11-15-2016

Family Communication Concerning End-of-Life Care Preferences

Lindsay Jo Peterson
University of South Florida, ljpeterson@mail.usf.edu

Scholar Commons Citation
Peterson, Lindsay Jo, "Family Communication Concerning End-of-Life Care Preferences" (2016). *USF Tampa Graduate Theses and Dissertations.*
https://digitalcommons.usf.edu/etd/6566

Family Communication Concerning End-of-Life Care Preferences

by

Lindsay J. Peterson

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
School of Aging Studies
College of Behavioral and Community Sciences
University of South Florida

Major Professor: Kathryn Hyer, PH.D., MPP
Debra Dobbs, Ph.D.
Alyssa Gamaldo, Ph.D.
Hongdao Meng, Ph.D., MPH
Kevin O'Neil, M.D.

Date of Approval:
November 8, 2016

Keywords: Advance care planning, stages of change, transtheoretical model, mixed methods

DEDICATION

This dissertation is dedicated to Makenna and Madden Stewart and your fabulous parents Danielle and Derrick. You are my hope for the future.

ACKNOWLEDGMENT

I am grateful to the members of my committee for their time, support, and excellent advice throughout this process. Thank you to Drs. Hyer, Dobbs, Gamaldo, Meng, and O'Neil. I am very grateful for all that I have learned from each one of you. And thank you to Dr. Harleah Buck for some key last-minute guidance. Very special thanks to Dr. Hyer. It was through her guidance and apt suggestions that I began this work, and she kept me going by always knowing how to solve each problem as it arose. Her answer to every question was "you can do this."

I also am grateful to everyone in the School of Aging Studies, most especially the faculty who prepared me to undertake this project. I learned something that I used in this project from every class I took. Others helped me in so many ways, particularly Rosa Diaz and Pam Stobaugh. I especially thank Cathy McEvoy for paying attention to my appeal to begin this Ph.D. program and believing in me enough to make it possible. The experience has set me on a new path. I also owe great thanks to the Center for Hospice, Palliative Care, and End of Life Studies at USF, whose generous support made this project possible. This is an exceptional organization that performs an important service by enabling the multidisciplinary educators, researchers, and professionals in this field to share and build their knowledge.

I deeply thank my husband, who encouraged me to begin this challenge and has coached and encouraged me along the way and is celebrating my completion possibly more than I am. Finally, I can't leave out the "Divas," my loyal compatriots, each of whom makes my life richer and who helped keep our friendships going as all of us began new lives.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABSTRACT

Communication concerning the care one wishes to receive at the end of life (EOL) is central to ensuring that wishes are honored. Many studies have examined doctor-patient or doctor-family EOL communication. However, relatively few studies have focused on the occurrence of EOL care discussions among family members. This is an important topic, as research suggests that advance directives (ADs) are ineffective if patients have not involved surrogate decision-makers, most of whom are family members. This study examined EOL care discussions among family members. It used quantitative and qualitative data from a diverse sample of older adults from West Central Florida collected for the purpose of this examination. The quantitative and qualitative data were analyzed separately and together.

This study employed the Transtheoretical Model, which proposes that individuals are in varying behavioral "stages of change" and that bringing about a behavioral change requires understanding their particular stage and adapting interventions appropriately. Statistical analysis of the quantitative data (*N*=364) using multinomial logistic regression showed that participants were in distinct stages that were associated with several factors, including family involvement with health care decision-making and communications with doctors. Racial and ethnic differences were not found in controlled analysis, though Hispanics were less likely to be in more advanced EOL care discussion stages in unadjusted analyses.

Several themes were found in qualitative analysis of focus groups (*n*=36) drawn from the larger sample. Findings suggested that those who engaged in family EOL care discussions were

more careful planners overall, more accepting of death, and able to manage complex family dynamics. They also had greater knowledge of EOL matters, largely related to knowledge of loved ones EOL wishes.

The quantitative-qualitative (mixed-methods) study reinforced the role of family relationships in general in whether EOL care discussions occurred. It also highlighted the role of being proactive and having EOL care knowledge. All three studies – the quantitative, qualitative, and mixed methods showed the potential for doctors and other health professionals to help families with EOL care discussions and ACP overall.

CHAPTER ONE:

BACKGROUND

For more than two decades, researchers and public policy makers have tried to explain why people receive aggressive medical treatments in their final days when this is not the treatment most of them want (Institute of Medicine, 2014; Pew Research Center, 2013). To ameliorate this discordance between the care people say they want and the care they receive, public policy makers have promoted the use of written advance directives (ADs) (Brown, 2003; Ramsaroop, Reid, Adelman, 2007). While these efforts have shown some success (Silveira, Wiitala, & Piette, 2014; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007), questions persist concerning written documents and how well they ensure that patient's end-of-life (EOL) care wishes are known and honored (Oulton, Rhodes, Howe, Fain, & Mohler, 2015).

Research has shown that use of intensive health care services at the end of life (EOL) is rising (Teno et al., 2013), as are concerns about the numbers of adults living into late life with chronic conditions that complicate care coordination (IOM, 2014). Racial and ethnic disparities in EOL care quality have been documented in the literature and are a continuing concern. A frequently cited problem is inadequate communication between heath care providers and the family members of dying patients. Studies have also shown evidence of care that is inconsistent with the stated preferences of minority families (Conner & Chase, 2014; Lee, Long, Curtis, & Engelberg, 2016; Loggers et al., 2009; Welch, Teno, & Mor, 2005).

The Role of Family Discussion in Advance Care Planning

McMahan and colleagues (2013) suggested that ADs overall are ineffective if patients have not talked to their surrogate decision-makers with sufficient detail for the surrogates to know what to do to honor the patients' wishes. Other research has shown that surrogates often lack the knowledge they need of patients' wishes or values (Hawkins, Ditto, Danks, & Smucker, 2005; Shalowitz, Garrett-Mayer, & Wendler, 2006; Sudore & Fried, 2010). As a result, interest has grown in increasing discussions between individuals and those who may play a role in their EOL decision making (Sudore & Fried, 2010; Tulsky, 2005). Many people do want to have these discussions (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013), but studies show that many others are averse to talking about the prospect of their own illness and death (Abba, Byrne, Horton, & Lloyd-Williams, 2013; Waldrop & Meeker, 2013).

Conceptual Framework

Programs exist to promote family EOL care discussions and other ACP (Butler, Ratner, McCreedy, Shippee, & Kane, 2014), but researchers analyzing the limited success of some programs have highlighted the need to consider whether an individual is ready to engage in ACP, proposing the use of the Transtheoretical Model (TTM) of behavior change (Pearlman, Cole, Patrick, Starks, & Cain, 1995; Schickedanz, Schillinger, Landefeld, Knight, Williams, & Sudore, 2009). They have conceptualized ACP as a health behavior for which individuals are at differing levels of action or readiness to act. Pearlman and colleagues (1995) proposed that the TTM could be used to design more effective ACP interventions because the TTM accounted for the dynamic, complex nature of ACP. In keeping with this line of thinking, others have proposed that increasing ACP requires understanding an individual's "stage of change" as the TTM proposes (e.g. Fried, Bullock, Iannone, & O'Leary, 2009; Ramsaroop et al., 2007).

