relationship between the surrogate decision maker variable and decisional conflict (total score). The respondents who indicated no to the question has your loved one ever name them as a surrogate decision maker have a higher mean total score than those respondents who indicated yes to the question (*p*=0.020). Additionally, there is no difference in the mean informed subscore when the terms Allow Natural Death or Do Not Resuscitate are used (*p*=0.778) and, there is no relationship between any selected demographic variable and the informed subscore.

Analyses revealed that there is no difference in the mean value clarity subscore when the terms Allow Natural Death or Do Not Resuscitate are used (*p*=0.080). However, there is a relationship between the surrogate decision maker variable and the value clarity subscore (*p*=0.004). The respondents who indicated no to the question has your loved one ever name them as a surrogate decision maker have a higher mean value clarity subscore than those respondents who indicated yes to the question.

Additionally, there is no difference in the mean support subscore when the terms Allow Natural Death or Do Not Resuscitate are used (*p*=0.349), and that there is no relationship between any of the selected demographic variables and the support subscore. There is no difference in the mean uncertainty subscore when the terms Allow Natural Death or Do Not Resuscitate are used (*p*=0.165). There is a difference in the mean effective decision subscore when the terms Allow Natural Death or Do Not Resuscitate are used (*p*=0.032). The respondents who responded to the Allow Natural Death version had a lower mean effective decision subscore than those who responded to the Do Not Resuscitate version. Additionally, there is a relationship between the surrogate decision maker variable and the effective decision subscore (*p*=0.001). The respondents who indicated no to the question has your loved one ever named you as a surrogate decision maker have a higher mean effective decision subscore than those respondents who indicated yes to the question.

Research Questions Three and Four

The second pair of research questions is:

3) Is there a difference in surrogate decision makers' decision delay based upon the terminology Allow Natural Death or Do Not Resuscitate?

4) What is the relationship between select demographic variables and decision delay among surrogate decision makers?

Statistical Method

The version and select demographic variables were assessed for a relationship with decision delay. Decision delay was coded as 1 (yes) when the DCS score is larger than 37.5 and as 0 (no) when DSC score is less than or equal to 37.5. Modeling was conducted using a two-step approach. First, bivariate (single factor) analyses were conducted to identify individual predictors (version and select demographics) separately for the dependent variable (decision delay). Chi-square tests or Fisher's exact tests were used for the bivariate analyses. Then, the version and select demographic variables that were significant ($p<0.05$) at the first step were included in the logistic regression.

Descriptive Statistics and Bivariate Analyses Results

Descriptive statistics including the frequencies and percentages were calculated for the AND version, the DNR version, the demographic groups for decision delay, and the p values from the bivariate statistics (Table 10).

Table 10

Decision Delay, Version, and Select Demographics

	Decision Delay			*p*-value
	Yes	No	Total	
	N (%)			
Version				
A	12 (35.3)	108 (54.0)	120 (51.3)	0.044*
D	22 (64.7)	92 (46.0)	114 (48.7)	
Age				
50-59	2 (5.9)	13 (6.6)	15 (6.5)	0.205
60-69	17 (50.0)	88 (44.4)	105 (45.3)	
70-79	14 (41.2)	66 (33.3)	80 (34.5)	
>=80	1 (2.9)	31 (15.7)	32 (13.8)	
Sex				
Female	15 (44.1)	114 (57.9)	129 (55.8)	0.136
Male	19 (55.9)	83 (42.1)	102 (44.2)	
Race				
White, non-Hispanic	34 (100.0)	187 (94.4)	221 (95.3)	0.375
Non-white	0 (0.0)	11 (5.6)	11 (4.7)	
Marital Status				
Married	27 (79.4)	150 (75.8)	177 (76.3)	0.841
Widowed	6 (17.6)	34 (17.2)	40 (17.2)	
Single, Single living with partner, Separate, Divorced	1 (2.9)	14 (7.1)	15 (6.5)	
Education				
High school and below	12 (35.3)	88 (44.4)	100 (43.1)	0.320
Some college and above	22 (64.7)	110 (55.6)	132 (56.9)	
Religion				
None	2 (6.1)	5 (2.6)	7 (3.1)	0.430
Christian	26 (78.8)	159 (83.7)	185 (83.0)	
Other	5 (15.2)	26 (13.7)	31 (13.9)	
Religious Service				
Never	3 (8.8)	13 (6.8)	16 (7.1)	0.604
Rarely	12 (35.3)	55 (28.9)	67 (29.9)	
Sometimes	7 (20.6)	33 (17.4)	40 (17.9)	
Frequently	12 (35.3)	89 (46.8)	101 (45.1)	
Household Income				
<50,000	7 (26.9)	60 (37.0)	67 (35.6)	0.296

	Decision Delay			*p*-value
	Yes	No	Total	
50,000-99,000	15 (57.7)	67 (41.4)	82 (43.6)	
>=100,000	4 (15.4)	35 (21.6)	39 (20.7)	
Relationship				
Spouse	22 (66.7)	135 (67.8)	157 (67.7)	0.894
All other categories	11 (33.3)	64 (32.2)	75 (32.3)	
Living Will				
Yes	11 (33.3)	101 (50.8)	112 (48.3)	0.097
No	17 (51.5)	65 (32.7)	82 (35.3)	
Not sure	5 (15.2)	33 (16.6)	38 (16.4)	
Made the decision in real life				
Yes	9 (26.5)	88 (44.4)	97 (41.8)	0.050*
No	25 (73.5)	110 (55.6)	135 (58.2)	
Surrogate decision maker				
Yes	10 (31.3)	95 (48.5)	105 (46.1)	0.070
No	22 (68.8)	101 (51.5)	123 (53.9)	
Discussed preferences				
Yes	6 (75.0)	85 (96.6)	91 (94.8)	0.054
No	2 (25.0)	3 (3.4)	5 (5.2)	
Having AD or HCP legal document				
Do not have both Docs	2 (12.5)	14 (10.4)	16 (10.7)	0.681
Have AD, HCP or both	14 (87.5)	120 (89.6)	134 (89.3)	
Worked in the health care field				
Yes	4 (11.8)	44 (22.1)	48 (20.6)	0.168
No	30 (88.2)	155 (77.9)	185 (79.4)	
Site				
1	3 (8.8)	21 (10.5)	24 (10.3)	0.750
2	1 (2.9)	9 (4.5)	10 (4.3)	
3	1 (2.9)	6 (3.0)	7 (3.0)	
4	1 (2.9)	19 (9.5)	20 (8.5)	
5	7 (20.6)	35 (17.5)	42 (17.9)	
6	12 (35.3)	47 (23.5)	59 (25.2)	
7	9 (26.5)	63 (31.5)	72 (30.8)	

*statistically significant at 0.05 significance level

Results From Bivariate Analyses

All Chi-square tests or Fisher's exact tests showed that there is no relationship between decision delay and the demographic variables except the version variable (*p*=0.044) and the made decision in real life variable (p=0.050).

Data Analyses Results Using Logistic Regression

To evaluate this data, decision delay was used as the dependent variable. The version and made the decision in real life were the independent variables (Table 11).

Table 11

Results for Logistic Regression

	Odds ratio	95% CI	*p*-value
Version			
AND (reference)	-	[0.22, 1.02]	0.057
DNR	2.08	-	
Made the decision in real life			
No	2.11	[0.93, 4.79]	0.073
Yes (reference)			

Conclusions

Analyses revealed that there is no statistical difference in surrogate decision makers' decision delay based upon the terminology Allow Natural Death or Do Not Resuscitate. Additionally, there is no relationship between the made decision in real life variable and decision delay among surrogate decision makers.

Research Questions Five and Six

The third pair of research questions is:

5) Is there a difference in surrogate decision makers' decision implementation based upon the terminology Allow Natural Death or Do Not Resuscitate?

6) What is the relationship between select demographic variables and decision implementation among surrogate decision makers?

Statistical Method

The version and select demographic variables were assessed for a relationship with decision implementation (DI). DI was coded as 1 (yes) when DCS score was less than 25; and as 0 (no) when DSC score was greater than or equal to 25. Modeling was conducted using a two-step approach. First, bivariate (single factor) analyses were conducted to identify individual predictors (version and select demographic variables) separately for the dependent variable (decision implementation). Chi-square tests or Fisher's exact tests were used for the bivariate analyses. Secondly, the version and select demographic variables that were significant ($p<0.050$) in the first step were included in the logistic regression.

Descriptive Statistics and Bivariate Analyses Results

Descriptive statistics including the frequencies and percentages were calculated for the AND version, the DNR version (Appendix P), and demographic groups by the groups of decision implementation (Appendix Q).

Results of the Bivariate Analyses

All the Chi-square tests or Fisher's exact tests showed that there are no relationships between decision implementation and all of variables except the religious service, living will and surrogate decision variables.

Data Analyses Results using Logistic Regression

To evaluate this data, decision implementation was used as a dependent variable. The version, religious service, living will and surrogate decision maker variables that were significant ($p<0.050$) from bivariate analyses are the independent variables.

Conclusions

Analyses revealed that there is no statistical difference in surrogate decision maker's decision implementation based upon the terminology Allow Natural Death or Do Not Resuscitate (p=0.279). However, there is a relationship between religious service and decision implementation; where the predicted odds of decision implementation for those who rarely attend religious services are about 0.5 times the odds of those frequently attending religious service (Table 12).

Table 12

Data Analyses Results using Logistic Regression

	OR	95% CI	*P*-value
Version			
AND	1.37	[0.78, 2.40]	0.279
DNR (reference)	-	-	
Attend Religious Service			
Never	1.4	[0.46, 4.28]	0.557
Rarely	0.46	[0.23, 0.89]	0.021*
Sometimes	1.16	[0.53, 2.55]	0.712
Frequently (reference)	-	-	
Living Will			
Yes	0.53	[0.23, 1.23]	0.139
No	0.97	[0.42, 2.25]	0.950
Not sure (reference)			
Surrogate decision maker			
No	0.56	[0.31, 1.03]	0.060
Yes (reference)			

*statistically significant at 0.05 significance level

Research Questions Seven and Eight

The fourth pair of research questions is:

7) Is there a difference in surrogate decision makers' end of life decision making based upon the terminology Allow Natural Death or Do Not Resuscitate?

8) What is the relationship between select demographic variables and end of life decision making?

Statistical Method

The version and select demographic variables were assessed for their relationship with end of life decision making. End of life decision making was based on the question, Will you sign the AND or DNR document? The choices for this question are yes, no and unsure. The dependent variable was analyzed three ways:

a) yes versus no

b) sure decision (yes and no combined) versus unsure, where yes and no were combined and interpreted as participants having made a sure decision.

c) yes versus actual no or default no (no and unsure combined), where unsure was interpreted as a default way of saying no because the document would remain unsigned under the unsure circumstances.

Modeling was conducted using a two-step approach. First, bivariate (single factor) analyses were conducted to identify individual predictors (version and select demographics) separately for the dependent variable (end of life decision making). Chi-square tests or Fisher's exact tests were used for the bivariate analyses (Appendix R). Secondly, the version and select demographic variables that were significant (p<0.050) in the first step were included in the logistic regression.

Descriptive Statistics and Bivariate Analyses Results

Descriptive statistics including the frequencies and percentages were calculated for the AND version, the DNR version, and demographic groups for end of life decision making.

Results from Bivariate Analyses

Bivariate analyses are reported below.

a) For yes vs. no responses, the bivariate analyses showed that there is a significant difference in end of life decision making based upon the terminology Allow Natural Death or Do Not Resuscitate, ($p< 0.001$). Additionally, there is a significant difference in end of life decision making based on the religion, ($p=0.038$).

b) For sure decision ([yes or no] vs. unsure) responses, the bivariate analyses showed that there is a significant difference in end of life decision making based upon the terminology Allow Natural Death or Do Not Resuscitate, ($p< 0.001$). Additionally, there is a significant difference in end of life decision making based on made decision in real life, ($p=0.050$) and discussed preferences, ($p=0.032$).

c) For yes vs. actual or default no (no and unsure combined), the bivariate analyses showed that there is a significant difference in end of life decision making based upon the terminology Allow Natural Death or Do Not Resuscitate, ($p< 0.001$).

Data Analyses Results Using Logistic Regression

End of life decision making was the dependent variable. The version and select demographics variables that were significant ($p<0.05$) from bivariate analyses were calculated as the independent variables.

Conclusions for a. The predicted odds of indicating yes, for will you sign the document?, when using the terminology Allow Natural Death are about 8 times the odds when using the terminology Do Not Resuscitate (Table 13). Additionally, there is no relationship between the religion and end of life decision making (yes vs. no).

Table 13

Yes vs. No

	Odds ratio	95% CI	p-value
Version			
A	7.97	[3.41 – 18.63]	<0.001*
D (reference)			
Religions			
Christian	1.78	[0.27 – 11.75]	0.550
Other	13.89	[0.88 – 219.11]	0.062
None			

*statistically significant at 0.05 significance level

Conclusions for b (including made the decision in real life and discussed preferences). The predicted odds of indicating unsure at the time of end of life decision making for using the terminology Do Not Resuscitate are 6.25 times the odds for using the terminology Allow Natural Death. Additionally, having made the decision in real life and discussed preferences do not influence end of life decision making (Table 14).

Table 14

Sure decision (yes and no) vs. Unsure

	Odds ratio	95% CI	p-value
Version			
A (reference)		[0.03 – 0.77]	
D	6.25	[1.30 –3.33]	0.023*
Made decision real life			
No	0.74	[0.23 – 2.44]	0.622
Yes (reference)			
Discussed preferences			
No	5.24	[0.77 – 35.96]	0.092
Yes (reference)			

*statistically significant at 0.05 significance level

Conclusions for b (excluding discussed preferences). The predicted odds of indicating unsure at the time of end of life decision making for using the terminology Do Not Resuscitate is 7.69 times the odds for using the terminology Allow Natural Death (Table 15).

Table 15

Sure decision (Yes and No combined) vs. Unsure

	Odds ratio	95% CI	*p*-value
Version			
AND (reference)			
DNR	7.69	[3.33-16.67]	<0.001*
Made the decision in real life			
No	1.84	[0.89 – 3.82]	0.102
Yes (reference)			

*statistically significant at 0.05 significance level

Conclusions for c. The predicted odds of indicating yes at the time of end of life decision making for using the terminology Allow Natural Death are 10.3 times the odds for using the terminology Do Not Resuscitate, (Table 16).

Table 16

Yes vs. actual no and unsure combined

		Odds ratio	95% CI	*p*-value
Version	AND	10.29	[5.43-19.49]	<0.001*
	DNR (reference)			

*statistically significant at 0.05 significance level

Additional Analyses

As mentioned earlier in this chapter, thirty-three participants (9.2%) completed the designated loved one page, opened the booklet and did not complete the remainder of the survey (AND version *n*=9 [2.5%]; DNR version *n*=24 [6.7%]). They viewed the terms in their respective booklets as Allow Natural Death or Do Not Resuscitate. A Chi-square test was used to compare versions to see if there was a significant difference in the percentage of opened and not completed surveys. The p-value was 0.0050. Therefore, there was a significant difference in the percentage of opened and not completed surveys between the AND and DNR versions. The DNR version has higher percentage of opened and not completed surveys than the AND version (Table 17).

Table 17

Opened and Not Competed Surveys

	N	%	*p*-value
AND	9	5.0	0.0050*
DNR	24	13.5	

*statistically significant at the 0.05 level

Chapter Summary

This chapter presented the results of the study. Descriptive statistics, used to describe data from the Demographic Data Sheet (DDS) and the Decisional Conflict Scale (DCS) were addressed first. Then, internal consistency of DCS: AND version, DNR version, and combined were calculated. The alpha coefficient for the total instrument was .97 with subscore alpha coefficients ranging from .84 to .97 for both versions and the combined data.

Each research question was restated and inferential statistics for the independent and dependent variables followed. Findings included that the AND version was more likely to be signed than the DNR version, however, there was no significant difference in total DCS score based on AND and DNR versions. Frequent attendance at religious services was found to double the odds of decision implementation. Additionally, experienced decision makers emerged as a distinct group with lower mean total DCS scores. As a group, they were more likely to perceive their decision as a good decision, and were clear about personal values and benefits and risks of signing the document regardless of AND or DNR terminology. They were more likely to report that they felt more highly informed in making their decision. Finally, they were more likely to perceive that they had made the best choice. This indicates that AND terminology influenced the long term wellbeing of surrogate decision makers. Additional study findings identified that there was a statistically higher number of DNR participants who withdrew from the study when compared to AND participants.

Chapter 5: Discussion

This chapter will present the summary of the study, discuss the relevant findings, identify limitations, present implications for practice, propose recommendations for future research, and present conclusions of the study. Finally a synthesizing statement will be presented to summarize the value and scope of what has been undertaken in this research.