The Transtheoretical Model (TTM) is one of the primary models of behavior change, termed "transtheoretical" because it integrates major psychotherapeutic approaches, including psychoanalysis, cognitive-behavior therapy, and person-centered therapy to explain and influence health behavior (Prochaska, DiClemente, & Norcross, 1992; Prochaska, Redding, & Evers, 2008). The TTM has been used to investigate and develop interventions for a broad range of disorders, including alcohol abuse, bullying, eating disorders, using sun screens, and medication compliance (Prochaska et al., 2008).

Elements of the Transtheoretical Model

The TTM conceptualizes behavior change as a process unfolding over time and involving progression through five or six stages. Based on previous research (Ernecoff, Keane, & Albert, 2016), the present study uses the six-stage approach (Wright, Velicer, & Prochaska, 2008). These stages are as follows:

Precontemplation - The individual has no intention of changing in the next 6 months (though the time period may vary depending on the behavior) and may be unaware or under aware of the consequences of their behavior. Individuals may avoid reading, talking, or thinking about the behavior.

Contemplation – The individual is aware that a problem exists and is thinking about taking action in the next several months but not make a commitment.

Preparation – The individual intends to take action soon (in the next month), and may have already taken a small but meaningful step, such as beginning to develop a plan.

Action – The individual has taken action in the past 6 to 12 months, though this does not constitute behavior change.

Relapse - The individual has taken action, but not in the past 12 months and therefore is considered to have fallen out of action.

Maintenance – The individual has taken action and is working to consolidate gains attained during action and to not revert to previous avoidance behaviors.

The TTM includes three other constructs - processes of change (the activities individuals use to progress from one stage to another); decisional balance (an individual's weighing of the pros and cons of changing behavior); and self-efficacy (one's confidence in the ability to undertake the new behavior).

New Contribution

This study makes several new contributions to current research. Few studies have specifically examined EOL care discussions among family members (Wallace, 2014) using a racially and ethnically diverse older population. In a study of chronically ill older adults, Carr (2011) showed that both older Latinos and Blacks were less likely than Whites to discuss EOL care wishes with loved ones, though the differences disappeared when they controlled for socioeconomics and attitudes toward death. Other studies have examined EOL care discussions among family members (Carr & Khodyakov, 2007; Carr, Moorman, Boerner, 2013) but not using a diverse population.

Furthermore, a limited number of studies have used the TTM to examine family EOL care discussions. Fried et al. (2010) used the TTM to study several ACP behaviors, including talking to family about EOL concerns. In univariate analyses, they found significant associations between discussion stages and sociodemographic factors, AD knowledge, and other planning for the future (e.g., funeral planning). In a follow-up study, Fried and colleagues (2012) examined discussion stages and processes of change. They found that family EOL care discussions were significantly associated with only two of five ACP-related processes of change - evaluating the personal value of ACP and the ability to obtain ACP help. They concluded that more research was needed to define the change processes related to family discussions. They did not include the self-efficacy construct in their study. The present study extends on previous research by examining stages of change for family discussions using a broad range of covariates, including self-efficacy, family relationships concerning general health decision making, health literacy, and discussions with doctors concerning EOL care wishes. Furthermore, unlike many of the previous studies, the present study includes a racially and ethnically diverse sample. In addition, unlike the previous studies, it employs a mixed methods design using quantitative data followed by qualitative data to more fully explain the factors that influence the occurrence of EOL care discussions among family members.

Organization

This dissertation is divided into three papers, each taking a different methodological approach toward explaining the occurrence of family EOL care discussions. The first study quantitatively examines the association between stages of change for having an EOL care discussion and a range of factors including race and ethnicity and other sociodemographics, self-efficacy in health care, knowledge of palliative care, and other ACP. The second is a qualitative analysis using focus groups of those who have engaged in EOL care discussions and those who have not. It aims to explain what facilitates and what obstructs having such discussions. The third study in this dissertation uses a mixed methods approach, integrating the quantitative and qualitative data to explain how family relationships influence whether people have EOL care discussions with family members. Finally, the last chapter presents a discussion of the findings, limitations, and future research opportunities related to this study.

CHAPTER TWO:

PREDICTORS OF END OF LIFE CARE DISCUSSIONS WITH FAMILY MEMBERS

Introduction

Public policy makers have advocated for the use of written ADs for many years in their efforts to resolve the reported discordance between the EOL treatment that people say they want and the treatment that they receive (Brown, 2003; IOM, 2014; Pew Research Center, 2013). These efforts have shown some success (Silveira et al., 2014; Teno et al., 2007), though research continues to raise questions about how well ADs ensure that patient's end-of-life (EOL) care wishes are known (Oulton et al., 2015). Concern stems from research showing that intensive health services at EOL have risen (Teno et al., 2013) and general concerns about the numbers of adults living into late life with chronic conditions (IOM, 2014). In particular, studies have shown racial and ethnic EOL care disparities, including perceptions of inadequate communication between heath care providers and the family members of dying patients and care that is inconsistent with stated preferences (Conner & Chase, 2014; Lee, et al., 2016; Loggers et al., 2009; Welch et al., 2005).

Interest has grown in increasing discussions between individuals and those who may play a role in their EOL decision-making (Sudore & Fried, 2010; Tulsky, 2005), with research showing that decision-making surrogates often lack the knowledge they need of patients' wishes or values (Hawkins et al., 2005; Shalowitz et al., 2006; Sudore & Fried, 2010). A number of studies have concluded that it is important to consider whether an individual is ready to engage in ACP (Pearlman et al., 1995; Schickedanz et al., 2009). Several have used the TTM, proposing that increasing ACP requires understanding an individual’s "stage of change" (e.g. Fried et al., 2009; Ramsaroop, et al., 2007).

To our knowledge, a limited number of studies have focused on the varied factors associated with whether racially and ethnically diverse older adults discuss their EOL care wishes with family members (Wallace, 2014). A number of studies have used the TTM to examine ACP readiness, but none to our knowledge have used the TTM to examine readiness to engage in family discussions and associations of readiness and a broad range of covariates.

Aims

The present study investigated 3 aims:

Aim 1: Identify the percentage of older adults in each stage of EOL-discussion readiness and examine whether the rates of discussion readiness vary by racial and/or ethnic group.

Hypothesis: Race and/or ethnicity is associated with stage of readiness to have an EOL care family discussion.

Aim 2: Examine the factors associated with stage of EOL-discussion readiness (e.g., education, self-efficacy, health knowledge) and whether they explain the association between race/ethnicity and the stage of EOL-discussion readiness.

Hypothesis: Sociodemographic and other factors (e.g. self-efficacy, health knowledge) explain racial and/or ethnic differences in EOL-discussion readiness, and other factors related to behavior change are significantly associated with stage of discussion readiness.

Aim 3: Explore the extent to which the TTM applies to the study of family EOL care discussion.

Hypothesis: The TTM is applicable to the study of family EOL care discussion in that variables involving health behavior show significant differences by stage.

Methods

Study Design

This study employed a cross-sectional survey design. We created a structured questionnaire, and upon approval from the University of South Florida Institutional Review Board (#Pro00023404) a pilot study was conducted to test the acceptability of the questionnaire within a sample of older adults at a Sarasota, Fla., senior center. The survey questionnaires were in English and Spanish, with the Spanish questionnaire developed through back-translation. (See Appendix 1 for examples of the questionnaire.)

Sampling and Participants

Participants were recruited from a variety of settings in West Central Florida, including senior centers, senior housing apartments, community events, and service organizations. Participant eligibility criteria consisted of being age 50 or older; able to communicate in either English or Spanish; and able to understand and complete the 4-page questionnaire. Between October 2015 and May 2016 survey questionnaires were distributed at meetings with participants. A researcher was available at each meeting to explain the items as they related to EOL care and to obtain written informed consent from each participant. A native Spanish speaker who also spoke English provided translation and assistance with the questionnaires at the meetings with Spanish-speaking participants. Of the questionnaires that were originally collected, 16 (4%) were excluded because data were missing from the questionnaires. The final sample size was 364.

Measures

Dependent variable. The primary outcome measure in this study was stage of readiness to have an EOL care discussion with a family member. It was measured through a series of questions based on research by Fried and colleagues (2010) concerning EOL care discussions with family members. Figure 1 illustrates the questioning route. Based on their responses participants were classified as being in one of 6 stages – precontemplation, contemplation, preparation, action, relapse, or maintenance.

Independent variables.

Sociodemographics. Participants recorded their age, gender, marital status (married, single, divorced, or widowed), household composition, education (highest year completed up to 16+, which was grouped as high school or less, some college, or bachelor's or graduate degree), race (White, Black, other), and Hispanic ethnicity (yes/no). They also were asked to report whether the income at their disposal was sufficient.

Health. Heath conditions included self-reports of whether participants had been medically diagnosed (yes/no) with heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, cancer, or dementia. Responses were dichotomized according to whether participants had two or more conditions. Participants were asked to rate their general health as excellent, very good, good, fair or poor, and these were dichotomized into excellent, very good, and good vs. fair and poor. Participants also were asked a yes/no question about having been hospitalized overnight in the previous 12 months.

Family involvement with health care. Participants were asked about the extent to which they wanted to involve family members or friends in their health care decision-making and directed to choose one from the following progression, which was scored as a Likert scale: "I make decisions without much advice from them" (= 1); "I get their advice and then make decisions" (= 2); "We make decisions together" (= 3); "I leave decisions to them" (= 4). Higher scores reflect greater family involvement. This question and the scoring approach is from the National Health and Aging Trends Study's (NHATS) Round 2 module concerning individuals' preferences for involvement in health care decisions (Kasper & Freedman, 2015). To our knowledge, it has not been used in previous studies.

Health literacy. Participants were asked “How confident are you filling out medical forms?" and asked to choose from 1 (low health literacy) to 4 (high health literacy). This question was based on previous literature concerning ACP (McMahan, Knight, Fried, & Sudore, 2013) and has been found to perform well as a single question to detect inadequate health literacy, with an area under the Receiver Operating Characteristic Curve (AUROC) of 0.84 based on the Rapid Estimate of Adult Literacy in Medicine (REALM) (Chew et al., 2008).

Self-efficacy. Participants’ self-efficacy related to ACP was measured with the question, “How confident are you that you could ask your doctors the right questions to get information to help you make good medical decisions?" As with the previous question, the choices ranged from 1 (low self-efficacy) to 4 (high self-efficacy). This question was based on previous ACP literature and is part of a larger validated survey that measures several aspects of ACP, one of which is self-efficacy (Chiu, Feuz, McMahan, Miao, & Sudore, 2016; Sudore et al., 2013) (The other aspects of ACP included in the above-mentioned survey are assessed in the present study using other measures, such as the stages of change questioning route.) General self-efficacy was assessed with two questions about the extent to which participants agreed that “When I really want to do something, I usually find a way to do it,” and “Other people determine most of what I can and cannot do.” Potential responses were agree not at all (=1), agree a little (=2), and agree a lot (=3). The “other people determine” question was reverse-coded and the responses were summed so that a higher score signified greater self-efficacy. These questions were based on questions from the full NHATS (Kasper & Freedman, 2015). They have been used together in previous studies measuring self-efficacy and shown to be associated with personal activity limitations (Lin & Wu, 2014). To our knowledge, they have not been used in ACP studies.

Knowledge of palliative care. Participants responded yes/no/don't know to a set of statements concerning EOL care, adapted from Schulman-Green et al. (2012). They were: 1) Palliative care includes chemotherapy and radiation; 2) Palliative care helps manage pain and other symptoms; 3) Palliative care includes psychological, social and spiritual care. A correct answer was scored as a 1, an incorrect or don't know answer was scored as a 0. They were summed for a total score of 0-3. The Cronbach's alpha for this version of the Schulman-Green scale was $\alpha = .70$.

Advance Care Planning (ACP). Several questions were used to assess level of ACP. Participants were asked yes/no questions about whether they had a living will; had named a health care proxy (and if so, whether it was a spouse/partner, son, daughter, grandchild, other relative, friend/other); and whether they had talked with a doctor or other health care provider in the past year about their EOL care wishes. Also, participants are asked to consider two ACP scenarios: 1) "What if you could speak, walk, and recognize others, but you were in constant, severe physical pain?" 2) "What if you were not in pain, but could not speak, walk, or recognize others?" After each scenario, they were asked to choose from one of three options - receive life prolonging treatments; stop/reject treatments; or don't know. These scenario questions came from an ACP module included in Round 2 of the NHATS (Kasper & Freedman, 2015). Finally, participants were asked whether in the past year, their EOL care preferences had changed.

Religion and values. Participants rated the strength of their religious or spiritual orientation from 1 (low religiosity/spirituality) to 4 (high religiosity/spirituality) with the following question: "What is the strength of your spiritual or religious orientation?" (Dobbs et al., 2012). Previous research has shown that religious and spiritual orientation are highly correlated (Garrido, Leventhal, & Carr, 2012). Also participants indicated their strength of agreement, from 1 (low strength of belief) to 4 (high strength of belief) with three statements about God's role in their health and the length of life (Garrido et al, 2012). The statements were “It is God’s will when a person's life will end”; “The length of a person's life is determined by God”; and “I turn my health problems over to God.” Scores were summed; higher scores indicated greater strength of belief. Finally, participants were given the statement, "The quality of a person's life is more important than duration." (Sharp, Carr, & Macdonald, 2012) and asked to choose from 1 (low emphasis on quality of life) to 4 (high emphasis on quality of life).

Statistical Analysis

Data analysis was conducted using SAS (Version 9.4. Cary, NC: SAS Institute Inc. 2011). We examined the univariate associations between family discussion stage and the independent variables using the Chi-square test for categorical variables, and analysis of variance for the independent continuous variables. We used a Bonferroni correction to account for multiple comparisons. Bivariate multinomial logistic regression was used to test the association between discussion stages and a single race/ethnicity variable.

Independent variables that were significantly associated with discussion stage in the analyses ($p < 0.05$) were included in a multinomial logistic regression analysis examining the associations between discussion stage and the independent variables. These included family involvement with health care decisions, confidence talking to doctors (health care self-efficacy), and health literacy. We also included sociodemographics (e.g., sex, race, education) based on previous research. The reference category in the regression analysis was precontemplation.

Results

Descriptive Sample Characteristics

More than 44% of the sample was between 65-75 (*n* = 159) and 38% was older than 75 (*n*=138). Whites made up 61% (*n*=222), Blacks made up 26% (*n*=95), Hispanics made up 13% (*n*=46). Women made up 75% (*n*=273). The sample had a relatively high education level, as 32% (*n*=116) had a bachelor's degree or higher and 28% (*n*=102) had some post high school education. Nearly 62% (*n*=229) considered their disposable income to be sufficient. Nearly 40% (*n*=145) was married.