Summary of the Study

DNR is the predominant terminology used in today's health care system to address end of life decisions. There has been a movement toward using the words Allow natural death (AND). This study's problem statement was: surrogate decision makers' decisional conflict may be affected by the terminology used at the time of end of life decision making. The purposes of this study were: to explore: a) the relationship between the two terminologies and select demographic variables examining decisional conflict and decision delay; b) the extent to which each term predicted decision delay; and c) contributions to the Ottawa Decision Support Framework (ODSF) and Patient Decision Aids (PtDAs).

The ODSF describes how to facilitate the decision making process (O'Connor et al. 1998: Murray et al., 2004). The ODSF was conceptualized as a guide for interventions, and as a preparation for shared decision making (O'Connor et al., 1998). It looks at health decisions that fall into the following categories: the decision is necessitated by a new situation, diagnosis, or life transition; where careful deliberation is fundamental based on the value laden nature of the risk and/or benefits; and greater effort is required during the consideration phase than during the actual implementation of the decision (Ottawa Health Research Institute (OHRI), 2013). The ODSF hypothesizes that improved decision making quality will have a positive influence on patients' outcomes, (Legare et al., 2003). It applies to individuals involved in the decision making process and posits that decisional needs will influence informed values-based choices; that in turn influence actions and behaviors such as decision delay, outcomes, emotions (such as regret and blame); in addition to the appropriate use of health services (Ottawa Health Research Institute (OHRI), 2013). The ODSF provides an approach for supporting patients and their families in the decision making process with a goal of minimizing decisional conflict, decision delay, and decision regret. It uses patient decision aids (PtDAs) with the aim of supporting patients and their families in the decision making process.

The use of patient decision aids (PtDAs), as a tool to support individuals with decision making needs is well researched. PtDAs have been found to improve decision quality and measures of feeling informed and clear about values (O'Connor et al., 2007). Several systematic reviews have examined outcomes and limitations of PtDAs (Feldman-Stewart, Brundage, Siemens, & Skarsgard, 2006; Whelan, McKinley, Boulet, Macrae & Kamholz, 2001; O'Connor. et al., 2003; O'Connor et al., 2009; Coulter & Ellins, 2007) and found improved patient knowledge and understanding of their condition.

This study was conducted as a quantitative descriptive study of a sample of 234 adults age 50 and older at active adult communities and senior centers in New Jersey. Participants were randomized into two groups and each received and personalized a vignette. The vignettes were identical except for the use of the words Allow Natural Death or Do Not Resuscitate. After participants read the vignette, a patient decision aid specific to the terminology used was presented in the research packet. The Decisional Conflict Scale (DCS) was administered to each participant to measure their perception of uncertainty in choosing the options offered; and which factors contributed to uncertainty and effective decision making such as feeling the choice is informed, value based, likely to be implemented, and expressed satisfaction with the choice.

The need for the study was supported by prior research as well as gaps in research. Prior to the inception of the study, few studies compared AND and DNR. During the process of this research, a single study was published that compared AND and DNR using the Decisional Conflict Scale (Bernato & Arnold, 2013).

Discussion of the Findings

This section discusses the implications of the findings for each of the eight research questions. The question will be restated; then the findings of each question will be summarized; additional findings will be discussed; and then a final summarization of relevant findings will be presented.

Research question one. Is there a difference in surrogate decision makers' decisional conflict when the terms Allow Natural Death or Do Not Resuscitate are used? The findings indicate that there is no significant difference in surrogate decision makers' total score for decisional conflict when the terms Allow Natural Death or Do Not Resuscitate are used. This finding is consistent with the findings of Bernato and Arnold (2013), who evaluated the effect of the terminologies AND versus DNR on surrogate decision makers' decisional conflict and found that none of the experimental conditions including the terminologies AND and DNR, impacted decisional conflict.

Additionally, findings indicate that there is no significant difference in surrogate decision makers' informed subscore when the terms Allow Natural Death or Do Not Resuscitate are used. This reflects on the patient decision aid having met its goal as a tool to support individuals with decision making needs. As stated earlier, PtDAs improve decision quality and measures of feeling informed and clear about values (O'Connor et al., 2007); and improve patient knowledge and understanding of their condition (Feldman-Stewart, Brundage, Siemens, & Skarsgard, 2006;

Whelan, McKinley, Boulet, Macrae & Kamholz, 2001; O'Connor. et al., 2003; O'Connor et al., 2009; Coulter & Ellins, 2007).

Findings also indicated a difference in the mean effective decision subscore when the terms Allow Natural Death or Do Not Resuscitate were used. The effective decision subscore consists of four items: I feel that I have made an informed choice; my decision shows what is important to me; I expect to stick with my decision; and I am satisfied with my decision. This scale measured the extent to which a patient perceives the decision as effective, in that it was based on information, consistent with personal values, and implemented on these values. The respondents who responded to the Allow Natural Death version had a lower mean effective decision subscore than those who responded to the Do Not Resuscitate version, indicating that AND respondents perceived their decision as a good decision, and felt more positive about the decision. The DNR respondents perceived their decisions as a bad decision. They felt more negative about the decision indicating that DNR respondents were more likely to suffer the long term effects of decision regret. This is consistent with Cohen (2004) who found negative feelings in surrogate decision makers when signing a DNR. Additionally, it is consistent with Tversky and Kahneman (1984), and De Martino, Kumaran, Seymour, and Dolan (2006), who found that decisions may be influenced by framing effects or the manner in which options were presented. Furthermore, the manner in which end of life discussions are framed can contribute to how families make decisions about life-sustaining treatment (Tilden, Tolle, Garland, & Nelson, 1995). It is also consistent with the conclusions of Jones et al. (2008) that it is important to investigate how healthcare providers frame such end of life discussions, focusing specifically on the actual terminology they use to discuss withdrawal of life-sustaining treatment with families. They concluded that the term AND empowers families to make difficult end of life decisions.

Research question two. What is the relationship between select demographic variables and decisional conflict among surrogate decision makers?

Firstly: those who had been named as the surrogate decision maker by the designated loved one had a lower total decisional conflict score than those who had not been named as the surrogate decision maker. This may reflect the discussions of preferences at the time that the surrogate was selected; indicating that the interpersonal process that occurred when surrogate and patient communicated about acting as a surrogate decision maker decreased the surrogate's level of decisional conflict with end of life decision making. Findings of this study also indicated that surrogates who had discussed preferences with the designated loved one had a lower total decisional conflict score.

Secondly: those who had made the decision in real life had a lower informed subscore than those who had not had experience with end of life decision making; and those who had actually been named by the designated loved one as the surrogate decision maker had a lower informed subscore than those who had not been formally named as a surrogate decision maker. This indicates that having had experience as a surrogate decision maker or the process of being named as a surrogate decision maker enhances an exchange of information and increased the feeling of being informed.

Thirdly: those who had been named as the surrogate decision maker had a lower values clarity subscore than those who had not been named as surrogate decision maker; and those who had discussed preferences with the designated loved one had a lower value clarity subscore than those who had not discussed preferences with the designated loved one. The values clarity subscore encompasses three statements: I am clear about what matters most to me; I am clear about which risks and side effects matter most; and I am clear about which is more important to me (the benefits or the risks and side effects). In summary, surrogate decision makers were clearer about personal values; and the benefits and risks of side effects. Therefore, actually having been formally named and the interpersonal process that occurred when surrogate and patient communicated about acting as a surrogate decision maker increased the surrogate's clarity about personal values; and the benefits and risks of side effects with end of life decision making.

Fourthly: those who had made the decision in real life had a lower support subscore than those who had never made the decision in real life; those who had been named as the surrogate decision maker had a lower support subscore than those who were not named as the surrogate; those who had discussed preferences with the designated loved one had a lower support score than those who had not discussed preferences with the designated loved one. The support encompasses three statements: I have enough support from others to make a choice; I am choosing without pressure from others; and I have enough advice to make a choice. This indicates that the experience of having made an end of life decision and the process of communication with the designated loved one felt clearer about personal values for benefits and risks or side effects (the final outcome of death).

Fifthly: those who had discussed preferences with the designated loved one had a lower uncertainty subscore than those who had not discussed preferences with the designated loved one. The uncertainty subscore encompasses three statements: I am clear about the best choice from me; I feel sure about what to choose; and this decision is easy for me to make. In summary, surrogate decision makers felt more certain that they had made the best choice. This indicates that having had experience as a surrogate decision maker or the process of being named as a surrogate decision maker enhanced an exchange of information and increased the surrogate's certainty that the right choice was made.

Sixthly: those who reported having some sort of advance directive had a lower effective decision subscore than those who reported that they do not have an advance directive; those who had been named as surrogate decision maker by the designated loved one had a lower effective decision subscore than those who had not been named as the surrogate decision maker; and those who reported that they had discussed preferences with the designated loved one had a lower effective decision subscore than those who had not discussed preferences with the designated loved one. They felt that they had made an informed choice that reflected what was important to them; and were satisfied with their decision and expected to stick with their decision.

Finally: those who had been named as the surrogate decision maker by the designated loved one had a lower mean effective decision subscore than those who were not named as the surrogate decision maker by the designated loved one. The effective decision subscore encompasses four statements: I feel I have made an informed choice; my decision shows what is important to me; I expect to stick with my decision; and I am satisfied with my decision. Being named as the surrogate decision maker increased the likelihood of thinking that they had made a good decision.

Research question three. Is there a difference in surrogate decision makers' decision delay based upon the terminology Allow Natural Death or Do Not Resuscitate? No statistically significant difference in surrogate decision makers' decision delay based upon the terminology Allow Natural Death or Do Not Resuscitate was identified in this study. Decision delay occurs along the continuum leading to decisional conflict and this finding is consistent with the findings of research question one, which found no difference in decisional conflict when the two terms were compared.

Research question four. What is the relationship between select demographic variables and decision delay among surrogate decision makers? No statistically significant relationship was found between the demographic variables and decision delay among surrogate decision makers.

Research question five. Is there a difference in surrogate decision makers' decision implementation based upon the terminology Allow Natural Death or Do Not Resuscitate? No statistically significant statistical difference in surrogate decision maker's decision implementation based upon the terminology Allow Natural Death or Do Not Resuscitate was identified in this study.

Research question six. What is the relationship between select demographic variables and decision implementation among surrogate decision makers? There is a relationship between those who frequently attend religious services and decision implementation. Those who frequently attend religious services are twice as likely as those who rarely attend religious services of implementing their decision; whether the decision is to sign or not to sign the AND or DNR. Church attendance and church resources lend social support to individuals in crisis (Ellison & George, 1994; Iverson et al., 2013; and Taylor & Chatters, 1998). Additionally, churches are increasingly contributing to the conversation and making proclamations on natural death instructions and end of life decision making (Bollig, 2006).

Research question seven. Is there a difference in surrogate decision makers' end of life decision making based upon the terminology Allow Natural Death or Do Not Resuscitate? Participants were eight times more likely to sign the document when it was an

AND (allow natural death) document than were participants who were asked to sign a DNR (do not resuscitate) document. This indicates that framing influences surrogate decision making at the end of life, and quite possibly substantiates the anecdotal findings of Meyer (1998), who proposed that that AND terminology is both gentler and more definitive; and that DNR terminology is harsh, insensitive, and confusing. Additionally, Venneman et al (2008) proposed that “DNR orders elicit negative reactions from stakeholders that may decrease appropriate end of life care” (2008, p. 2). Hence, even though AND and DNR did not influence the total decisional conflict score, they did influence the choice to actually sign or not sign the document. These findings are consistent with the findings of Venneman et al. (2008), and Bernato and Arnold (2013).

Research question eight. What is the relationship between select demographic variables and end of life decision making? The predicted odds of indicating yes, for will you sign the document? when using the terminology Allow Natural Death are about 8 times the odds when using the terminology Do Not Resuscitate. The preference for the AND terminology is consistent with the findings of Venneman et al. (2008) who found that participants receiving the AND scenario were statistically more likely to endorse it than their counterpart receiving the DNR scenario.

Surrogate decision makers who had made the decision in real life or discussed preferences with the designated loved one were more likely to be to be sure of their decision when the term Allow Natural Death was used, indicating that experienced decision makers respond more favorably to the words Allow Natural Death. Hence, long term wellbeing of the surrogate decision maker can be positively influenced by changing the term to Allow Natural Death. Indicating that they were unsure of their decision was not influenced by experience or lack of experience in decision making, but was influenced by terminology, with DNR respondents reporting more uncertainty with their decision. Thus, the term Allow Natural Death leads to increased likelihood of actually making a decision. Additionally, a greater number of respondents to the DNR terminology were likely to not sign or postpone signing, leading to prolongation of life of dying individuals.

Additional Analyses

Thirty-three participants (9.2%) completed the designated loved one page, opened the booklet and did not complete the remainder of the survey (AND version *n*=9 [2.5%]; DNR version *n*=24 [6.7%]). This indicated that they viewed the terms in their respective booklets: Allow Natural Death or Do Not Resuscitate, and then decided to withdraw from the study. The significant difference in the percentage of opened and not completed surveys based on version indicates desire to not read, deal with, or think about the material. The DNR version had higher percentage of opened and not completed surveys than the AND version. Therefore it is thought that the mere sight of the terminology is a deterrent to action.

In summary, there was no difference in total DCS score based on AND and DNR versions. This is thought to be due to the educational influence of the PtDA. PtDAs are not routinely used in end of life decision making. Further research controlling for the PtDA is recommended. Participants who had actually been named as the surrogate decision maker by the designated loved one had lower mean total DCS scores; lower mean effective decision subscores; and lower mean values clarity subscores. They were more likely to perceive their decision as a good decision, and were clear about personal values and benefits and risks of signing the document regardless of AND or DNR terminology.

Participants who had made the decision in real life had lower mean informed subscores, and lower mean support subscores. They were more likely to report that they felt more highly informed in making their decision, and felt better in their decision making. Additionally, participants who had discussed preferences with the designated loved one had lower mean uncertainty subscores, and lower mean effective decision subscores. They were more likely to perceive that they had made the best choice, and terminology influences the long term wellbeing of surrogate decision makers. Participants who had advance directives in place for themselves had a lower mean uncertainty subscore. They were more likely to perceive that they had made the best choice. This indicates that the act of preparing an advance directive is a learning experience that influences decision making. A critical element of advance directive conversations includes death preparedness. This involves the transition of communication with a healthcare provider that leads to the awareness and the acceptance of end of life, as evidenced by an implementation of a plan (McLeod-Sordjan, 2013).

In an overview of systematic reviews, Tamayo-Velázquez et al. (2010) identified the combination of informative material and repeated conversations over clinical visits was the most effective method of increasing the use of ADs. Additionally, they found that passive information alone has no significant effect on completion rates. They concluded that when interactive informative interventions are employed, AD completion rates increased and that multiple sessions were the most effective method for direct interaction between patients and health care professionals.

For the purpose of further discussion, the above-mentioned participants will now be grouped as participants who are experienced in end of life decision making. Experienced decision makers (EDMs) had lower mean total DCS scores and as a group had lower mean subscores. It appears that experience, (from formal or informal education; knowledge; information; actual signing of forms [psychomotor], and values clarification [affective]) is an important aspect of end of life decision making. Therefore, participants who lacked experience (non-EDMs) reported more decisional conflict; felt less certain that they had made the best choice; felt less informed; were less clear about their personal values; felt less supported in their decision making; and were more likely to perceive their decision as a bad decision.

Additionally, mean effective decision subscores were influenced more often than other scores in this research. AND and EDM participants were more likely to perceive their decision as good. DNR and non-EDM participants were more likely to perceive their decision as bad. AND and EDM participants were also more likely to be to be sure of their decision, indicating that experienced decision makers respond more favorably to the words Allow Natural Death. The term Allow Natural Death leads to increased likelihood of actually making a decision. Additionally, a greater number of respondents to the DNR terminology were likely to not sign or postpone signing, leading to prolongation of life of dying individuals. Finally, participants were more likely to withdraw from the study when the words Do Not Resuscitate were used. Thus the use of AND terminology benefits the dying and surrogate decision makers, as well as families and friends from the long term consequences; both emotional and physical associated with the stress of making this decision.

Implications for Nursing and Health Care

Healthy People 2020 encourages measures and interventions that build on current health communication and mobilize the implementation of Healthy People 2020, building on current health literacy and health communication efforts. Additionally, Healthy People 2020 supports the need for appropriate communication strategies and shared decision making between patients and providers to improve population health outcomes and health care quality, and to achieve health equity by delivering accurate, accessible, and actionable health information that is targeted or tailored (Healthy People 2020, 2010). Unwanted prolongation of life is considered by some to be costly in terms of dollars spent in futility in a time of shrinking financial resources.