On family health care involvement, only 8 participants chose the option of leaving health decisions to family or friends, so we combined them with the next highest involvement option, making decisions together. These two combined made up 39% of the sample (*n*=142). Those who reported making decisions after getting advice made up 30% (*n*=109) and those who made decisions on their own made up 31% (*n*=113).

More than 60% (*n*=218) reported having two or more chronic conditions, though only 17% (*n*=62) reported their health as fair or poor, compared to excellent, very good, or good, and only 20% (*n*=73) had been hospitalized in the previous year. Participants reported relatively high levels of health literacy (scoring an average of 3.3 of 4), health self-efficacy (3.4 of 4), and general self-efficacy (5.5 of 6). Their palliative care knowledge was moderate (2.1 of 3). Concerning preferences for care during serious illness, 31% (*n*=113) said they would want all available treatment if they were in severe pain though able to walk, talk, and recognize others, while 25% (*n*=87) said they would stop or reject treatment. Nearly 44% (*n*=160) reported that they did not know what they would want in this scenario. In the scenario of being free of pain but unable to walk, talk, or recognize others, 19% (*n*=69) said they would want all treatment, 47%

(*n*=171) said they would stop or reject care, and 34% (*n*=124) reported they did not know. Concerning advance care planning, 62% (*n*=226) reported having living wills and 68% (*n*=247) reported having named a health care proxy. Only 22% (*n*=80), however, had talked to their doctors about their EOL care wishes, and even fewer (13%, *n*=47) reported having changed their EOL care wishes in the 12 months. Participants reported high mean scores in religiosity (3.4 of 4), belief in the role of God in health and life span (9.5 of 12) and valuing the quality of life over quantity (3.6 of 4).

Sample Distribution of EOL Care Discussions

Among the participants, 24% (*n*=86) were in the precontemplation stage (unaware or unready to have a family EOL care discussion); 6% (*n*=23) were in contemplation (thinking of having a discussion in 6 months); 1% (*n*=4) were in preparation (preparing for a discussion in 30 days); and 7% (*n*=24) were in relapse (having had the discussion more than a year ago). In addition, 27% (*n*=98) were in action (having had one discussion in the past 12 months); and 35% (*n*=129) were in maintenance (having had a discussion twice are more in the past 12 months.). Because of the low numbers of participants in the contemplation and preparation stages, these two were combined into a preparation category. In addition, those in the relapse stage were added to this category. Individuals who have taken action but not maintained it in a year’s time are considered to have fallen out of action back into preparation. As with those in contemplation and preparation they have shown inclinations to act but cannot be considered “active” (Ernecoff et al., 2016). They would potentially need similar interventions to those in the contemplation and preparation stages. Overall, this created four discussion stages for analysis, precontemplation, preparation, action, and maintenance. Participant characteristics by stage of conversation readiness are shown in Table 1.

EOL Care Discussion Stage and Sociodemographic and Other Factors

Turning to the associations between EOL care discussion stage and our independent variables, we found in the unadjusted regression analysis (not shown) that Hispanics were significantly less likely than Whites to be in the action stage (p = .02). They were also less likely to be in the maintenance stage, though the association was marginal (p = .08). There were no significant stage differences among Blacks compared to Whites. These findings supported our hypothesis that there would be racial and/or ethnic differences in discussion-stage differences, in that Hispanics were less likely to engage in family EOL care discussions. Blacks were not.

In univariate analyses (shown in Table 1) we found that higher levels of education were significantly associated with higher discussion stages (e.g. action and maintenance), as was one’s assessment that his or her income was sufficient. Greater family involvement in general health care decisions (e.g. making decisions together) also was associated with higher discussion stages, as was greater confidence in one’s ability to communicate with his or her doctor, and greater confidence in one’s ability to complete medical forms.. Similarly higher knowledge of palliative care was significantly associated with higher discussion stage. Not knowing one's own wishes in the incapacity scenario (free of pain but unable to function mentally or physically) was significantly associated with being at a lower discussion stage, with half of those in precontemplation answering that they did not know what they would want. Having talked to a doctor about one's EOL care wishes, having a living will, and having a health care proxy each were significantly associated with higher discussion stages.

Table 2 shows the odds of being in the preparation, action, or maintenance stage of discussing EOL care with family (compared to being in precontemplation) while controlling for sociodemographics, health, and other factors related to knowledge and understanding (e.g. self-efficacy and knowledge of palliative care). There were no associations between race or ethnicity and discussion stage, supporting our second hypothesis. On the other hand, women (vs. men) were 2.6 times more likely to be in the maintenance stage (*p* = .04). Participants with greater family involvement in health care decision-making were 2.4 times more likely to be in the action stage (*p* <.001) and 2.9 times more likely to be in maintenance (*p* < .001). Those with greater confidence in their ability to communicate with doctors were 1.9 times more likely to be in the maintenance stage (*p* =.009).

Those who did not know what they would want if they were incapacitated were significantly less likely to be in the action and maintenance stages (68% [*p* = .006] and 64% [*p* = .01] respectively). Those who had talked to their doctors about their EOL care preferences, however, were significantly more likely to be at a higher discussion stage. They were 3 times more likely to be in the action stage (*p* = .049) and 4.6 times more likely to be in the maintenance stage (*p* = .004). Having named a health care proxy was significantly associated with a 2.9 times greater likelihood of being in the maintenance stage (*p* = .03). These finding support our third hypothesis that there would be significant discussion stage differences in variables related to health behavior and that as a behavior change model, the TTM is applicable for the study of family EOL care discussion.

Discussion

Communication concerning the care one wishes to receive at the end of life is recognized as a key aspect of ensuring that wishes are honored. While important, living wills and health care proxies often don’t go far enough to communicate people's wishes for their last days and weeks. The purpose of the present study was to examine the occurrence of discussions between individuals and their family members, considering not only whether the discussion had taken place but whether the individual was ready to have such a discussion. We utilized the TTM to identify older adults' behavior patterns in EOL care discussion and potential ways to encourage behavior change.

The present study showed that among a diverse sample of older adults, a third had not discussed their care wishes with family members. The majority of these participants who had not had the discussion were in the precontemplation stage, meaning they were either not aware of the concept of having family EOL care discussions or they were not ready to do so. It is encouraging, however, that a substantial number of participants had engaged in at least one family discussion. The present study further examined the differences among participants at varied stages of change for having a family discussion, to understand more about what might influence one's willingness to have such a discussion.

We found in unadjusted analyses that there were no significant differences between Blacks and Whites in their discussion stages. Previous research has found Black-White differences in unadjusted analyses, with a lower likelihood among Blacks to discuss their EOL care wishes with family members. These differences became non-significant after controlling for religious beliefs (Carr, 2011). In our study, there were no significant associations between religious beliefs and discussion stages, in unadjusted analyses. Overall participant scores on the religion variables were high.

Concerning Hispanics, previous research found that they were less likely than Whites to discuss their EOL care wishes with family (in unadjusted analyses) but that these differences became non-significant after controlling for sociodemographic and attitude factors (Carr, 2011). Our results were similar, with the discussion stage differences between Hispanics and Whites becoming non-significant in adjusted analyses. Future research, including qualitative research, is needed to understand the factors that influence Hispanics' engagement in family EOL care discussions and other aspects of ACP.

Our results showed several other significant relationships, including between sex and EOL care discussion. Women were more than twice as likely as men to be in maintenance (to have had at least two family discussions in the previous 12 months.) Previous research also has found that women are more likely to talk about their EOL care wishes than men (Keary & Moorman, 2015). In addition, we found significant associations between higher discussion stages and greater engagement in varied aspects of health care decision making. These included communication and cooperation with family members and communication with doctors. In both unadjusted and adjusted analyses, there were significant associations between involvement of family in general health decision making and EOL care discussion stage. Participants who relied more on family to make their health care decisions were more than twice as likely to be in the action stage (to have talked once to a family member in the past 12 months) and nearly three times as likely to be in maintenance (to have talked twice or more in the past 12 months).

This aligns with recent research showing that better overall family functioning and higher levels of support from a spouse increased one's odds of discussing EOL care wishes with a loved one (Boerner, Carr, & Moorman, 2013). It also supports research indicating that long-standing family dynamics in decision making, positive and negative, play out in EOL care planning (van Eechoud et al., 2014). This further supports the need to involve family members in EOL care discussions and consider family limitations before the late stages of an illness, after which there may be little time to address the planning barriers and complications.

Our research also showed significant associations related to participants' relationships with doctors. Those with higher levels of health self-efficacy (confidence in their ability to communicate with their doctors to make appropriate medical decisions) were nearly twice as likely to be in the maintenance stage of family discussion. It is interesting that two measures concerning general health care discussions (with family and with doctors) were significantly associated with EOL care discussions. This shows the value of integrating ACP with general health care. Related to this, we found that those who had talked with a doctor specifically about their EOL care wishes were three times more likely to be in action and more than four times more likely to be in maintenance. It is not clear which preceded the other, family or doctor discussions. Having a family discussion may promote discussions with doctors, but doctor discussions may in turn promote further family discussions. Our findings align with recent research using the Wisconsin Longitudinal Survey (Keary & Moorman, 2015), which found a significant association between having had discussions with doctors and with family members concerning preferred EOL care. However, this study's participants were predominantly White. Our study adds to this finding by showing this relationship in a population that is different by race, ethnicity, and geography.

Combined with the findings concerning the importance of doctor-patient communication in general health care, this further highlights the potential of doctors to encourage EOL care conversations among family members. These are important findings in light of the new Medicare benefit for ACP consultations, which went into effect after the surveys for the present study had been completed. It shows the value of these discussions and particularly the value of meaningful doctor-patient communication for promoting family EOL care discussions. At this point it is unclear whether the Medicare consultation benefit will improve ACP. However, it is hoped that empirical evidence, including the findings of the current study, will further encourage health professional to offer ACP consultations.

Related to the issue of patient understanding is the finding concerning participants' understanding of their own wishes. Our results showed that those who did not know what they would want if they were mentally or physically incapacitated were significantly less likely to have engaged in an EOL care conversation with family members. This highlights the importance of patients' abilities to consider their own future health outcomes and of the negative impact of uncertainty on ACP. Research has shown that people who are uncertain about their care preferences are unwilling to engage in EOL care planning (Fried et al., 2009). TTM posits that people can plan for themselves only when they are ready (Moorman & Inoue, 2012; Prochaska et al., 2008), and uncertainty about EOL care preferences could pose a barrier to readiness.

Further considering ACP, our results showed that those who had formally named a health care proxy were significantly more likely to be in maintenance discussion stages. This is not surprising, considering that the process of choosing a proxy likely involves a discussion with that person. It would be important to know more about this relationship to understand its direction, whether having a discussion leads to increased proxy completion, thereby showing the value of the discussion for ACP overall. It is worth noting that there was a marginally significant relationship between having a living will and being in maintenance (p = .054). Previous studies have shown different levels of engagement in ACP behaviors (i.e. discussion with loved ones, living will, health care proxy). Carr (2011) reported that the predictors were not the same for each. For instance, being female predicted having had a discussion and having a proxy but not having a living will. In qualitative research, Fried and colleagues (2009) found that some participants had completed living wills but had not discussed the contents with their loved ones. It is worth noting that in the present study, more than 12% of the sample reported having named health care proxies who were family members but not having had EOL care discussions with family. Further research is needed to understand the relationship among having living wills, health care proxies and EOL care discussions and how to promote all three behaviors.

The TTM and EOL Care Discussions

Our study also addressed the use of the TTM to study family EOL care discussions, and it supported the applicability of the TTM model as we hypothesized. With several key variables, participants were in significantly different discussion stages. There were clear differences between participants in the precontemplation stage (our reference) and action or maintenance stages. In addition, with some of the variables, there was a pattern of increasing likelihood as the stages increased. On the family health care engagement variable, participants were 1.6 times more likely to be in the preparation stage (marginally significant at $p = .09$), 2.4 times more likely to be in action and nearly 2.9 times more likely to be in maintenance. On the doctor EOL-talk variable, those who had talked were 3 times more likely to be in action, but 4.6 times more likely to be in maintenance. It should be noted that the confidence intervals were wide, which is likely related to the small sample size. Other variables were significant only in one stage. Women were significantly more likely than men to have had a family discussion only for those in the maintenance stage. The same was true for those who reported having a health care proxy and those with a higher level of health care self-efficacy.

It is worth focusing on self-efficacy because it is a key construct in the TTM, relating to one’s confidence in his or her ability to perform a behavior. It is relevant to the question of discussion stage because the ability to talk about future care may depend on one's understanding of his or her own health trajectory, which could largely depend on effective communication with a doctor. According to Prochaska, Redding, & Evers (2008), self-efficacy helps drive movement through the stages of change. Prochaska and others have theorized that people who are further along in their stages of change are likewise more confident that they can maintain the target behavior and not relapse (DiClemente, Prochaska, and Gibertini 1985; Levesque, Cummins, J.M. Prochaska, & J.O. Prochaska, 2006). As such, it makes sense that those with the highest level of health-self-efficacy would be at the highest conversation stage.

Limitations

This study had a number of limitations. The sample size was relatively small for a study examining multiple group differences. It included only people who were willing to complete the 4-page questionnaire, so it may have left out many who were averse to EOL discussions. Also it was cross-sectional, limiting the ability to see causal relationships and to assess change over time, which is an important aspect of the TTM. Further, it did not measure other TTM constructs. Stages of change are considered to be the model's defining construct, but understanding how to move people through the stages requires consideration of processes of change, which were not included. It is also important to measure decisional balance, which is the perception of pros and cons of adopting a behavior. Our study did include measures of self-efficacy, one used in other ACP research (Chiu et al., 2016). However, this measure was part of a larger measure, and it did not specifically measure self-efficacy for having an EOL care discussion. Further research is needed to develop a measure of self-efficacy for the separate behaviors of ACP. Further research also is needed to understand the processes that could lead to increased family EOL care discussions, particularly processes that relate to personality factors, which may be less susceptible to change or require approaches that take personality into account.

Conclusion

Overall the present research shows significant relationships between individuals' readiness for an EOL care discussion and their engagement in their own health care involving both family and health care providers. In particular, it shows the important role that doctors can play in encouraging such discussions. It also suggests that the TTM can be used to understand more about this aspect of ACP. Such research could be used to develop interventions to increase the occurrence of these discussions and potentially improve the quality of EOL care.