The results of this study indicated that completions of ADs were influenced by information framing, experience with end of life decision making, and attendance at religious services. Nurses interact with patients and families formally and informally in a variety of health care settings and can assist patients and families with end of life decisions while acting as facilitators, communicators, role models, patient educators, and advocates. According to the American Nurses Association Position Statement registered nurses (RNs) have specific roles and responsibilities in providing expert care and counselling at the end of life, which include:

> Dying is part of the normal process of living. Nurses' roles and responsibilities for care at the end of life are intensified by circumstance, but ultimately are grounded in the fundamentals of nursing ethics and practice throughout the life continuum. The counseling a nurse provides regarding end of life choices and preferences for individuals facing life-limiting illness, as well as throughout the patient's lifespan, honors patient autonomy and helps to prepare individuals and families for difficult decisions that may lie ahead. While often rewarding, this is demanding work that requires the nurse to marshal her or his professionalism and compassion, while honoring her or his own personal integrity (2010, p. 1).

RNs face challenges including but not limited to paucity in nursing school curricula on the death and dying process; evidence based communication needs at the end of life; outdated policies and practices in healthcare systems; and various statutes and interpretations of legal language (Thacker, 2008; Hebert, Moore & Rooney, 2011). For successful use of ADs, patients, surrogates, nurses, and physicians must communicate in a manner that helps them believe that what they are sharing is valuable and that their wishes will be honored. Nurses are implored by the American Nurses Association to prepare patients and families for end of life decision making. This study identified experience with advance directives and end of life decision making; attendance at religious services; and using the terminology Allow Natural Death as adjuncts in improving communication at the end of life. Implementation at all levels of nursing: in nursing education, in policy making, and in nursing practice, and in research; with the end goal of increasing public awareness is recommended.

Nursing education. Nursing students can be better educated about end of life issues by weaving them throughout the curricula. Faculty can facilitate this by becoming proficient in end of life care and issues. The End-of-Life Nursing Education Consortium (ELNEC) project provides undergraduate and graduate nursing faculty, continuing education providers, staff development educators, and nurses with this training so they can teach this essential information to nursing students and practicing nurses (End-of-Life Nursing Education Consortium, 2013). Educators should include experience with decision making as part of the nursing care plan. They can expose students to patient decision aids and shared decision making to assist individuals in making these decisions. The Ottawa Decision Support Tutorial (ODST), an online continuing education program facilitates the process of improving practitioners' decision support skills (Ottawa Health Research Institute (OHRI), 2013).

RNs need to be increasingly educated in the research based nuances of end of life discussions so that they can facilitate communication within families as parts of primary, secondary, and tertiary prevention programs. Communication modalities, information framing, and decision aids are all critical aspects of end of life decision making. Clearly, there is no one size fits all approach to disseminating information about ADs.

Policy. Changes can be implemented at several levels of policy making. Policy makers should consider instituting a national I am Prepared™ week (Fairlie, 2014), similar to the Family Dinner Night, and the No TV Night, with the objective of increasing public awareness and encouraging discussions among family members. Educational programs that disseminate information about ADs to the public need to move out of the hospital setting and into the community; as part of primary, secondary, and tertiary health promotion programs. Administrators can adopt decision aids to assist individuals in making these decisions. Data about surrogate decision makers should be captured in the electronic health record.

The concept of advance care planning can be introduced as part of high school health class discussion or as part of an electronic "game of life". The literature supports using electronic media to change behavior in youth (Hieftje, Edelman, Camenga, & Fiellin, 2013). The game can be expanded in college courses that address life skills. Adult learning programs that focus on the legal aspects of retirement planning should include a module on self-determination and ADs. A program called I am Prepared™ will be designed and implemented and the participants would be awarded buttons that say I am Prepared™ at the time of signing of advance directives. This would stimulate further conversations amongst all.

Nursing Practice. Registered nurses, as patient advocates are implored to actively discuss end of life decision making. It is the duty of RNs to prepare individuals and their surrogates. They should use the words "Allow Natural Death" when discussing advance directives. RNs must continue to support individuals and their surrogates with ongoing conversation to facilitate this process. The following three paragraphs provide several examples of resources that RNs can use as a framework for educational program development:

The CPR Decision Aid was created to prepare patients and their families for shared decision making about cardiopulmonary resuscitation. It is a video decision aid that presents non-biased, patient centered information about cardiopulmonary resuscitation (Kryworuchko, 2012). Patients can be encouraged to view this decision aid in physicians' offices, in outreach presentations, and public health settings.

The PREPARE website, created by the University of California, San Francisco (UCSF) Office of Technology Management provides an excellent 5-step program that walks the patient through the process. The steps are: 1) choose a medical decision maker; 2) decide what matters most in life; 3) choose flexibility for your decision maker; 4) tell others about your wishes; and 5) ask doctors the right questions (Sudore et al., 2012).

The U.S. Living Will Registry provides educational materials to the public as well as a secure centralized storage location for ADs. Advance directives that are deposited in the registry are available to family members, surrogates, and physicians at all times. Additionally, it contains videos and state specific advance directive forms that can be downloaded for use by individuals and health care providers. Services are available to health care providers and institutions to integrate the registry into practice (U.S. Living Will Registry, 2014).

Limitations of the Study

This study has several limitations that warrant discussion and point to future research. The first limitation of this study was that of internal validity. Internal validity was impacted by the use of a vignette that introduced the possibility of discrepancy between responses in a simulated versus an actual situation. Vignettes controlled for the situation, they did not control for individual interpretation of the hypothetical experience, and the personal decision making characteristics of the participants. Lastly, the use of a vignette in lieu of actual experiences limited the social context under which end of life decisions are actually made. A vignette approach was selected after considering the ethical implications of conducting a real life comparative study of this nature, The benefits of the knowledge gained from doing the study with a vignette provided valuable information to fill in the gaps in research and help guide practice and policy protocols.

The use of a vignette was a necessary limitation given the sensitive nature of the topic. Additionally, external validity, or the generalizability of the study was limited due to unknown sample variables and the use of a convenience sample of participants over the age of 50 who were mainly Caucasian, educated, relatively affluent, and present and willing to participate in the study on the day the instrument is administered. Additionally, this study did not control for usual care (no decision aid). Patient decision aids themselves have been shown to decrease decisional conflict, so it is unclear what effect the decision aid had verses the usual care that patients and families receive. Finally, more specific information about religion and religious attendance should be gathered. For example, the various denominations of Christianity view end of life decision making and implement support differently, and more individualized care could be provided (Allen, 2008; Bollig , 2010; and Daaleman & VandeCreek, 2000). Additionally, practice of expected beliefs and individual interpretations of religious teachings or rules within each religion vary.

Recommendations for Further Research

The research community is encouraged to continue to synthesize data regarding programs that support the signing of ADs. Additional insight into decreasing long term distress in experienced and non-experienced surrogate decision makers can be gathered. The role of religious support, communication, and framing should be further explored. Additionally, the following recommendations for further research are presented. A comparative interventional study employing the International Patient Decision Aid Standards *(*IPDAS*)* *c*riteria to develop a print format decision aid and a computerized decision aid with embedded video representations of possible end of life scenarios could be implemented. Both formats would use the Allow Natural Death (AND) terminology. Decisional conflict would be measured using the Decisional Conflict Scale and decision support and related communication would be measured using the Decision Support Analysis Tool (DSAT, Guimond et al, 2003). The target population would include individuals over the age of 18. Additionally, enhanced demographic data including that specific to religion and religious practices and beliefs would be collected and analyzed. Finally, measurement of usual care (no decision aid) could be explored to illuminate the role of decision aids in end of life decision making and decisional conflict.

Chapter Summary

This chapter discussed the relevant findings, identified limitations, presented implications for practice, and proposed recommendations for future research. Findings included: AND respondents felt more positive about the decision and DNR respondents felt more negative about the decision; participants were eight times more likely to sign the document when it was an AND document than when it was a DNR document; AND terminology leads to increased likelihood of actually making a decision; and participants were more likely to withdraw from the study when the words Do Not Resuscitate were used. Additionally, frequent attendance of religious services increased decision implementation. Finally, experienced decision makers as a group responded more favorably to the words Allow Natural Death. They had lower mean total DCS subscores; felt more informed; were clearer about personal values; felt more certain they had made the best choice and that their decision was a good decision.

The terminology Allow Natural Death is increasingly but slowly being adopted by health care institutions worldwide. Recommendations to promote adoption have been explored. In the meantime, nurses can assist patients and their families with end of life decision making by using the words Allow Natural Death to enhance decisions about cardiopulmonary resuscitation and to ease long term strife in surrogate decision makers. Recommendations to increase education of students about end of life communication by weaving experiences throughout the curricula were explored. Continuing education of health care professionals and education of the public via the I am Prepared™ program were discussed. Future research into decreasing long term distress in experienced and non-experienced surrogate decision makers was recommended as well as continued synthesis of data regarding programs that support the signing of ADs. Finally, additional exploration of the role of religious support, communication, and framing was recommended.

Appendix A

Information Sheet

My name is Dawn Fairlie. I am a doctoral student in the Nursing Science Doctoral Program at The Graduate Center of the City University of New York (CUNY), and Principal Investigator of this project, entitled "Does End of Life Terminology Influence Decisional Conflict in Surrogate Decision Makers?" This is a research study of end of life decision making. The study is expected to assist people who are faced with making end of life choices for a loved one. I would like your permission to administer a survey and would like you to fill out the questionnaire anonymously.

This questionnaire should take approximately 10 minutes to complete. All information gathered will be kept strictly confidential, and will be stored in a locked file cabinet, to which only I, and my advisor, will have access. At any time you can refuse to answer any questions or end this survey.

The risk involved in this study, is that it may cause emotional upset. The benefits of your participation is that the results may help others making similar decisions. There will be approximately 150 participants taking part in this study.

I may publish results of the study, but names of people, or any identifying characteristics, will not be used in any of the publications. If you would like a copy of the study, please provide me with your address and I will send you a copy in the future.

If you have any questions or concerns about this research, you can contact me at (212) 817-7980 dfairlie@gc.cuny.edu or my advisor Dr. Marianne Jeffreys, EdD, RN at (212) 817-7980 or marianne.jeffreys@csi.cuny.edu. If you have questions about your rights as a participant in this study, you can contact Kay Powell, IRB Administrator, The Graduate Center/City University of New York, (212) 817-7525, kpowell@gc.cuny.edu.

By completing this survey, you are indicating that you have read this consent and agree to its terms.

10/24/11

Investigator's Signature/ Date

Appendix B

Designated Loved One Page

1. Please write the first name of an adult loved one (not your child)

here:_______________________

2. What is your relationship to your adult loved one?

He or she is my (choose one)

_____Spouse

_____Significant other

_____Brother or sister

_____Father or mother

_____Grandfather or grandmother

_____Aunt or uncle

_____Cousin

_____Other _______________________

3. Does your loved one have a living will, health care proxy, or advance directive?

_____No

_____Yes

_____Not sure

Appendix C

Decision Aid Version 1 (AND)

The information requested below is intended for use as a guide for improving communication between health care providers, patients, and those chosen to act as health care proxies or have legal power of attorney for health care when quality of life issues are being addressed. I would appreciate your feedback on this information.

PLEASE READ THE INFORMATION IN THE FOLLOWING DECISION AID

<u>What is an "Allow Natural Death" document?</u>

An "Allow Natural Death" document is a request **<u>NOT</u>** to have cardiopulmonary resuscitation (CPR) if a person's heart stops or if the person stops breathing. (Unless given other instructions, hospital staff will try to help all patients whose heart has stopped or who have stopped breathing.) You can use an "Allow Natural Death" document or tell the doctor that you don't want CPR performed on your loved one. In this case, an "Allow Natural Death" document is put in the medical chart by the doctor.

When is CPR important?

CPR may be done when a person stops breathing or the heart stops beating (like when a person has a heart attack). When it's possible that the person may get better, CPR is important. However, when a patient has an advanced life threatening illness and is dying, CPR may not be the option to choose. It's important for the patient, family members and doctor to talk about this issue before the need arises.

What happens during CPR?

During CPR, the chest is pressed on forcefully. Electric stimulation to the chest and special medicines are sometimes used. This is usually done for 15 to 30 minutes. A tube may also be put through the mouth or nose into the lung. This tube is then connected to a breathing machine.

What happens if CPR isn't done?

A person will become unconscious almost immediately and will die in 5 to 10 minutes.

What are the benefits of CPR?

For a patient with an advanced life threatening illness who is dying, there are really no benefits. CPR may prolong life for patients with a better health status or who are younger. CPR may also prolong life if it's done within 5 to 10 minutes of the time that the person's heart stopped beating or breathing stopped.

What are the risks of CPR?

Pressing on the chest can cause a sore chest, broken ribs or a collapsed lung. Patients with breathing tubes usually need medicine to keep them comfortable. Most patients who survive will need to be on a breathing machine in the intensive care unit to help them breathe. Few patients (less than 10%) in the hospital who have had CPR survive and are able to function the way they used to. Many patients live for a short time after CPR, but still die in the hospital. CPR may also prolong the dying process.

Patients who have more than one illness usually don't survive after CPR. Almost no one with advanced disease survives CPR and lives long enough to leave the hospital. Of the few patients who do, many get weaker or have brain damage. Some patients may need to live on a breathing machine for the rest of their lives.

Approximate chance that the person receiving CPR will recover and leave the hospital

Different diseases have different chances that a patient will survive CPR and leave the hospital. For example, for every 100 cancer patients receiving CPR, 2 will survive and leave the hospital; for every 100 patients will severe kidney failure receiving CPR, 5 will survive and leave the hospital: for every 100 heart attack patients receiving CPR, 15 will survive and leave the hospital.

(Adapted from http://familydoctor.org/x2178.xml?printxml)

SOME THINGS TO THINK ABOUT:

Possible reasons to sign an “Allow Natural Death” document:

- You believe that it is probable that your loved one will not be cured
- Day to day quality of life is more important than how much longer the person lives
- Physical, emotional, and spiritual needs are more important than treatment

Possible reasons to *not* sign an “Allow Natural Death” document:

- You believe it is possible that your loved one will be cured
- How much longer the person lives is more important than day to day quality of life
- Treatment is more important than physical, emotional, and spiritual needs

Appendix D

Decision Aid Version 2

The information requested below is intended for use as a guide for improving communication between health care providers, patients, and those chosen to act as health care proxies or have legal power of attorney for health care when quality of life issues are being addressed. I would appreciate your feedback on this information.

PLEASE READ THE INFORMATION IN THE FOLLOWING DECISION AID

What is a "Do Not Resuscitate" document?

A "Do Not Resuscitate" document is a request **NOT** to have cardiopulmonary resuscitation (CPR) if a person's heart stops or if the person stops breathing. (Unless given other instructions, hospital staff will try to help all patients whose heart has stopped or who have stopped breathing.) You can use a "Do Not Resuscitate" document or tell the doctor that you don't want CPR performed on your loved one. In this case, a "Do Not Resuscitate" document is put in the medical chart by the doctor.

<u>When is CPR important</u>?

CPR may be done when a person stops breathing or the heart stops beating (like when a person has a heart attack). When it's possible that the person may get better, CPR is important. However, when a patient has an advanced life threatening illness and is dying, CPR may not be the option to choose. It's important for the patient, family members and doctor to talk about this issue before the need arises.

<u>What happens during CPR</u>?

During CPR, the chest is pressed on forcefully. Electric stimulation to the chest and special medicines are sometimes used. This is usually done for 15 to 30 minutes. A tube may also be put through the mouth or nose into the lung. This tube is then connected to a breathing machine.

<u>What happens if CPR isn't done</u>?

A person will become unconscious almost immediately and will die in 5 to 10 minutes.

<u>What are the benefits of CPR</u>?

For a patient with an advanced life threatening illness who is dying, there are really no benefits. CPR may prolong life for patients with a better health status or who are younger. CPR may also prolong life if it's done within 5 to 10 minutes of the time that the person's heart stopped beating or breathing stopped.

<u>What are the risks of CPR</u>?

Pressing on the chest can cause a sore chest, broken ribs or a collapsed lung. Patients with breathing tubes usually need medicine to keep them comfortable. Most patients who survive will need to be on a breathing machine in the intensive care unit to help them breathe. Few patients (less than 10%) in the hospital who have had CPR survive and are able to function the way they used to. Many patients live for a short time after CPR, but still die in the hospital. CPR may also prolong the dying process. Patients who have more than one illness usually don't survive after CPR. Almost no one with advanced disease survives CPR and lives long enough to leave the hospital. Of the few patients who do, many get weaker or have brain damage. Some patients may need to live on a breathing machine for the rest of their lives.

Approximate chance that the person receiving CPR will recover and leave the hospital

Different diseases have different chances that a patient will survive CPR and leave the hospital. For example, for every 100 cancer patients receiving CPR, 2 will survive and leave the hospital; for every 100 patients will severe kidney failure receiving CPR, 5 will survive and leave the hospital: for every 100 heart attack patients receiving CPR, 15 will survive and leave the hospital.