Table 1. Baseline Characteristics of the Quantitative Sample

		EOL care Discussion Stages				
	Total (*n*=364)	Precontemplation (*n*= 86)	Preparation (*n*=51)	Action (*n*=98)	Maintenance (*n*=129)	*p value*
Age						*.14*
Less than 65	67 (18.4)	16 (18.6)	8 (15.7)	24 (24.5)	19 (14.7)	
65-75	159 (43.7)	46 (53.5)	23 (45.1)	37 (37.8)	53 (41.1)	
More than 75	138 (38.0)	24 (27.9)	20 (39.2)	37 (37.8)	57 (44.2)	
Female	273 (75.0)	59 (68.6)	39 (76.5)	71 (72.5)	104 (80.6)	*.21*
Race/ethnicity						*.28*
White, non-Hispanic	223 (61.3)	47 (54.7)	29 (56.9)	67 (68.4)	80 (62.0)	
Black, non-Hispanic	95 (26.1)	22 (25.6)	15 (29.4)	23 (23.5)	35 (27.1)	
Hispanic[a]	46 (12.6)	17 (19.8)	7 (13.7)	**8 (8.2)**	14 (10.9)	
Education						***.01***
High school or less	147 (40.4)	43 (50.0)	23 (45.1)	25 (25.5)	56 (43.4)	
Some vocational training/ college	101 (27.8)	24 (27.9)	12 (23.5)	35 (35.7)	30 (23.3)	
Bachelor's degree or higher	116 (31.9)	19 (22.1)	16 (31.4)	38 (38.8)	43 (33.3)	
Income sufficient	**229 (62.9)**	**45 (52.3)**	**29 (56.9)**	**69 (70.4)**	**86 (66.7)**	***.04***
Married	144 (39.6)	37 (43.0)	15 (29.4)	40 (40.8)	52(40.3)	*.44*
Poor self-rated health (fair/poor)	63 (17.3)	17 (19.8)	7 (13.7)	12 (12.2)	27 (21.0)	*.28*
Chronic health conditions, >1	221 (60.7)	53 (61.6)	27 (52.9)	59 (60.2)	82 (63.6)	*.62*
Hospitalized in past 12 mos.	75 (20.6)	20 (23.3)	7 (14.0)	26 (26.9)	29 (22.5)	*.53*
Family involvement in general health care decisions						***<.001***
Make decisions together	142 (39.0)	22 (25.6)	18 (35.3)	39 (39.8)	63 (48.8)	
Get advice and make own	109 (30.0)	23 (26.7)	13 (25.5)	33 (33.7)	40 (31.0)	
Make decision, little advice	113 (31.0)	41 (47.7)	20 (39.2)	26 (26.5)	26 (20.2)	
Health literacy, completing forms (1-4)	**3.3 (0.94)**	**3.1 (0.99)**	**3.3 (0.99)**	**3.5 (0.76)**	**3.3 (0.99)**	***.009***
Health self-efficacy, understands doctor (1-4)	**3.4 (0.80)**	**3.2 (0.96)**	**3.5 (0.79)**	**3.6 (0.72)**	**3.5 (0.75)**	***.01***
General self-efficacy (2-6)	5.5 (0.80)	5.6 (0.69)	5.4 (0.92)	5.5 (0.81)	5.5 (0.82)	*.52*
Wants life support if in pain						*.48*
Yes	114 (31.4)	31 (36.1)	10 (19.6)	32 (32.7)	40 (31.0)	
No	92 (25.3)	17 (19.8)	15 (29.4)	24 (24.5)	36 (27.9)	
Do not know	159 (43.7)	38 (44.2)	26 (51.0)	42 (42.9)	53 (41.1)	

Table 1. (Continued)

		EOL care Discussion Stages				
	Total (*n*=364)	Precontemplation (*n*= 86)	Preparation (*n*=51)	Action (*n*=98)	Maintenance (*n*=129)	*p value*
Wants life support if incapacitated						***.004***
Yes	68 (18.7)	18 (20.9)	10 (19.6)	16 (16.3)	24 (18.6)	
No	171 (47.0)	25 (29.1)	22 (43.1)	56 (57.1)	68 (52.7)	
Do not know	124 (34.3)	43 (50.0)	19 (37.3)	26 (26.5)	37 (28.7)	
Knowledge of palliative care (1-3)	**1.5 (1.08)**	**1.3 (1.12)**	**1.2 (1.07)**	**1.7 (1.02)**	**1.6 (1.05)**	***.009***
Talked to doctor about EOL wishes	**79 (21.7)**	**7 (8.1)**	**9 (17.7)**	**24 (24.5)**	**39 (30.2)**	***.001***
EOL care wishes have changed in year	48 (13.2)	10 (11.6)	5 (9.8)	9 (9.1)	24 (18.6)	*.14*
Has a living will	**224 (61.5)**	**19 (37.2)**	**29 (56.9)**	**69 (70.4)**	**94 (72.9)**	***<.001***
Has health care proxy	**248 (68.1)**	**35 (40.7)**	**33 (64.7)**	**76 (77.5)**	**104 (80.6)**	***<.001***
Religiosity (1-4)	3.4 (0.91)	3.4 (0.88)	3.5 (0.81)	3.3 (0.93)	3.4 (0.95)	.73
God's role in health (3-12)	9.5 (3.06)	9.7 (2.87)	9.8 (2.88)	9.2 (3.22)	9.5 (3.12)	.67
Values life's quality over quantity (1-4)	3.6 (0.75)	3.4 (0.86)	3.6 (0.76)	3.6 (0.68)	3.6 (0.73)	.15

Note. [a] Unadjusted multinomial logistic regression analysis (performed separately) showed significant association of action stage (referent = precontemplation) and Hispanic ethnicity (referent = White).

The numbers in the cells represent frequency (percent) for the categorical variables and mean (standard deviation) for the continuous variables.

Bold type indicates significance.

Table 2. Multinomial Logistic Regression for Stages of Change for Family EOL care Discussion[a]

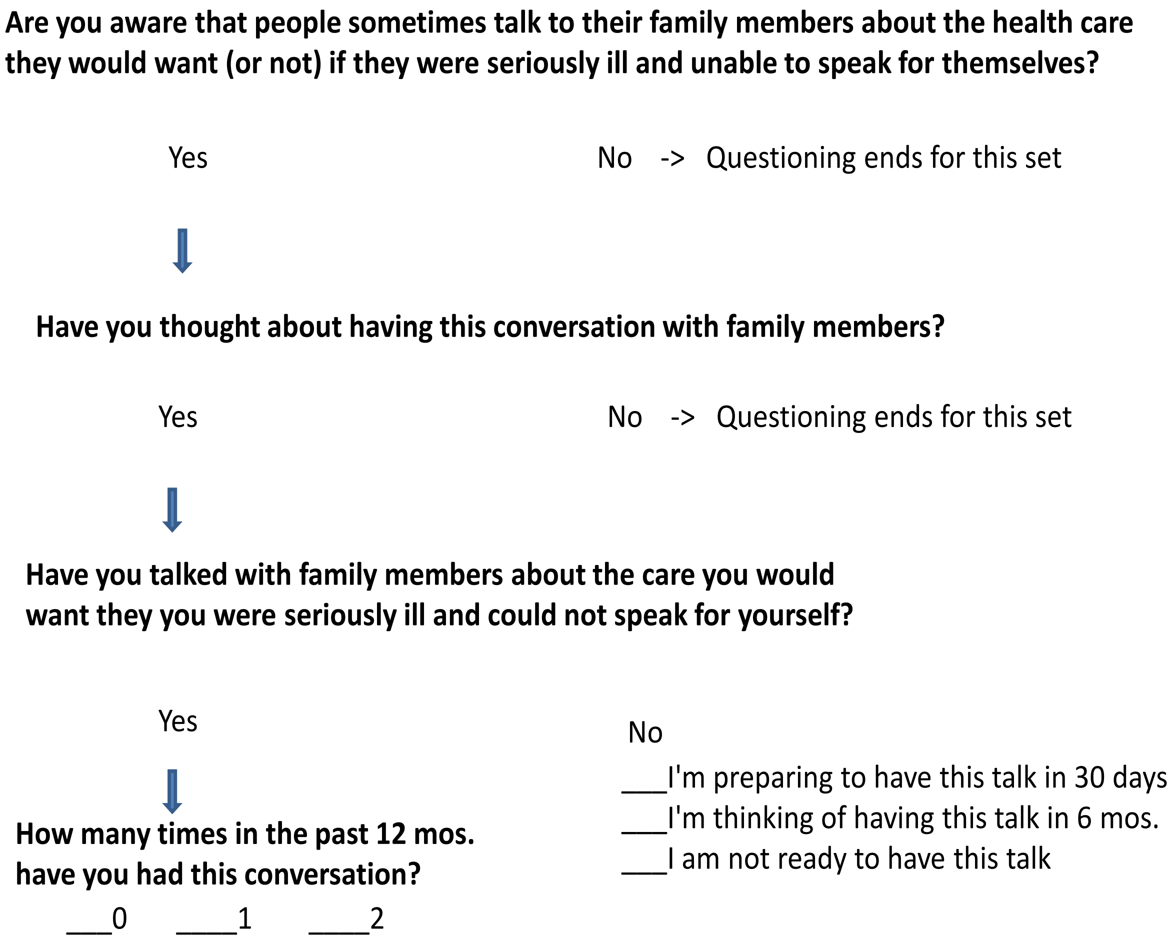
	Preparation (*n*=51)	Action (*n*=98)	Maintenance (*n*=129)
	OR (95% CI)	OR (95% CI)	OR (95% CI)
Age			
Less than 65	0.87 (0.25-2.97)	1.55 (0.52-4.63)	0.92 (0.32-2.71)
65-75	0.73 (0.29-1.85)	0.78 (0.32-1.86)	0.71 (0.31-1.61)
More than 75	referent	referent	Referent
Female	1.57 (0.61-4.01)	1.40 (0.56-3.47)	2.60 (1.06-6.39)*
Male	referent	referent	Referent
Race/ethnicity			
Black	1.23 (0.37-4.12)	1.36 (0.50-3.69)	1.50 (0.55-4.11)
Hispanic	0.62 (0.15-2.65)	0.40 (0.11-1.39)	0.45 (0.15-1.34)
White	referent	referent	Referent
Education			
High school or less	0.80 (0.21-2.82)	0.66 (0.23-1.95)	1.00 (0.35-2.89)
Some vocational training/ college	0.66 (0.21-2.04)	1.14 (0.42-3.11)	0.73 (0.27-1.96)
Bachelor's degree or higher	referent	referent	Referent
Income sufficient	0.84 (0.32-2.23)	1.07 (0.44-2.60)	1.07 (0.43-2.64)
Income not sufficient	referent	referent	Referent
Married	0.43 (0.15-1.23)	0.48 (0.20-1.17)	0.66 (0.27-1.62)
Not married	referent	referent	Referent
Poor health	1.26 (0.38-4.15)	0.98 (0.34-2.80)	0.64 (0.25-1.63)
Better health	referent	referent	Referent
Greater family involvement in health care	1.64 (0.92-2.94)	2.43 (1.48-4.00)***	2.87 (1.75-4.69)***
Lower family involvement in health care	referent	referent	Referent
Greater health literacy	1.16 (0.70-1.92)	1.40 (0.85-2.31)	1.01 (0.67-1.55)
Lower health literacy	referent	referent	Referent
Greater health self-efficacy (understands doctor)	1.50 (0.87-2.57)	1.55 (0.87-2.75)	1.86 (1.17-2.97)**
Lower health info self-efficacy	referent	referent	Referent
Wants life support if can't talk, walk, recognize others			
Yes	0.70 (0.21-2.40)	0.45 (0.16-1.29)	0.53 (0.20-1.40)
No	referent		
Do not know	0.58 (0.23-1.48)	0.32 (0.14-0.72)**	0.36 (0.16-0.82)*

Table 2. (Continued)

	Preparation (n=51)	Action (n=98)	Maintenance (n=129)
	OR (95% CI)	OR (95% CI)	OR (95% CI)
Greater knowledge of palliative care	0.89 (0.59-1.32)	1.24 (0.84-1.85)	1.09 (0.75-1.59)
Lower knowledge of palliative care	referent	referent	Referent
Talked to doctor about EOL wishes	2.16 (0.63-7.43)	3.02 (1.00-9.11)*	4.56 (1.64-12.66)**
Not talked to doctor about EOL wishes	referent	referent	Referent
Living will	1.63 (0.45-5.85)	2.25 (0.79-6.41)	2.66 (0.98-7.19)
No living will	referent	referent	Referent
Health care proxy	2.11 (0.69-6.40)	2.25 (0.81-6.25)	2.85 (1.14-7.14)*
No proxy	referent	referent	Referent

Note. [a]Reference category is precontemplation (*n* = 86)

$^{*}p$ <.05. $^{**}p$ <.01. $^{***}p$ <.001



Are you aware that people sometimes talk to their family members about the health care they would want (or not) if they were seriously ill and unable to speak for themselves?

Yes

No -> Questioning ends for this set

↓

Have you thought about having this conversation with family members?

Yes

No -> Questioning ends for this set

↓

Have you talked with family members about the care you would want they you were seriously ill and could not speak for yourself?

Yes

↓

How many times in the past 12 mos. have you had this conversation?

___0 ____1 ____2

No

___I'm preparing to have this talk in 30 days
___I'm thinking of having this talk in 6 mos.
___I am not ready to have this talk

Figure 1. Question Flow to Determine Stages of Change for Family EOL care Discussion

CHAPTER 3:

FAMILY EOL CARE DISCUSSIONS: A QUALITATIVE STUDY

Introduction

As the U.S. population ages in the coming years, an increasing number of people will face serious illness and complex decisions concerning their health care (IOM, 2014; Wilper et al., 2008). For decades, researchers and public policy makers have promoted the use of ADs to prepare patients and their surrogate decision makers for the often difficult choices. Nevertheless research suggests that ADs do not provide the information necessary to reduce the confusion and conflict of EOL decision-making (Abadir, Finucane, & McNabney, 2011; Oulton et al., 2015; Wendler & Rid, 2011). Racial and ethnic disparities in EOL care quality are a continuing concern (Conner & Chase, 2014; Lee, et al., 2016; Loggers et al., 2009; Welch et al., 2005).

Research has recognized the importance of increasing discussions between individuals and those who may play a role in their decision-making at EOL (Sudore & Fried, 2010; Tulsky, 2005). Such discussions provide surrogate decision-makers with critical information and could help to make ADs more effective (Hawkins et al., 2005; McMahan et al., 2013; Shalowitz et al., 2006). While many people do want to have these discussions (Bischoff et al, 2013), many others are averse to talking about the prospect of their own illness and death (Abba et al., 2013; Waldrop & Meeker, 2013). Research has begun to view such discussions as personal and interpersonal behaviors that are subject to change, proposing that changing behavior requires understanding one’s willingness or readiness to engage in ACP (e.g. Fried et al., 2009).