(Adapted from http://familydoctor.org/x2178.xml?printxml)

SOME THINGS TO THINK ABOUT:

Possible reasons to sign a "Do Not Resuscitate" document:

- You believe that it is probable that your loved one will not be cured
- Day to day quality of life is more important than how much longer the person lives
- Physical, emotional, and spiritual needs are more important than treatment

Possible reasons to *not* sign a "Do Not Resuscitate" document:

- You believe it is possible that your loved one will be cured
- How much longer the person lives is more important than day to day quality of life
- Treatment is more important than physical, emotional, and spiritual needs

Appendix E

Personalized Vignette (AND)

Insert the name of the loved one from page 1 into the three spaces below and then read the case.

Case:

Imagine that ____________________ is in the hospital and is no longer conscious. The physician comes to me and tells me that the health situation is not good and explains that death is near. ___________________ has given me legal power of attorney for health care. I am being asked by the physician to make a decision concerning signing an “Allow Natural Death” document. Cardiopulmonary resuscitation (CPR) will **NOT** be administered; but all other measures to provide comfort and dignity to __________________ will be continued when the “Allow Natural Death” document is signed.

Appendix F

Personalized Vignette (DNR)

Insert the name of the loved one from page 1 into the three spaces below and then read the case.

Case:

Imagine that ____________________ is in the hospital and is no longer conscious. The physician comes to me and tells me that the health situation is not good and explains that death is near. ___________________ has given me legal power of attorney for health care. I am being asked by the physician to make a decision concerning signing a "Do Not Resuscitate" document. Cardiopulmonary resuscitation (CPR) will **NOT** be administered; but all other measures to provide comfort and dignity to __________________ will be continued when the "Do Not Resuscitate" document is signed.

Appendix G

The Decisional Conflict Scale (AND)

Please answer some brief questions by checking the appropriate box:

My difficulty in making this choice

A. Will you sign the Allow Natural Death document? Please check ☑ one option.

☐ YES

☐ NO

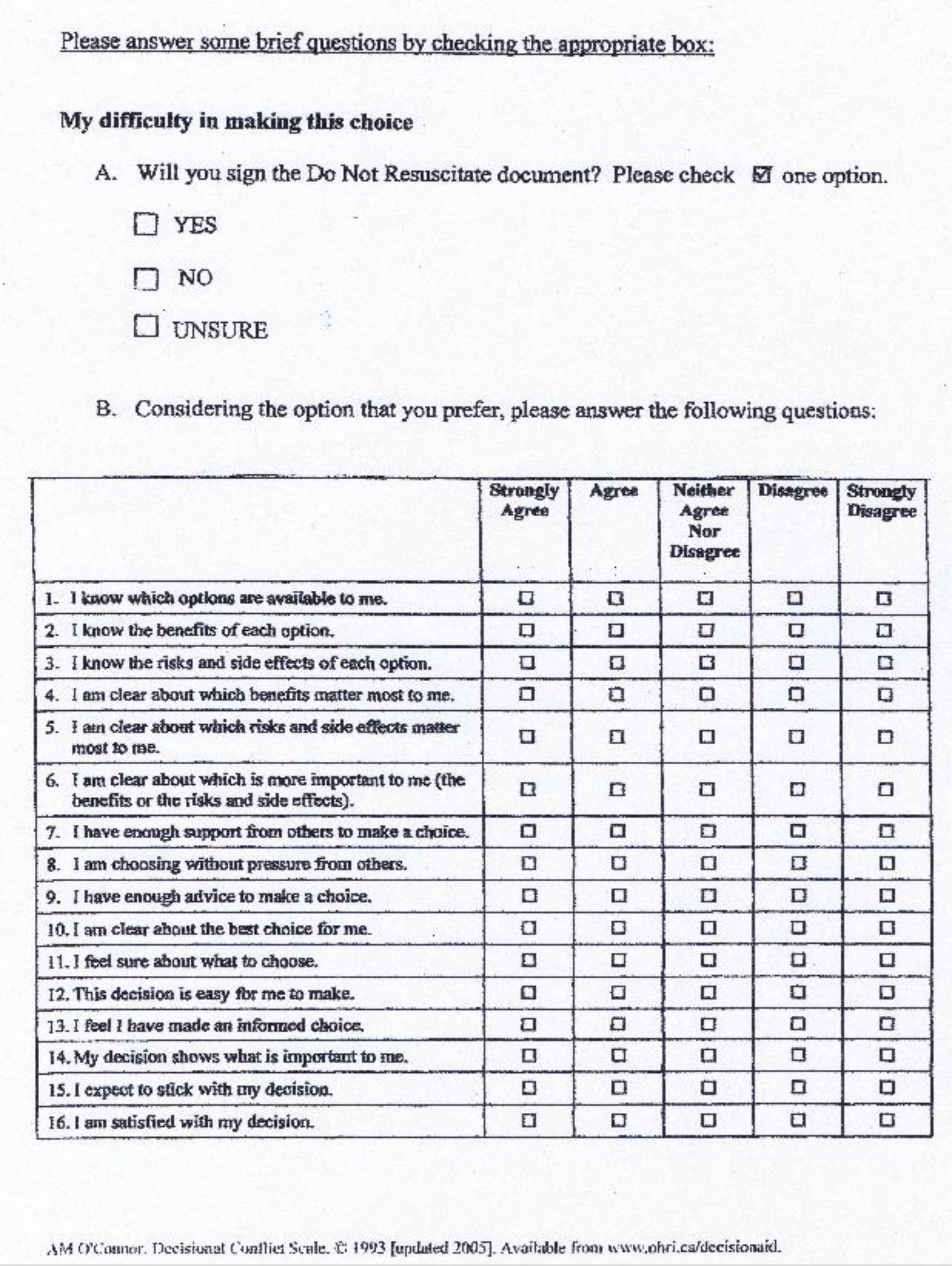
☐ UNSURE

B. Considering the option that you prefer, please answer the following questions:

	Strongly Agree	**Agree**	**Neither Agree Nor Disagree**	**Disagree**	**Strongly Disagree**
1. I know which options are available to me.	☐	☐	☐	☐	☐
2. I know the benefits of each option.	☐	☐	☐	☐	☐
3. I know the risks and side effects of each option.	☐	☐	☐	☐	☐
4. I am clear about which benefits matter most to me.	☐	☐	☐	☐	☐
5. I am clear about which risks and side effects matter most to me.	☐	☐	☐	☐	☐
6. I am clear about which is more important to me (the benefits or the risks and side effects).	☐	☐	☐	☐	☐
7. I have enough support from others to make a choice.	☐	☐	☐	☐	☐
8. I am choosing without pressure from others.	☐	☐	☐	☐	☐
9. I have enough advice to make a choice.	☐	☐	☐	☐	☐
10. I am clear about the best choice for me.	☐	☐	☐	☐	☐
11. I feel sure about what to choose.	☐	☐	☐	☐	☐
12. This decision is easy for me to make.	☐	☐	☐	☐	☐
13. I feel I have made an informed choice.	☐	☐	☐	☐	☐
14. My decision shows what is important to me.	☐	☐	☐	☐	☐
15. I expect to stick with my decision.	☐	☐	☐	☐	☐
16. I am satisfied with my decision.	☐	☐	☐	☐	☐

AM O'Connor. Decisional Conflict Scale. © 1993 [updated 2005]. Available from www.ohri.ca/decisionaid.

The Decisional Conflict Scale (DNR)



Please answer some brief questions by checking the appropriate box:

My difficulty in making this choice

A. Will you sign the Do Not Resuscitate document? Please check ☑ one option.

☐ YES

☐ NO

☐ UNSURE

B. Considering the option that you prefer, please answer the following questions:

	Strongly Agree	**Agree**	**Neither Agree Nor Disagree**	**Disagree**	**Strongly Disagree**
1. I know which options are available to me.	☐	☐	☐	☐	☐
2. I know the benefits of each option.	☐	☐	☐	☐	☐
3. I know the risks and side effects of each option.	☐	☐	☐	☐	☐
4. I am clear about which benefits matter most to me.	☐	☐	☐	☐	☐
5. I am clear about which risks and side effects matter most to me.	☐	☐	☐	☐	☐
6. I am clear about which is more important to me (the benefits or the risks and side effects).	☐	☐	☐	☐	☐
7. I have enough support from others to make a choice.	☐	☐	☐	☐	☐
8. I am choosing without pressure from others.	☐	☐	☐	☐	☐
9. I have enough advice to make a choice.	☐	☐	☐	☐	☐
10. I am clear about the best choice for me.	☐	☐	☐	☐	☐
11. I feel sure about what to choose.	☐	☐	☐	☐	☐
12. This decision is easy for me to make.	☐	☐	☐	☐	☐
13. I feel I have made an informed choice.	☐	☐	☐	☐	☐
14. My decision shows what is important to me.	☐	☐	☐	☐	☐
15. I expect to stick with my decision.	☐	☐	☐	☐	☐
16. I am satisfied with my decision.	☐	☐	☐	☐	☐

AM O'Connor. Decisional Conflict Scale. © 1993 [updated 2005]. Available from www.ohri.ca/decisionaid.

Appendix H

Demographic Data Sheet (DDS)

Please answer the following questions.

1. Have you ever made this type of decision in real life?

_____No
_____Yes

2. Has your loved one from the previous scenario ever named you as their surrogate decision maker?

_____ No
_____Yes If yes, have they discussed their preferences with you? ____No___Yes

3. Right now, do you personally have any of the following legal documents to delegate your care if you are unable to make decisions? (Choose all that apply)

_____Advance Directive (a legal document that a person uses to make known his or her wishes regarding life prolonging medical treatments in the event that he or she is unable to make medical decisions)

_____Health Care Proxy (a legal document to appoint a trusted person who will make to make health care decisions for you if you lose the ability to make decisions yourself)

4. Your age:

_____50-54
_____55-59
_____60-64
_____65-69
_____70-74
_____75-79
_____80-84
_____85-89
_____90 and over

5. Your sex:

_____Female
_____Male

6. Your marital status:

______Single
______Single, living with partner
______Married
______Separated
______Divorced
______Widowed

7. Highest level of education completed (Choose one)

______Some High School
______High School Graduate
______Trade School Certificate
______Some College
______College Undergraduate Degree (Associates Degree)
______College Undergraduate Degree (Bachelor’s Degree)
______College Graduate School Degree

8. Do you now or have you ever worked in the health care field?

______No
______Yes (if yes give job title in space)

____

9. Which category best describes you (Choose all that apply)

______African American or Black
______American Indian or Alaska Native
______Asian
______Hispanic or Latino
______Native Hawaiian or Other Pacific Islander
______White, non-Hispanic
______Other_____________________________

10. Religious Affiliation, if any (Choose all that apply)

_____None (Atheist or Agnostic)
_____Buddhist
_____Christian
_____Hindu
_____Jewish
_____Muslim
_____Other

11. Do you attend religious services (Choose one)

_____Never
_____Rarely (several times a year)
_____Sometimes (at least once a month)
_____Frequently (at least once a week)

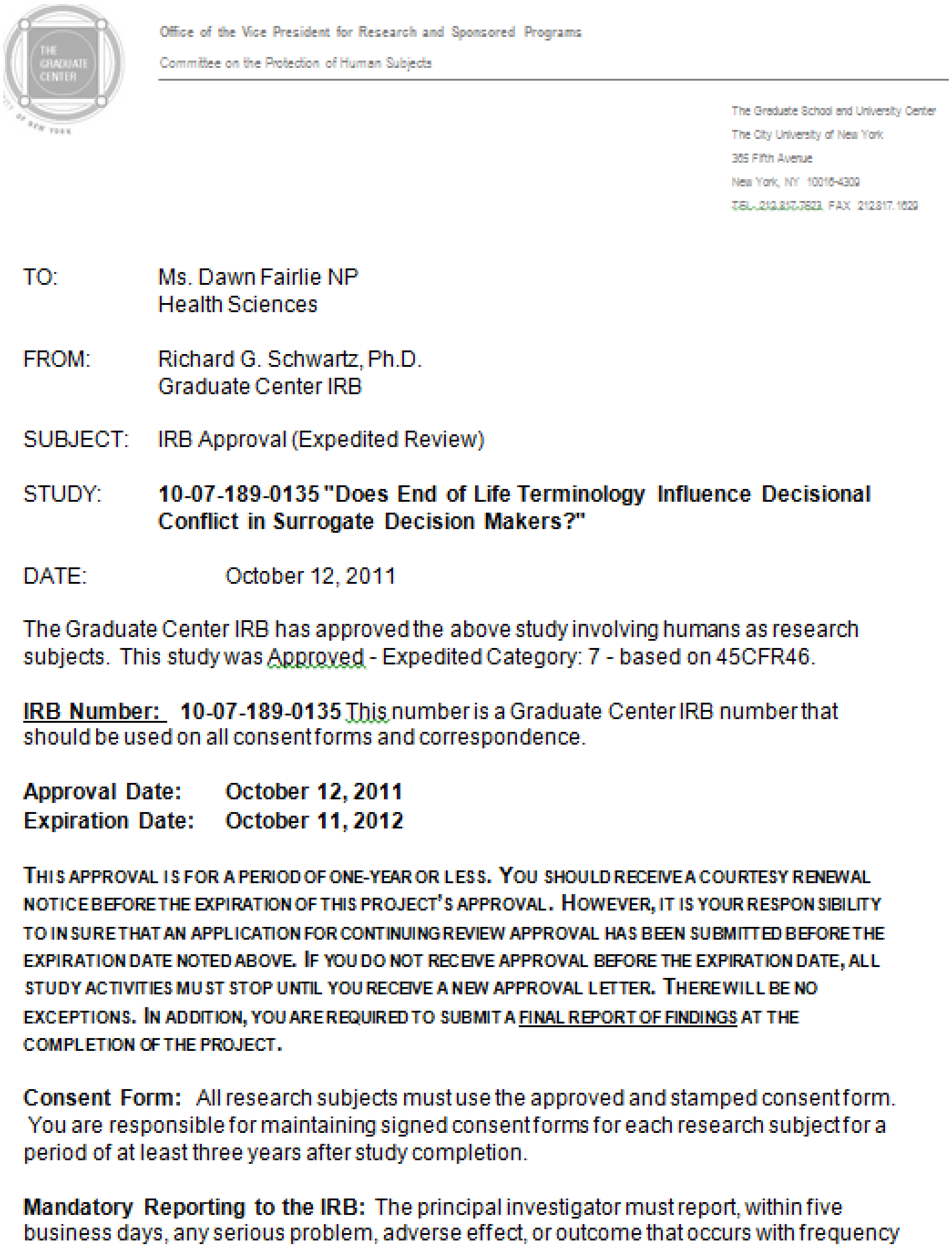
12. What is your total yearly household income? (Choose one)

_____less than $50,000
_____between $50,000 and $99,999
_____between $100,000 and $150,000
_____more than $150,000

Thank you for completing this survey. You may put your papers in the envelope supplied to you, place the envelope in the box at the front of the room and leave the room.

Appendix I

IRB Approval Documents



Office of the Vice President for Research and Sponsored Programs
Committee on the Protection of Human Subjects

The Graduate School and University Center
The City University of New York
365 Fifth Avenue
New York, NY 10016-4309
TEL 212.817.7523 FAX 212.817.1629

TO: Ms. Dawn Fairlie NP
Health Sciences

FROM: Richard G. Schwartz, Ph.D.
Graduate Center IRB

SUBJECT: IRB Approval (Expedited Review)

STUDY: **10-07-189-0135 "Does End of Life Terminology Influence Decisional Conflict in Surrogate Decision Makers?"**

DATE: October 12, 2011

The Graduate Center IRB has approved the above study involving humans as research subjects. This study was Approved - Expedited Category: 7 - based on 45CFR46.

IRB Number: **10-07-189-0135** This number is a Graduate Center IRB number that should be used on all consent forms and correspondence.

Approval Date: **October 12, 2011**
Expiration Date: **October 11, 2012**

THIS APPROVAL IS FOR A PERIOD OF ONE-YEAR OR LESS. YOU SHOULD RECEIVE A COURTESY RENEWAL NOTICE BEFORE THE EXPIRATION OF THIS PROJECT'S APPROVAL. HOWEVER, IT IS YOUR RESPONSIBILITY TO INSURE THAT AN APPLICATION FOR CONTINUING REVIEW APPROVAL HAS BEEN SUBMITTED BEFORE THE EXPIRATION DATE NOTED ABOVE. IF YOU DO NOT RECEIVE APPROVAL BEFORE THE EXPIRATION DATE, ALL STUDY ACTIVITIES MUST STOP UNTIL YOU RECEIVE A NEW APPROVAL LETTER. THERE WILL BE NO EXCEPTIONS. IN ADDITION, YOU ARE REQUIRED TO SUBMIT A FINAL REPORT OF FINDINGS AT THE COMPLETION OF THE PROJECT.

Consent Form: All research subjects must use the approved and stamped consent form. You are responsible for maintaining signed consent forms for each research subject for a period of at least three years after study completion.

Mandatory Reporting to the IRB: The principal investigator must report, within five business days, any serious problem, adverse effect, or outcome that occurs with frequency or degree of severity greater than that anticipated. In addition, the principal investigator must report any event or series of events that prompt the temporary or permanent suspension of a research project involving human subjects or any deviations from the approved protocol.

Amendments/Modifications: All amendments/modifications of protocols involving human subjects must have prior IRB approval, except those involving the prevention of immediate harm to a subject. Amendments/modifications for the prevention of immediate harm to a subject must be reported within 24 hours to the IRB.

Stipulations: None.

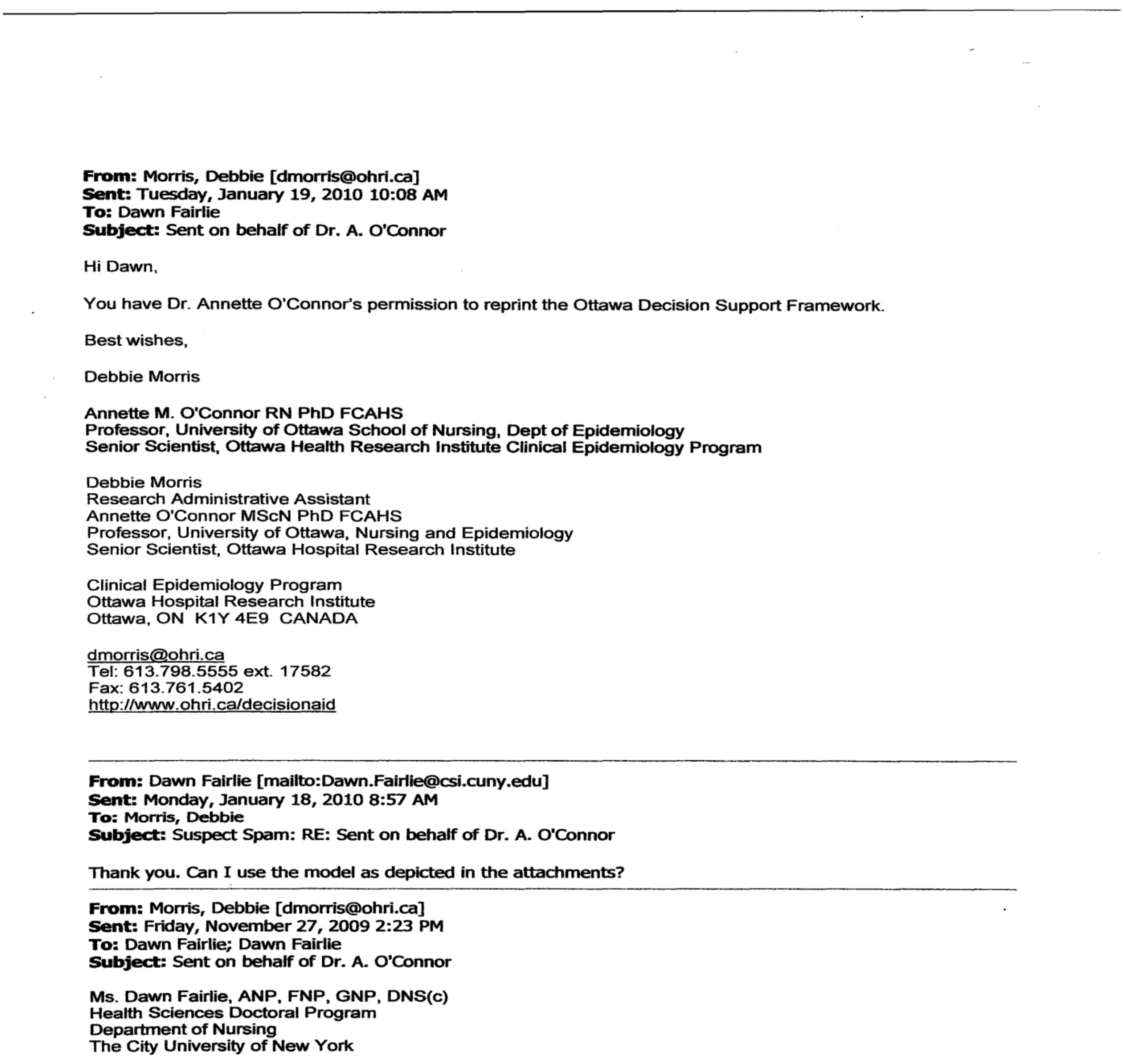
If you have any questions, please do not hesitate to contact Kay Powell in the IRB Office at 212-817-7525.

Good luck on your project.

cc: Marianne Jeffreys Ed.D.
Nursing

Appendix J

O’Connor Correspondence



From: Morris, Debbie [dmorris@ohri.ca]
Sent: Tuesday, January 19, 2010 10:08 AM
To: Dawn Fairlie
Subject: Sent on behalf of Dr. A. O'Connor

Hi Dawn,

You have Dr. Annette O'Connor's permission to reprint the Ottawa Decision Support Framework.

Best wishes,

Debbie Morris

Annette M. O'Connor RN PhD FCAHS
Professor, University of Ottawa School of Nursing, Dept of Epidemiology
Senior Scientist, Ottawa Health Research Institute Clinical Epidemiology Program

Debbie Morris
Research Administrative Assistant
Annette O'Connor MScN PhD FCAHS
Professor, University of Ottawa, Nursing and Epidemiology
Senior Scientist, Ottawa Hospital Research Institute

Clinical Epidemiology Program
Ottawa Hospital Research Institute
Ottawa, ON K1Y 4E9 CANADA

dmorris@ohri.ca
Tel: 613.798.5555 ext. 17582
Fax: 613.761.5402
http://www.ohri.ca/decisionaid

From: Dawn Fairlie [mailto:Dawn.Fairlie@csi.cuny.edu]
Sent: Monday, January 18, 2010 8:57 AM
To: Morris, Debbie
Subject: Suspect Spam: RE: Sent on behalf of Dr. A. O'Connor

Thank you. Can I use the model as depicted in the attachments?

From: Morris, Debbie [dmorris@ohri.ca]
Sent: Friday, November 27, 2009 2:23 PM
To: Dawn Fairlie; Dawn Fairlie
Subject: Sent on behalf of Dr. A. O'Connor

Ms. Dawn Fairlie, ANP, FNP, GNP, DNS(c)
Health Sciences Doctoral Program
Department of Nursing
The City University of New York

Dear Ms. Fairlie,

Thank you for your letter/attachments dated November 15, 2009 which was received today.

If you decide to use the DCS scale in your research, you have my permission to do so provided you cite its source on any questionnaire or publication.

For the latest information on the Decisional Conflict Scale, please refer to url:
http://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Decisional_Conflict.pdf

Regarding the term 'decision delay'...it depends on the context.

Decision delay (nominal scale): deferring of making decision at a specific time point after counseling or intervention, scaled nominally as 1 (yes) or 0 (no).

You can create a delay variable from the 'enacted decision' question on the website.

http://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_ChoicePredisposition_Decision.pdf

If a person has ticked off 'haven't decided yet', this would be a delay.

Best wishes with your research project.

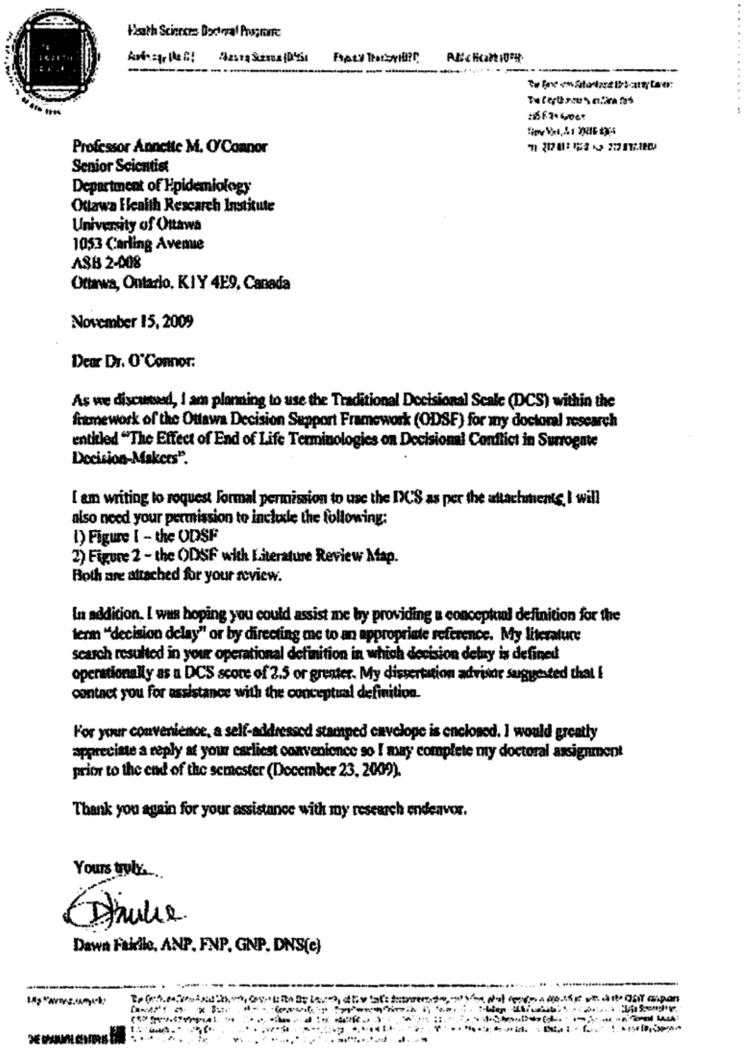
Sincerely,

Annette M. O'Connor RN PhD FCAHS
Tier 1 Canada Research Chair
Professor, University of Ottawa School of Nursing, Dept of Epidemiology
Senior Scientist, Ottawa Health Research Institute Clinical Epidemiology Program

Debbie Morris
Research Administrative Assistant
Annette O'Connor MScN PhD FCAHS
Professor, University of Ottawa, Nursing and Epidemiology
Senior Scientist, Ottawa Hospital Research Institute

Clinical Epidemiology Program
Ottawa Hospital Research Institute
Ottawa, ON K1Y 4E9 CANADA

dmorris@ohri.ca
Tel: 613.798.5555 ext. 17582
Fax: 613.761.5402
http://www.ohri.ca/decisionaid



Health Sciences Doctoral Program

Professor Annette M. O'Connor
Senior Scientist
Department of Epidemiology
Ottawa Health Research Institute
University of Ottawa
1053 Carling Avenue
ASB 2-008
Ottawa, Ontario. K1Y 4E9, Canada

November 15, 2009

Dear Dr. O'Connor:

As we discussed, I am planning to use the Traditional Decisional Scale (DCS) within the framework of the Ottawa Decision Support Framework (ODSF) for my doctoral research entitled "The Effect of End of Life Terminologies on Decisional Conflict in Surrogate Decision-Makers".

I am writing to request formal permission to use the DCS as per the attachment. I will also need your permission to include the following:
1) Figure 1 – the ODSF
2) Figure 2 – the ODSF with Literature Review Map.
Both are attached for your review.

In addition, I was hoping you could assist me by providing a conceptual definition for the term "decision delay" or by directing me to an appropriate reference. My literature search resulted in your operational definition in which decision delay is defined operationally as a DCS score of 2.5 or greater. My dissertation advisor suggested that I contact you for assistance with the conceptual definition.

For your convenience, a self-addressed stamped envelope is enclosed. I would greatly appreciate a reply at your earliest convenience so I may complete my doctoral assignment prior to the end of the semester (December 23, 2009).

Thank you again for your assistance with my research endeavor.

Yours truly,

Dawn Fairlie, ANP, FNP, GNP, DNS(c)

Confidentiality Statement - The contents of this e-mail, including its attachment, are intended for the exclusive use of the recipient and may contain confidential or privileged information. If you are not the intended recipient, you are strictly prohibited from reading, using, disclosing, copying, or distributing this e-mail or any of its contents. If you received this e-mail in error, please notify the sender by reply e-mail immediately or the Privacy Office (privacy@ottawahospital.on.ca) and permanently delete this e-mail and its attachments, along with any copies thereof. Thank you.

Avis de confidentialit? ? Ce courriel, y compris ses pi?ces jointes, s?adresse au destinataire uniquement et pourrait contenir des renseignements confidentiels. Si vous n??tes pas le bon destinataire, il est strictement interdit de lire, d?utiliser, de divulguer, de copier ou de diffuser ce courriel ou son contenu, en partie ou en entier. Si vous avez re?u ce courriel par erreur, veuillez en informer imm?diatement l?exp?diteur ou le bureau de la Protection des renseignements personnels (info.privee@hopitalottawa.on.ca), puis effacez le courriel ainsi que les pi?ces jointes et toute autre copie. Merci.

Appendix K

Content Validity Index Ratings Packages

April 1, 2010

Mary Ellen McMorrow, RN, EdD
Professor, Nursing
College of Staten Island, CUNY
2800 Victory Boulevard
Staten Island, New York 10314

Dear Dr. McMorrow:

For my doctoral dissertation research, I am studying “Does End of Life Terminology Influence Decisional Conflict in Surrogate Decision Makers?”

As part of the study, I will be using a research packet which includes three components: a) the Patient Decision Aid (PtDA); b) the personalized vignette; and c) the demographic data sheet (DDS).

Because of your expertise in end-of-life care, I would like to invite you to be a content validity reviewer for these three research packet components.

Please use the enclosed content validity rating form and return to me at your earliest convenience but by **April 10, 2010**. If you require additional information, please do not hesitate to contact me.

Thank you in advance for your time and expertise as a content validity expert.

Sincerely,

Dawn Fairlie, RN, APRN-BC, DNS(c)
Assistant Professor, Nursing

Enc.

April 1, 2010

Patricia Murray Given, RN, APRN-BC, PhD
Assistant Professor, Nursing
College of Staten Island, CUNY
2800 Victory Boulevard
Staten Island, New York 10314

Dear Dr. Given:

For my doctoral dissertation research, I am studying “Does End of Life Terminology Influence Decisional Conflict in Surrogate Decision Makers?”

As part of the study, I will be using a research packet which includes three components: a) the Patient Decision Aid (PtDA); b) the personalized vignette; and c) the demographic data sheet (DDS).

Because of your expertise in ethics, and surrogate’s end of life decision making, I would like to invite you to be a content validity reviewer for these three research packet components.

Please use the enclosed content validity rating form and return to me at your earliest convenience but by **April 10, 2010**. If you require additional information, please do not hesitate to contact me.

Thank you in advance for your time and expertise as a content validity expert.

Sincerely,

Dawn Fairlie, RN, APRN-BC, DNS(c)
Assistant Professor, Nursing

Enc.

Evaluation Form

Instructions to Expert Rater: Please type one X in the appropriate column for each of the 9 criteria.

-1 = Does not measure criterion objective

0 = Undecided

+1 = Meets criterion objective

	-1	**0**	**+1**
The AND Vignette			
1. Evokes feelings and thoughts that are appropriate for this type of decision			
2. Is thoughtful and reflective			
3. Is clear			
4. Is brief			
5. Is informative			
6. Is appropriate for use in the targeted population			
7. Reflects a realistic end-of-life scenario			
8. Describes relevant features of an end-of-life scenario			
9. Is easy to administer			

Please Comment on the Patient Decision Aid (PtDA):

Please Comment on the personalized vignette:

Please Comment on the Demographic Data Sheet (DDS):

Evaluation Form

Instructions to Expert Rater: Please type one X in the appropriate column for each of the 9 criteria.

-1 = Does not measure criterion objective

0 = Undecided

+1 = Meets criterion objective

	-1	**0**	**+1**
The DNR Vignette			
1. Evokes feelings and thoughts that are appropriate for this type of decision			
2. Is thoughtful and reflective			
3. Is clear			
4. Is brief			
5. Is informative			
6. Is appropriate for use in the targeted population			
7. Reflects a realistic end-of-life scenario			
8. Describes relevant features of an end-of-life scenario			
9. Is easy to administer			

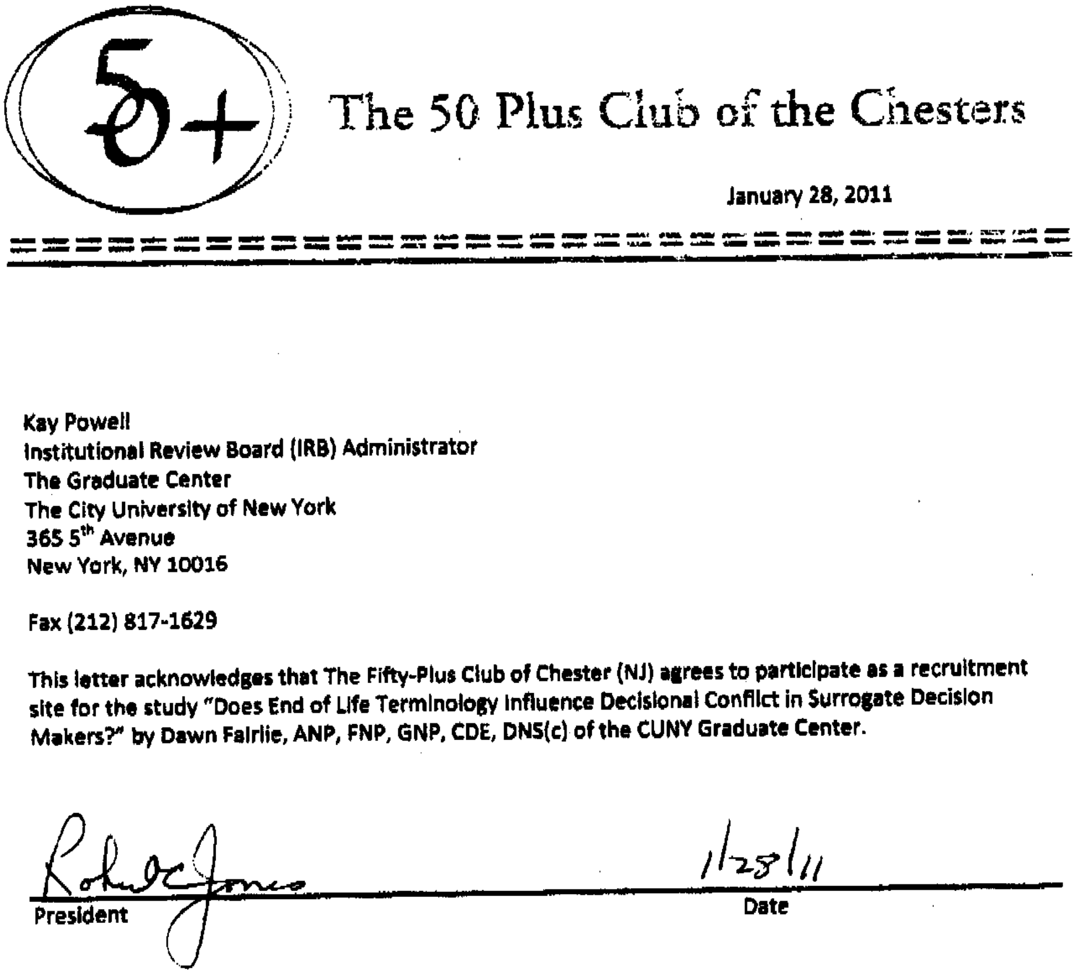
Please Comment on the Patient Decision Aid (PtDA):

Please Comment on the personalized vignette:

Please Comment on the Demographic Data Sheet (DDS):

Appendix L

Site Letters



5+ The 50 Plus Club of the Chesters

January 28, 2011

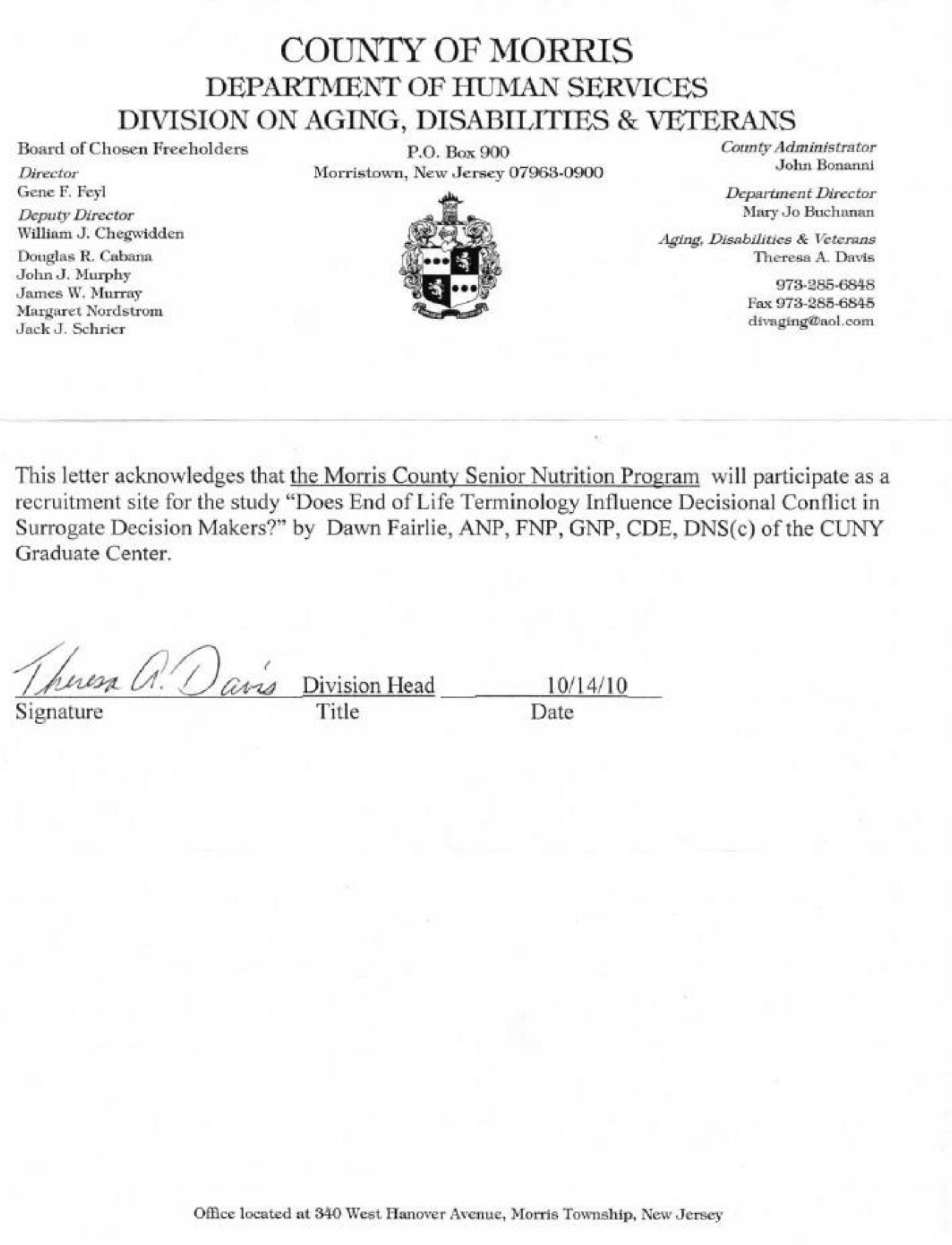
Kay Powell
Institutional Review Board (IRB) Administrator
The Graduate Center
The City University of New York
365 5th Avenue
New York, NY 10016

Fax (212) 817-1629

This letter acknowledges that The Fifty-Plus Club of Chester (NJ) agrees to participate as a recruitment site for the study "Does End of Life Terminology Influence Decisional Conflict in Surrogate Decision Makers?" by Dawn Fairlie, ANP, FNP, GNP, CDE, DNS(c) of the CUNY Graduate Center.

Robert C Jones
President

1/28/11
Date



COUNTY OF MORRIS
DEPARTMENT OF HUMAN SERVICES
DIVISION ON AGING, DISABILITIES & VETERANS

Board of Chosen Freeholders
Director
Gene F. Feyl
Deputy Director
William J. Chegwidden
Douglas R. Cabana
John J. Murphy
James W. Murray
Margaret Nordstrom
Jack J. Schrier

P.O. Box 900
Morristown, New Jersey 07963-0900

County Administrator
John Bonanni

Department Director
Mary Jo Buchanan

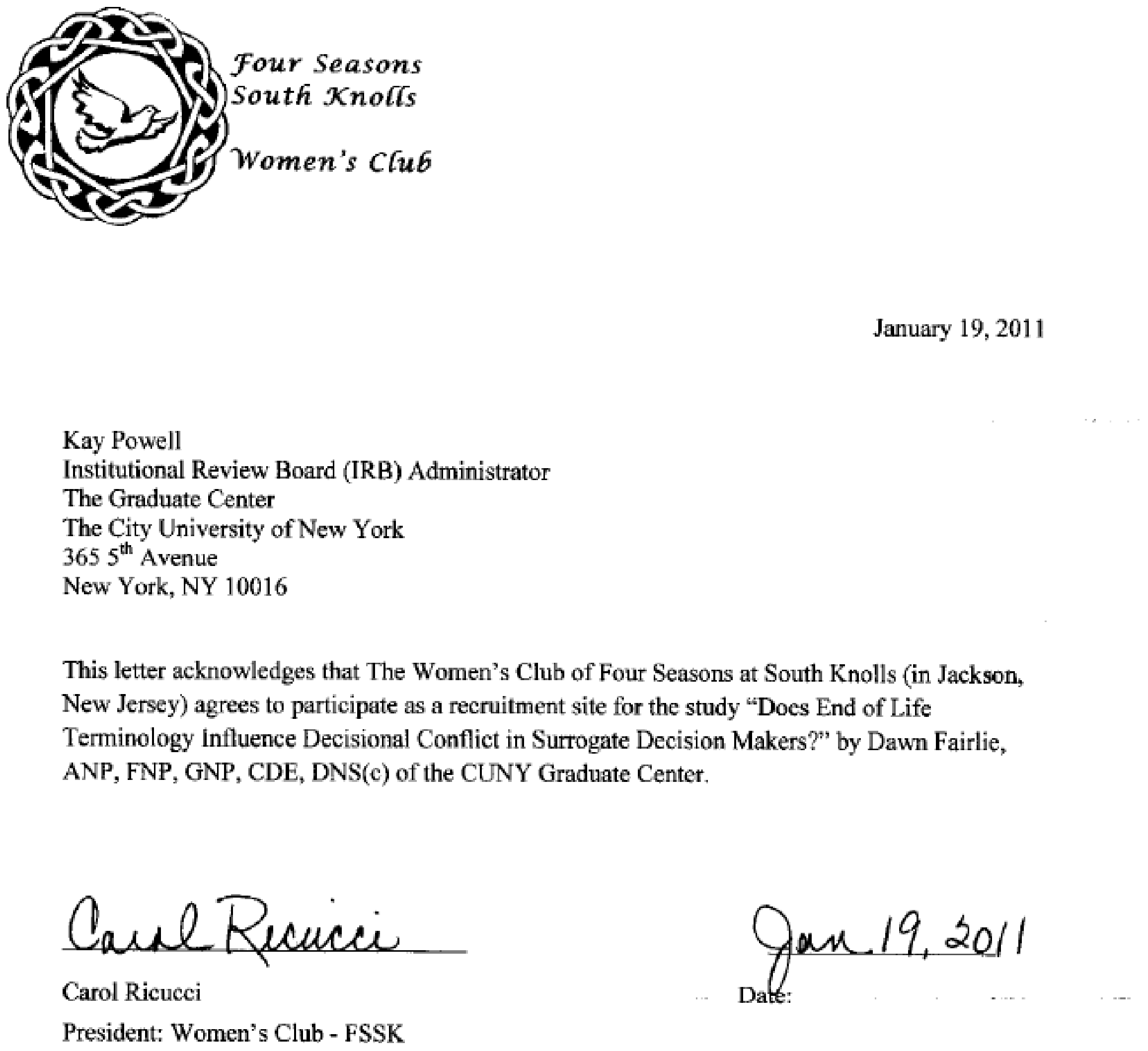
Aging, Disabilities & Veterans
Theresa A. Davis

973-285-6848
Fax 973-285-6845
divaging@aol.com

This letter acknowledges that the Morris County Senior Nutrition Program will participate as a recruitment site for the study "Does End of Life Terminology Influence Decisional Conflict in Surrogate Decision Makers?" by Dawn Fairlie, ANP, FNP, GNP, CDE, DNS(c) of the CUNY Graduate Center.

Theresa A. Davis	Division Head	10/14/10
Signature	Title	Date

Office located at 340 West Hanover Avenue, Morris Township, New Jersey



Four Seasons
South Knolls

Women's Club

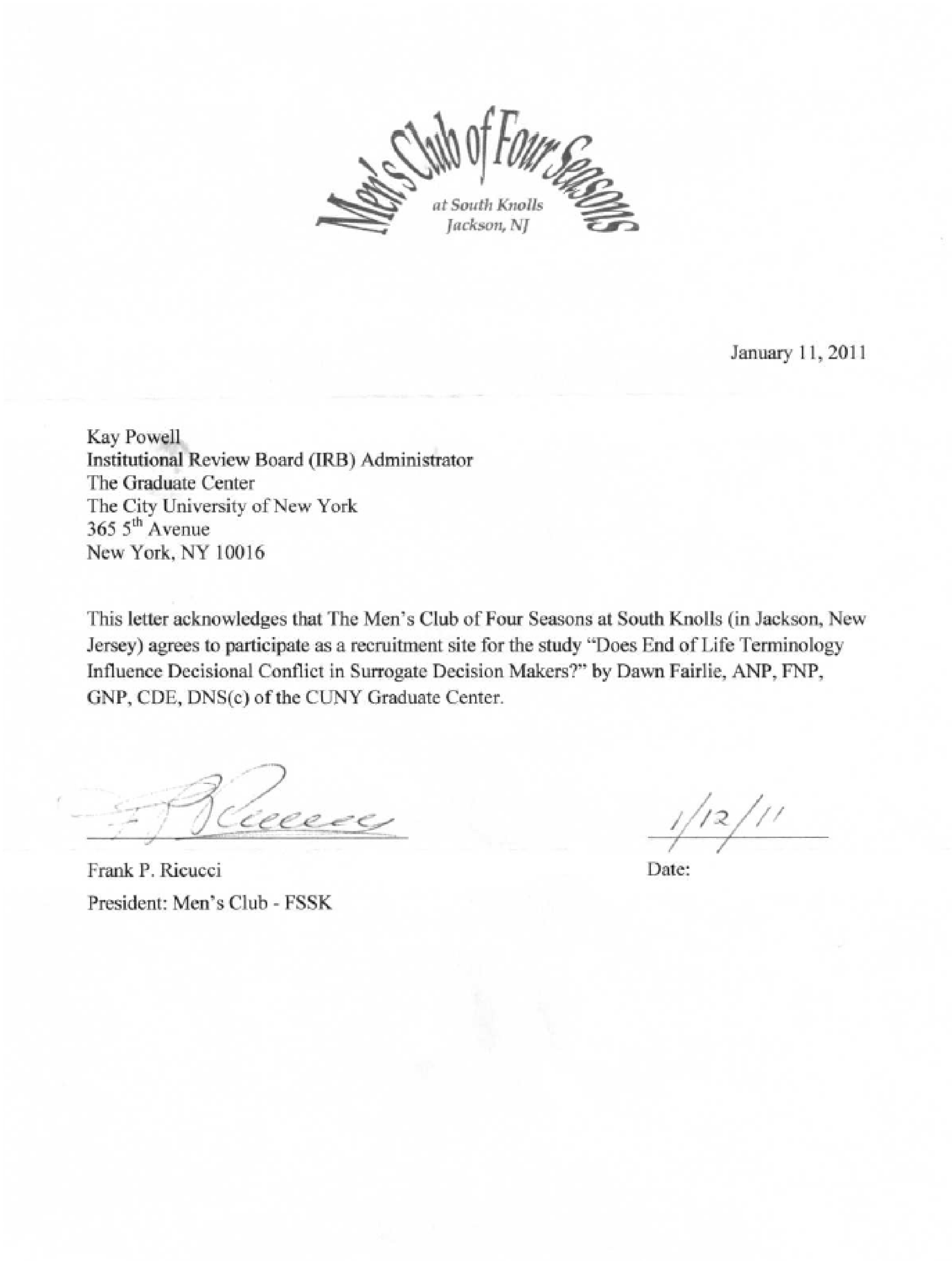
January 19, 2011

Kay Powell
Institutional Review Board (IRB) Administrator
The Graduate Center
The City University of New York
365 5th Avenue
New York, NY 10016

This letter acknowledges that The Women's Club of Four Seasons at South Knolls (in Jackson, New Jersey) agrees to participate as a recruitment site for the study "Does End of Life Terminology Influence Decisional Conflict in Surrogate Decision Makers?" by Dawn Fairlie, ANP, FNP, GNP, CDE, DNS(c) of the CUNY Graduate Center.

Carol Ricucci
Carol Ricucci
President: Women's Club - FSSK

Jan 19, 2011
Date:



Men's Club of Four Seasons
at South Knolls
Jackson, NJ

January 11, 2011

Kay Powell
Institutional Review Board (IRB) Administrator
The Graduate Center
The City University of New York
365 5th Avenue
New York, NY 10016

This letter acknowledges that The Men's Club of Four Seasons at South Knolls (in Jackson, New Jersey) agrees to participate as a recruitment site for the study "Does End of Life Terminology Influence Decisional Conflict in Surrogate Decision Makers?" by Dawn Fairlie, ANP, FNP, GNP, CDE, DNS(c) of the CUNY Graduate Center.

1/12/11

Frank P. Ricucci
President: Men's Club - FSSK

Date:

Appendix M

Script

The following survey will take 10-15 minutes to complete.
Thank you in advance for completing this survey.

I will now distribute consent forms and pencils which you will use to complete the survey. You may keep the pencil as a small token of my appreciation for your help in completing this survey for this study.

DISTRIBUTE CONSENT FORMS AND PENCILS

Please read the consent form. By completing the survey, you are indicating that you consent to participate in the study. If after reading the consent, you prefer not to complete the survey, you are free to leave the survey site. Please place the survey packet in the box at the front of the room before leaving.

Now that you have read consent form, we will begin the survey.

It is important that you read and follow the directions and that you do not speak with anyone during the time when you are completing the survey. The survey will be completed in two stages. First you will complete page 1. After completing page 1, you may break the seal on the rest of the packet and complete the remainder of the survey.

If you have any questions, please ask them now. (Ask, “Are there any questions?”)

I will now distribute the survey packets (Distribute survey packets.)

OK. Remember, when you have finished, please place your survey back in the envelope, leave the envelope in this box, and leave the room.

I will leave the room and wait outside until you have all left the room.

Thank you again for completing this survey

Appendix N

Descriptive Statistics

The descriptive statistics and p-values from the bivariate analyses for total score

	N	Mean	Standard Deviation	*p*-value
Version				
A	120	20.85	17.19	0.137
D	114	24.19	17.04	
Age				
50-59	15	24.48	11.11	0.809
60-69	105	22.83	16.84	
70-79	80	22.85	20.24	
>=80	32	19.94	11.86	
Sex				
Female	129	22.19	16.67	0.653
Male	102	23.21	17.82	
Race				
White, non-Hispanic	221	22.85	17.33	0.325
Non-white	11	17.61	13.3	
Marital Status				
Married	177	22.99	17.79	0.772
Widowed	40	20.88	13.49	
Single, Single living with partner, Separate, Divorced	15	21.78	19.34	
Education				
High school and below	100	21.57	14.51	0.385
Some college and above	132	23.48	18.88	
Religion				
None	7	22.99	23.05	0.793
Christian	185	23.1	16.89	
Other	31	20.81	18.67	
Religious Service				
Never	16	19.68	20.73	0.371
Rarely	67	25.5	14.86	
Sometimes	40	20.08	16.72	
Frequently	101	22.71	18.36	
Household Income				
<50,000	67	21.84	16.97	0.887
50,000-99,000	82	23.09	18.11	

	N	Mean	Standard Deviation	*p*-value
>=100,000	39	23.16	14.85	
Relation				
Spouse	157	22.41	18.1	0.918
All other categories	75	22.66	15.09	
Living Will				
Yes	112	20.34	16.71	0.060
No	82	26.04	17.4	
Not sure	38	20.88	17.02	
Made the decision in real life				
Yes	97	19.69	15.47	0.032*
No	135	24.59	18.1	
Surrogate decision maker				
Yes	105	19.03	14.82	0.006**
No	123	25.3	18.62	
Discuss preferences				
Yes	91	17.68	13.93	0.004**
No	5	36.25	11.29	
Having AD or HCP legal document				
Do not have both Docs	16	22.32	13.08	0.603
Have AD, HCP or both	134	20.07	16.63	
Worked in the health care field				
Yes	48	19.94	15.89	0.236
No	185	23.24	17.44	
Site				
1	24	21.35	13.54	0.613
2	10	16.56	13.86	
3	7	17.41	15.08	
4	20	18.66	17.38	
5	42	22.89	21.28	
6	59	25.29	18.29	
7	72	22.69	15.13	

*statistically significant at 0.05 significance level
**statistically significant at 0.01 significance level

The descriptive statistics and *p*-values from the bivariate analyses for informed subscore

	N	Mean	*SD*	*p*-value
Version				
A	120	19.72	20.12	0.663
D	113	18.66	16.86	
Age				
50-59	15	26.67	24.23	0.424
60-69	105	18.10	16.64	
70-79	79	19.20	21.24	
>=80	32	19.79	14.47	
Sex				
Female	128	18.68	18.11	0.546
Male	102	20.18	19.28	
Race				
White, non-Hispanic	220	19.47	18.87	0.722
Non-white	11	17.42	11.46	
Marital Status				
Married	177	20.20	19.13	0.312
Widowed	39	15.17	14.42	
Single, Single living with partner, Separate, Divorced	15	18.89	21.70	
Education				
High school and below	100	18.17	14.76	0.368
Some college and above	131	20.29	21.03	
Religion				
None	7	26.19	22.79	0.454
Christian	184	20.06	18.24	
Other	31	16.94	20.35	
Religious Service				
Never	16	16.15	19.36	0.269
Rarely	67	21.89	14.78	
Sometimes	39	15.38	17.78	
Frequently	101	20.79	20.87	
Household Income				
<50,000	66	20.71	20.48	0.638
50,000-99,000	82	20.33	19.03	
>=100,000	39	17.31	15.10	
Relation				
Spouse	157	19.53	18.56	0.849
All other categories	74	19.03	18.74	

	N	Mean	*SD*	*p*-value
Living Will				
Yes	111	17.04	18.10	0.134
No	82	22.46	18.83	
Not sure	38	18.86	19.15	
Made the decision in real life				
Yes	97	16.41	17.03	0.047*
No	134	21.33	19.48	
Surrogate decision maker				
Yes	105	16.27	18.25	0.031*
No	122	21.58	18.61	
Discuss preferences				
Yes	91	15.93	18.41	0.634
No	5	20.00	20.92	
Having AD or HCP legal document				
Do not have both Docs	16	13.02	12.53	0.781
Have AD, HCP or both	133	17.42	18.25	
Worked in the health care field				
Yes	47	15.60	16.54	0.128
No	185	20.23	18.99	
Site				
1	24	17.36	11.50	.950
2	10	17.50	16.41	
3	7	19.05	15.00	
4	19	19.74	18.47	
5	42	19.25	20.62	
6	59	21.61	21.89	
7	72	17.94	17.34	

*statistically significant at 0.05 significance level

The descriptive statistics and p-values from the bivariate analyses for value clarity subscore

	N	Mean	*SD*	*p*-value
Version				
A	119	18.45	17.66	0.177
D	114	21.67	18.64	
Age				
50-59	15	20	11.27	0.93
60-69	104	20.15	18.04	
70-79	80	20.78	20.98	

	N	Mean	*SD*	*p*-value
>=80	32	18.23	13.95	
Sex				
Female	129	18.93	16.63	0.239
Male	101	21.78	19.99	
Race				
White, non-Hispanic	220	20.23	18.49	0.619
Non-white	11	17.42	11.46	
Marital Status				
Married	177	19.96	18.57	0.868
Widowed	40	21.25	17.08	
Single, Single living with partner, Separate, Divorced	14	18.45	17.66	
Education				
High school and below	100	19.75	15.05	0.732
Some college and above	131	20.55	20.27	
Religion				
None	7	20.24	27.58	0.367
Christian	185	21.06	17.9	
Other	30	15.97	17.65	
Religions Service				
Never	16	16.15	20.06	0.18
Rarely	67	23.2	15.63	
Sometimes	40	15.94	16.29	
Frequently	101	20.71	19.89	
Household Income				
<50,000	67	19.65	17.21	0.993
50,000-99,000	82	19.97	19.18	
>=100,000	39	19.98	16.23	
Relation				
Spouse	156	19.95	18.89	0.763
All other categories	75	20.72	16.65	
Living Will				
Yes	111	18.24	18.42	0.248
No	82	22.61	17.65	
Not sure	38	19.41	17.92	
Made the decision in real life				
Yes	96	17.4	16.14	0.058
No	135	22.01	19.37	
Surrogate decision maker				
Yes	104	16.43	16.43	0.007**

	N	Mean	*SD*	*p*-value
No	123	22.97	19.34	
Discuss preferences				
Yes	90	14.86	15.12	0.003**
No	5	36.67	21.73	
Having AD or HCP legal document				
Do not have both Docs	16	19.27	14.18	0.816
Have AD, HCP or both	133	18.17	18.2	
Worked in the health care field				
Yes	48	17.19	16.46	0.211
No	184	20.88	18.56	
Site				
1	24	20.83	14.74	0.817
2	10	16.67	17.57	
3	7	21.43	17.25	
4	20	16.67	17.36	
5	42	20.04	22.17	
6	58	22.92	20.7	
7	72	18.69	14.93	

**statistically significant at 0.01 significance level

The descriptive statistics and p-values from the bivariate analyses for support subscore

	N	Mean	Standard Deviation	*P*-value
Version				
A	119	20.2	18.96	0.335
D	114	22.51	17.49	
Age				
50-59	15	22.78	16.2	0.958
60-69	104	21.67	17.81	
70-79	80	20.52	20.32	
>=80	32	21.87	15.66	
Sex				
Female	129	20.83	18.19	0.553
Male	101	22.28	18.38	
Race				
White, non-Hispanic	220	21.76	18.42	0.367
Non-white	11	16.67	13.44	

	N	Mean	Standard Deviation	*P*-value
Marital Status				
Married	177	22.39	18.65	0.274
Widowed	40	17.29	15.72	
Single, Single living with partner, Separate, Divorced	14	20.24	19.53	
Education				
High school and below	100	19.83	16.1	0.22
Some college and above	131	22.81	19.65	
Religion				
None	7	21.43	20.33	0.588
Christian	185	22.32	18.16	
Other	30	18.61	18.53	
Religious Service				
Never	16	17.71	18.23	0.4
Rarely	67	23.88	14.64	
Sometimes	40	18.75	17.37	
Frequently	101	22.57	20.59	
Household Income				
<50,000	67	21.27	17.96	0.933
50,000-99,000	82	21.34	18.57	
>=100,000	39	22.54	18.72	
Relation				
Spouse	156	21.31	18.75	0.989
All other catogories	75	21.28	17.06	
Living Will				
Yes	111	18.84	16.69	0.06
No	82	25.05	19.09	
Not sure	38	20.39	19.44	
Made the decision in real life				
Yes	96	18.23	16.72	0.027*
No	135	23.61	19.03	
Surrogate decision maker				
Yes	104	18.03	16.26	0.013*
No	123	24.09	19.5	
Discuss preferences				
Yes	90	16.76	15.92	0.041*
No	5	31.67	6.97	
Having AD or HCP legal document				

	N	Mean	Standard Deviation	*P*-value
Do not have both Docs	16	22.4	16.87	0.403
Have AD, HCP or both	133	18.61	17.07	
Worked in the health care field				
Yes	48	19.36	18.52	0.379
No	184	21.97	18.18	
Site				
1	24	21.18	14.74	0.888
2	10	20	17.21	
3	7	15.48	15.54	
4	20	17.08	17.83	
5	42	21.63	23.43	
6	58	22.84	18.51	
7	72	21.93	16.50	

*statistically significant at 0.05 significance level

The descriptive statistics and p-values from the bivariate analyses for uncertainty subscore

	N	Mean	Standard Deviation	*P*-value
Version				
A	120	26.35	22.05	0.101
D	114	31.21	23.12	
Age				
50-59	15	32.78	11.98	0.228
60-69	105	30.12	23.65	
70-79	80	29.48	24.73	
>=80	32	21.35	16.11	
Sex				
Female	129	28.75	22.65	0.857
Male	102	29.29	22.74	
Race				
White, non-Hispanic	221	29.32	22.74	0.206
Non-white	11	20.45	20.19	
Marital Status				
Married	177	29.21	23.11	0.910
Widowed	40	27.92	20.02	
Single, Single living with partner, Separate, Divorced	15	27.22	25.48	
Education				

	N	Mean	Standard Deviation	*P*-value
High school and below	100	26.75	19.83	0.181
Some college and above	132	30.65	24.43	
Religion				
None	7	25	26.79	0.896
Christian	185	29.08	21.99	
Other	31	29.03	25.63	
Religious Service				
Never	16	29.95	28.27	0.509
Rarely	67	32.46	21.13	
Sometimes	40	26.67	25.68	
Frequently	101	27.72	21.48	
Household Income				
<50,000	67	25.37	21.24	0.242
50,000-99,000	82	30.95	24.31	
>=100,000	39	31.41	19.26	
Relation				
Spouse	157	28.69	23.64	0.994
All other categories	75	28.67	20.19	
Living Will				
Yes	112	26.49	22.52	0.187
No	82	32.27	22.6	
Not sure	38	26.75	23.02	
Made the decision in real life				
Yes	97	25.95	22.11	0.097
No	135	30.96	22.93	
Surrogate decision maker				
Yes	105	25.87	21.05	0.077
No	123	31.2	23.84	
Discuss preferences				
Yes	91	24.18	19.45	0.002*
No	5	53.33	26.09	
Having AD or HCP legal document				
Do not have both Docs	16	30.21	17.97	0.439
Have AD, HCP or both	134	25.75	22.14	
Worked in the health care field				
Yes	48	26.39	22.3	0.400
No	185	29.48	22.73	
Site				

	N	Mean	Standard Deviation	*P*-value
1	24	23.61	16.42	0.149
2	10	17.5	13.29	
3	7	19.05	17.16	
4	20	22.08	25.97	
5	42	29.96	27.55	
6	59	33.12	22.48	
7	72	30.44	21.22	

*statistically significant at 0.01 significance level

The descriptive statistics and p-values from the bivariate analyses for effective decision subscore

	N	Mean	Standard Deviation	*P*-value
Version				
A	120	19.95	18.61	0.014*
D	114	26.33	20.79	
Age				
50-59	15	21.25	16.16	0.639
60-69	105	23.95	20.44	
70-79	80	23.91	22.36	
>=80	32	19.14	12.69	
Sex				
Female	129	23.56	20.43	0.755
Male	102	22.73	19.48	
Race				
White, non-Hispanic	221	23.43	20.18	0.261
Non-white	11	16.48	14.86	
Marital Status				
Married	177	23.25	20.63	0.977
Widowed	40	22.5	17.78	
Single, Single living with partner, Separate, Divorced	15	22.92	19	
Education				
High school and below	100	23.02	18.78	0.902
Some college and above	132	23.34	20.83	
Religion				
None	7	22.32	23.9	0.967
Christian	185	23.17	19.63	
Other	31	22.24	21.41	

	N	Mean	Standard Deviation	*P*-value
Religious Service				
Never	16	19.53	25.09	0.521
Rarely	67	26.12	18.58	
Sometimes	40	22.66	20.83	
Frequently	101	22.11	20.03	
Household Income				
<50,000	67	22.2	19.04	0.881
50,000-99,000	82	23.3	20.62	
>=100,000	39	24.09	17.24	
Relation				
Spouse	157	22.56	20.35	0.698
All other categories	75	23.64	18.58	
Living Will				
Yes	112	20.78	18.71	0.032*
No	82	27.64	21.83	
Not sure	38	19.79	17.25	
Made the decision in real life				
Yes	97	20.25	19.03	0.066
No	135	25.14	20.48	
Surrogate decision maker				
Yes	105	18.59	16.69	0.003**
No	123	26.52	21.86	
Discuss preferences				
Yes	91	16.83	15.8	0.003**
No	5	38.75	14.25	
Having AD or HCP legal document				
Do not have both Docs	16	25.78	17.81	0.271
Have AD, HCP or both	134	20.3	18.86	
Worked in the health care field				
Yes	48	20.79	18.22	0.368
No	185	23.7	20.38	
Site				
1	24	23.18	17.04	0.311
2	10	12.5	17.68	
3	7	13.39	15.49	
4	20	18.13	18.01	
5	42	23.51	21.77	
6	59	25.85	20.21	

	N	Mean	Standard Deviation	*P*-value
7	72	24.25	20.34	

*statistically significant at 0.05 significance level
**statistically significant at 0.01 significance level

Appendix O

N-way ANOVA Results

N-way ANOVA result for DCS total score

Group	N	Mean	Standard Deviation	*P*-value
Version				
A	120	20.85	17.19	0.085
D	114	24.19	17.04	
Made the decision in real life				
Yes	97	19.69	15.47	0.279
No	135	24.59	18.1	
Surrogate decision maker				
Yes	105	19.03	14.82	0.020*
No	123	25.3	18.62	

*statistically significant at 0.05 significance level

Table 2a.

N-way ANOVA result for informed subscore

Group	N	Mean	Standard Deviation	*P*-value
Version				
A	120	19.72	20.12	0.778
D	113	18.66	16.86	
Made the decision in real life				
Yes	97	16.41	17.03	0.159
No	134	21.33	19.48	
Surrogate decision maker				
Yes	105	16.27	18.25	0.148
No	122	21.58	18.61	

Table 3a.

N-way ANOVA result for value clarity subscore.

Group	N	Mean	Standard Deviation	*P*-value
Version				
A	119	18.45	17.66	0.08

Group	N	Mean	Standard Deviation	*P*-value
D	114	21.67	18.64	
Surrogate decision maker				
Yes	104	16.43	16.43	0.004*
No	123	22.97	19.34	

Table 4a.

N-way ANOVA result for support subscore.

Group	N	Mean	Standard Deviation	*P*-value
Version				
A	119	20.2	18.96	0.349
D	114	22.51	17.49	
Made the decision in real life				
Yes	96	18.23	16.72	0.153
No	135	23.61	19.03	
Surrogate decision maker				
Yes	104	18.03	16.26	0.051
No	123	24.09	19.5	

Table 5a.

N-way ANOVA results for uncertainty subscore.

Group	N	Mean	Standard Deviation	*P*-value
Version				
A	120	26.35	22.05	0.101
D	114	31.21	23.12	

Table 6a.

N-way ANOVA result for effective decision subscore.

Group	N	Mean	Standard Deviation	*P*-value
Version				
A	120	19.95	18.61	0.032*
D	114	26.33	20.79	
Living Will				
Yes	112	20.78	18.71	0.078
No	82	27.64	21.83	

Group	N	Mean	Standard Deviation	*P*-value
Surrogate decision maker	38	19.79	17.25	
Yes				
No	105	18.59	16.69	0.001**

*statistically significant at 0.05 significance level

Appendix P

Descriptive statistics and bivariate analyses result for the relationship between decision delay and version and select demographics.

	Decision Delay			*P*-value
	Yes	No	Total	
		N (%)		
Version				
AND	62 (53.9)	58 (48.7)	120 (51.3)	0.429
DNR	53 (46.1)	61 (51.3)	114 (48.7)	
Age				
50-59	6 (5.3)	9 (7.6)	15 (6.5)	0.719
60-69	50 (43.9)	55 (46.6)	105 (45.3)	
70-79	43 (37.7)	37 (31.4)	80 (34.5)	
>=80	15 (13.2)	17 (14.4)	32 (13.8)	
Sex				
Female	62 (54.9)	67 (56.8)	129 (55.8)	0.77
Male	51 (45.1)	51 (43.2)	102 (44.2)	
Race				
White, non-Hispanic	107 (94.7)	114 (95.8)	221 (95.3)	0.691
Non-white	6 (5.3)	5 (4.2)	11 (4.7)	
Marital Status				
Married	84 (73.7)	93 (78.8)	177 (76.3)	0.652
Widowed	22 (19.3)	18 (15.3)	40 (17.2)	
Single, Single living with partner, Separate, Divorced	8 (7.0)	7 (5.9)	15 (6.5)	
Education				
High school and below	49 (43.4)	51 (42.9)	100 (43.1)	0.938
Some college and above	64 (56.6)	68 (57.1)	132 (56.9)	
Religion				
None	4 (3.7)	3 (2.6)	7 (3.1)	0.507
Christian	87 (79.8)	98 (86.0)	185 (83.0)	
Other	18 (16.5)	13 (11.4)	31 (13.9)	
Religious Service				
Never	10 (9.3)	6 (5.2)	16 (7.1)	0.047*
Rarely	23 (21.3)	44 (37.9)	67 (29.9)	
Sometimes	22 (20.4)	18 (15.5)	40 (17.9)	
Frequently	53 (49.1)	48 (41.4)	101 (45.1)	
Household Income				
<50,000	33 (35.9)	34 (35.4)	67 (35.6)	0.741
50,000-99,000	38 (41.3)	44 (45.8)	82 (43.6)	

	Decision Delay			*P*-value
	Yes	No	Total	
	N (%)			
>=100,000	21 (22.8)	18 (18.8)	39 (20.7)	
Relation				
Spouse	77 (67.5)	80 (67.8)	157 (67.7)	0.967
All other categories	37 (32.5)	38 (32.2)	35 (32.3)	
Living Will				
Yes	28 (24.6)	54 (45.8)	82 (35.3)	0.003**
No	65 (57.0)	47 (39.8)	112 (48.3)	
Not sure	21 (18.4)	17 (14.4)	38 (16.4)	
Made the decision in real life				
Yes	49 (43.0)	48 (40.7)	97 (41.8)	0.722
No	65 (57.0)	70 (59.3)	135 (58.2)	
Surrogate decision maker				
Yes	61 (45.5)	44 (37.9)	105 (46.1)	0.012*
No	51 (54.5)	72 (62.1)	123 (53.9)	
Discuss preferences				
Yes	56 (98.2)	35 (89.7)	91 (94.8)	0.155
No	1 (1.8)	4 (10.3)	5 (5.2)	
Having AD or HCP legal document				
Do not have both Docs	7 (8.2)	9 (13.8)	16 (10.7)	0.27
Have AD, HCP or both	78 (91.8)	56 (86.2)	134 (89.3)	
Worked in the health care field				
Yes	29 (25.4)	19 (16.0)	48 (20.6)	0.074
No	85 (74.6)	100 (84.0)	185 (79.4)	
Site				
1	9 (7.8)	15 (12.6)	24 (10.3)	0.293
2	6 (5.2)	4 (3.4)	10 (4.3)	
3	4 (3.5)	3 (2.5)	7 (3.0)	
4	14 (12.2)	6 (5.0)	20 (8.5)	
5	22 (19.1)	20 (16.8)	42 (17.9)	
6	30 (26.1)	29 (24.4)	59 (25.2)	
7	30 (26.1)	42 (35.53)	72 (30.8)	

*statistically significant at 0.05 significance level
**statistically significant at 0.01 significance level

Appendix Q

Descriptive statistics and bivariate analyses result for the relationship between decision implementation and version and select demographics.

	Decision implementation				*P*-value
	Yes	No	Unsure	Total	
	N (%)				
Version					
A	102 (70.8)	9 (22.5)	8 (16.3)	119 (51.1)	a) <0.001** b) <0.001** c) <0.001**
D	42 (29.2)	31 (77.5)	41 (83.7)	114 (48.9)	
Age					
50-59	9 (6.3)	4 (10.5)	2 (4.1)	15 (6.5)	a) 0.406 b) 0.743 c) 0.370
60-69	66 (45.8)	14 (36.8)	25 (51.0)	105 (45.5)	
70-79	46 (31.9)	16 (42.1)	17 (34.7)	79 (34.2)	
>=80	23 (16.0)	4 (10.5)	5 (10.2)	32 (13.9)	
Sex					
Female	87 (60.4)	16 (43.2)	26 (53.1)	129 (56.1)	a) 0.060 b) 0.630 c) 0.086
Male	57 (39.6)	21 (56.8)	23 (46.9)	101 (43.9)	
Race					
White, non-Hispanic	136 (95.1)	38 (97.4)	46 (93.9)	220 (95.2)	a) 1.000 b) 0.705 c) 0.696
Non-white	7 (4.9)	1 (2.6)	3 (6.1)	11 (4.8)	
Marital Status					
Married	112 (77.8)	28 (73.7)	36 (73.5)	176 (76.2)	a) 0.621 b) 0.495 c) 0.853
Widowed	25 (17.4)	7 (18.4)	8 (16.3)	40 (17.3)	
Single, Single living with partner, Separate, Divorced	7 (4.9)	3 (7.9)	5 (10.2)	15 (6.5)	
Education					
High school and below	61 (42.4)	16 (42.1)	22 (44.9)	99 (42.9)	a) 0.977 b) 0.745 c) 0.918
Some college and above	83 (57.6)	22 (57.9)	27 (55.1)	132 (57.1)	
Religion					
None	5 (3.7)	2 (5.1)	0 (0.0)	7 (3.2)	a) 0.038* b) 0.504 c) 0.036*
Christian	108 (79.4)	36 (92.3)	40 (85.1)	184 (82.9)	
Other	23 (16.9)	1 (2.6)	7 (14.9)	31 (14.0)	
Religious Service					
Never	13 (9.6)	0 (0.0)	3 (6.3)	16 (7.2)	a) 0.126 b) 0.787 c) 0.181
Rarely	43 (31.6)	10 (25.6)	13 (27.1)	66 (29.6)	
Sometimes	21 (15.4)	8 (20.5)	11 (22.9)	40 (17.9)	
Frequently	59 (43.4)	21 (53.8)	21 (43.8)	101 (45.3)	

	Decision implementation				*P*-value
	Yes	No	Unsure	Total	
	N (%)				
Household Income					
<50,000	40 (34.8)	12 (37.5)	15 (37.5)	67 (35.8)	a) 0.951 b) 0.840 c) 0.945
50,000-99,000	50 (43.5)	13 (40.6)	18 (45.0)	81 (43.3)	
>=100,000	25 (21.7)	7 (21.9)	7 (17.5)	39 (20.9)	
Relation					
Spouse	102 (70.8)	26 (66.7)	28 (58.3)	156 (67.5)	a) 0.615 b) 0.126 c) 0.899
All other categories	42 (29.2)	13 (33.3)	20 (41.7)	75 (32.5)	
Living Will					
Yes	75 (52.1)	19 (48.7)	17 (35.4)	111 (48.1)	a) 0.474 b) 0.122 c) 0.472
No	46 (31.9)	16 (41.0)	20 (41.7)	82 (35.5)	
Not sure	23 (16.0)	4 (10.3)	11 (22.9)	38 (16.5)	
Made the decision in real life					
Yes	65 (45.1)	17 (43.6)	14 (29.2)	96 (41.6)	a) 0.863 b) 0.050* c) 0.778
No	79 (54.9)	22 (56.4)	34 (70.8)	135 (58.4)	
Surrogate decision maker					
Yes	67 (47.5)	20 (52.6)	17 (35.4)	104 (45.8)	a) 0.576 b) 0.103 c) 0.355
No	74 (52.5)	18 (47.4)	31 (64.6)	123 (54.2)	
Discuss preferences					
Yes	58 (98.3)	19 (95.0)	13 (81.3)	90 (94.7)	a) 0.445 b) 0.032* c) 1.000
No	1 (1.7)	1 (5.0)	3 (18.8)	5 (5.3)	
Having AD or HCP document					
Do not have both Docs	7 (7.4)	3 (11.1)	6 (21.4)	16 (10.7)	a) 0.690 b) 0.081 c) 1.000
Have AD, HCP or both	88 (92.6)	24 (88.9)	22 (78.6)	134 (89.3)	
Worked in the health care field					
Yes	27 (18.8)	6 (15.4)	14 (28.6)	47 (20.3)	a) 0.628 b) 0.103 c) 0.406
No	117 (81.3)	33 (84.6)	35 (71.4)	185 (79.7)	
Site					
1	13 (9.0)	1 (2.5)	10 (20.4)	24 (10.3)	a) 0.360 b) 0.084 c) <0.001**
2	8 (5.6)	2 (5.0)	0 (0.0)	10 (4.3)	
3	5 (3.5)	1 (2.5)	1 (2.0)	7 (3.0)	
4	9 (6.3)	5 (12.5)	6 (12.2)	20 (8.6)	
5	28 (19.4)	4 (10.0)	10 (20.4)	42 (18.0)	
6	34 (23.6)	14 (35.0)	10 (20.4)	58 (24.9)	
7	47 (32.6)	13 (32.5)	12 (24.5)	72 (30.9)	

*statistically significant at 0.05 significance level
**statistically significant at 0.001 significance level

Descriptive statistics and p-values from the single factor analyses using Chi-square tests or Fisher's Exact tests.

Variable (N=234)	*Group*	End of Life Decision Making				P-value
		Yes	No	Unsure	Total	
			N (%)			
Version	A	102 (70.8)	9 (22.5)	8 (16.3)	119 (51.1)	a) <0.001* b) <0.001* c) <0.001*
	D	42 (29.2)	31 (77.5)	41 (83.7)	114 (48.9)	
Age	50-59	9 (6.3)	4 (10.5)	2 (4.1)	15 (6.5)	a) 0.406 b) 0.743 c) 0.603
	60-69	66 (45.8)	14 (36.8)	25 (51.0)	105 (45.5)	
	70-79	46 (31.9)	16 (42.1)	17 (34.7)	79 (34.2)	
	>=80	23 (16.0)	4 (10.5)	5 (10.2)	32 (13.9)	
Sex	Female	87 (60.4)	16 (43.2)	26 (53.1)	129 (56.1)	a) 0.060 b) 0.630 c) 0.087
	Male	57 (39.6)	21 (56.8)	23 (46.9)	101 (43.9)	
Race	White, non-Hispanic	136 (95.1)	38 (97.4)	46 (93.9)	220 (95.2)	a) 1.000 b) 0.705 c) 1.000
	Non-white	7 (4.9)	1 (2.6)	3 (6.1)	11 (4.8)	
Marital Status	Married	112 (77.8)	28 (73.7)	36 (73.5)	176 (76.2)	a) 0.621 b) 0.495 c) 0.428
	Widowed	25 (17.4)	7 (18.4)	8 (16.3)	40 (17.3)	
	Single, Single living with partner, Separate, Divorced	7 (4.9)	3 (7.9)	5 (10.2)	15 (6.5)	
Education	High school and below	61 (42.4)	16 (42.1)	22 (44.9)	99 (42.9)	a) 0.977 b) 0.745 c) 0.845
	Some college and above	83 (57.6)	22 (57.9)	27 (55.1)	132 (57.1)	
Religions	None	5 (3.7)	2 (5.1)	0 (0.0)	7 (3.2)	a) 0.038* b) 0.504 c) 0.223
	Christian	108 (79.4)	36 (92.3)	40 (85.1)	184 (82.9)	
	Other	23 (16.9)	1 (2.6)	7 (14.9)	31 (14.0)	
Religion Service	Never	13 (9.6)	0 (0.0)	3 (6.3)	16 (7.2)	a) 0.126 b) 0.787 c) 0.192
	Rarely	43 (31.6)	10 (25.6)	13 (27.1)	66 (29.6)	
	Sometimes	21 (15.4)	8 (20.5)	11 (22.9)	40 (17.9)	
	Frequently	59 (43.4)	21 (53.8)	21 (43.8)	101 (45.3)	
Household Income	<50,000	40 (34.8)	12 (37.5)	15 (37.5)	67 (35.8)	a) 0.951 b) 0.840 c) 0.903
	50,000-99,000	50 (43.5)	13 (40.6)	18 (45.0)	81 (43.3)	
	>=100,000	25 (21.7)	7 (21.9)	7 (17.5)	39 (20.9)	

Variable (N=234)	*Group*	End of Life Decision Making				P-value
		Yes	No	Unsure	Total	
			N (%)			
Relation	Spouse	102 (70.8)	26 (66.7)	28 (58.3)	156 (67.5)	a) 0.615 b) 0.126 c) 0.168
	All other categories	42 (29.2)	13 (33.3)	20 (41.7)	75 (32.5)	
Living Will	Yes	75 (52.1)	19 (48.7)	17 (35.4)	111 (48.1)	a) 0.474 b) 0.122 c) 0.258
	No	46 (31.9)	16 (41.0)	20 (41.7)	82 (35.5)	
	Not sure	23 (16.0)	4 (10.3)	11 (22.9)	38 (16.5)	
Made the decision in real life	Yes	65 (45.1)	17 (43.6)	14 (29.2)	96 (41.6)	a) 0.863 b) 0.050* c) 0.155
	No	79 (54.9)	22 (56.4)	34 (70.8)	135 (58.4)	
Surrogate decision maker	Yes	67 (47.5)	20 (52.6)	17 (35.4)	104 (45.8)	a) 0.576 b) 0.103 c) 0.510
	No	74 (52.5)	18 (47.4)	31 (64.6)	123 (54.2)	
Discussed preferences	Yes	58 (98.3)	19 (95.0)	13 (81.3)	90 (94.7)	a) 0.445 b) 0.032* c) 0.066
	No	1 (1.7)	1 (5.0)	3 (18.8)	5 (5.3)	
Having AD or HCP document	Does not have both AD and HCP	7 (7.4)	3 (11.1)	6 (21.4)	16 (10.7)	a) 0.690
	Has AD, HCP or both documents	88 (92.6)	24 (88.9)	22 (78.6)	134 (89.3)	b) 0.081 c) 0.085
Worked in the health care field	Yes	27 (18.8)	6 (15.4)	14 (28.6)	47 (20.3)	a) 0.628 b) 0.103 c) 0.465
	No	117 (81.3)	33 (84.6)	35 (71.4)	185 (79.7)	
Site	1	13 (9.0)	1 (2.5)	10 (20.4)	24 (10.3)	a) 0.360 b) 0.084 c) <0.484
	2	8 (5.6)	2 (5.0)	0 (0.0)	10 (4.3)	
	3	5 (3.5)	1 (2.5)	1 (2.0)	7 (3.0)	
	4	9 (6.3)	5 (12.5)	6 (12.2)	20 (8.6)	
	5	28 (19.4)	4 (10.0)	10 (20.4)	42 (18.0)	
	6	34 (23.6)	14 (35.0)	10 (20.4)	58 (24.9)	
	7	47 (32.6)	13 (32.5)	12 (24.5)	72 (30.9)	

*Statistically significant at 0.05 significance level.

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