Therefore the TTM, using "stages of change," served at the framework for this study. The purpose of this study was to use focus groups to explore why older adults from diverse racial and ethnic backgrounds had or had not engaged in EOL care discussion with family members. We further proposed to explore the behavior of those who had not engaged in such discussions to determine whether and how interventions could be developed to overcome discussion barriers.

Methods

Study Design and Sample

This qualitative study used focus groups to explore the differences between people who had and had not engaged in discussions concerning their EOL care wishes. A racially and ethnically diverse sample was recruited through purposive sampling at a variety of settings in West Central Florida, including senior centers, senior housing apartments, community events, and service organizations. Participants were eligible if they were age 50 or older; able to communicate in either English or Spanish; and able to understand and complete a 4-page questionnaire. The focus group sample was drawn from the larger sample (N=364) of those who completed the questionnaire, which included a series of questions that placed participants in one of the six stages of change. See Figure 1 for the questioning route. Based on their responses participants were classified as being in either precontemplation, contemplation, preparation, action, relapse, or maintenance. For the purpose of the present qualitative study, we collapsed these into two groups. Those who had engaged in family EOL care discussions (in action and maintenance stages) were categorized separately from those who had not (in precontemplation, contemplation and preparation stages). Participants were recruited for the focus groups by telephone. The institutional review board at the University of South Florida approved the study (#Pro00023404). All participants provided written informed consent.

Based on prior research and input obtained from experts in geriatrics and gerontology, a focus group guide was developed to understand the occurrence of family discussions concerning EOL care wishes. The guide included questions about why, in the participants' opinions, these discussions were difficult (or not), and what encouraged people to have such discussions. See Appendices 1 and 2 for the focus group guides, which varied slightly to accommodate whether the participants had or had not had the discussion. A total of seven focus groups of 4 – 7 participants each (*N*=36) were conducted between May and June 2016. Four groups (*n*=19) were conducted with those who reported they had not engaged in family EOL care discussions and three (*n*=17) were conducted with those who had. The seven groups were held in senior centers (2), libraries (4) and a senior living community (1), each in a private room, and they lasted between 90-120 minutes. Five of the groups were facilitated by a graduate student in aging studies with a graduate background in communication, who was assisted by a note taker for one of the groups. One was facilitated by a PhD trained gerontologist with a graduate background in public policy, who was assisted by a note taker. One group consisted of Spanish-speaking adults and was recruited and facilitated by a native Spanish-speaker who also spoke English, who was assisted by a member of the research team who spoke Spanish. When there was no note-taker, the facilitator took notes. Field notes related to the participants' responses were shared and discussed after each group. The facilitators had no prior relationship with the participants, except the Spanish-speaking group, in which case the participants knew the facilitator through their association with a senior services volunteer group. At the end of each group, facilitators raffled two $25 gift certificates.

All groups were audio-recorded and transcribed verbatim (a native Spanish speaker who speaks English transcribed the Spanish-language focus group into English), and the data were entered into Atlas/ti version 7 (Scientific Software, Berlin, Germany). We used a standardized, iterative framework approach to analyze the data. Through independent readings of the transcripts, two authors (LP, DD) developed a coding scheme using Atlas/ti version 7. One of the coders was a graduate student in aging studies with graduate experience in communication and the other was a sociology PhD, both with EOL care research expertise). An "open coding" approach was used, with each code representing a distinct idea or information (Strauss & Corbin, 1998), although individual sections of data could be assigned multiple codes. The coding scheme was consistently refined using the constant comparative method (Corbin & Strauss, 2008). Coding discrepancies were discussed among the coding team of two until consensus was reached. Related codes were clustered as patterns emerged (axial coding) and axial codes were added to the list to reflect the relationships between the initial codes (Strauss & Corbin, 1998). For example, the codes of family EOL care experiences and knowledge of family EOL care wishes were found to occur together or in close proximity, such that knowledge seemed to result from these experiences. This led to knowledge becoming an axial code to reflect a grouping of open codes.

Results

The mean age of the participants was 70 (ranging from 58-87). Three-fourths were female (*n*=27), and more than half were White, non-Hispanic (*n*=20). Six were Hispanic and 10 were Black. About two thirds had come college or more (*n*=23) and more than half (*n*=21) had two or more chronic conditions.

Participants who had talked to family members about their EOL care wishes were on average older (mean age=73) compared to those who had not talked to family (mean age=67). Of those who had engaged in family discussions, more than 80% (*n* = 14) were female. In addition about half were White-non-Hispanic (*n*=9); two were Hispanic, and six were Black. Nearly 70% (*n* = 13) of those who had not engaged in discussions were female. More than half were White, non-Hispanic (*n*=11); four were Hispanic and four were Black.

More than three-fourths of those who had engaged in EOL care discussions reported have two or more chronic conditions (*n*=13), while of those who had not engaged in discussions less than half reported two or more chronic conditions (*n*=8). See Table 3 for more detail on the demographic and ACP characteristics of those who had and had not engaged in family discussion.

ACP as a process emerged as a theme across all of the focus groups (FG). This theme refers to the variety of behaviors that influence and constitute ACP, including the varied relationships of written and spoken preferences and participants' varied starting points. For instance, some participants had talked about their EOL care wishes with family but not completed written documents, while others expressed their preferences for completing written documents before, or instead of, the family discussion. Others had partially completed certain steps, such as starting but not finishing a living will.

Within this overarching theme of ACP as a process four separate themes emerged, 1) being proactive in the EOL discussion as part of ACP overall (activation of the process); 2) accepting the reality of aging and death as they relate to EOL care discussions and ACP (acceptance as an obstacle or facilitator of the process); 3) the effect of family dynamics (family dynamics as an obstacle or facilitator of the process); 4) the effect of knowledge on EOL care discussions and ACP (knowledge as a primer or facilitator of the process). The next section will discuss each theme in detail. Table 4 lists themes, subthemes, and selected quotes

Theme 1: Being Proactive

Many of those who had engaged in EOL care discussions described their “responsibility” or “obligation” to address the question of EOL care, and they viewed the discussion in the context of other ACP steps (e.g., completing a living will) they had taken to ensure that their wishes were known. A White female participant from FG5 who had engaged in family discussions explained:

> *I feel a responsibility because I am alone and it is my choice living here. So I have a responsibility of family and friends to make decisions. So that led to my conversation, the living will, all these legal papers. Plus I have two doctors and we’ve had that conversation.*

In the same vein, a Black female participant from FG6 explained that she had written out her wishes in addition to discussing them with her children because, “I feel like I owe it to my family.” To several participants, the discussion was distinct from the living will. A White male participant from FG5 described a living will as “a passive thing,” and added, “We all need to be proactive” and have the family discussion also.

Several of these participants were led to ACP through other planning or combined their ACP with other planning (e.g., estate planning), as shown by this quote from a White male participant from FG7:

> *I think that one led to the other. When we got through discussing about the securities, we went to the health care because that would impinge on how we were going to work with the securities.... I was very anxious that everything pass in order businesswise with the money and securities, that everybody knew what I wanted and that there would not be any question about it.*

Overall, these and other participants in their groups were more proactive by nature and more easily activated to have the EOL care discussion with family members. However, not all of the participants who had talked to family members about the EOL care wishes had completed living wills, including some of the Black or Hispanic participants. Some said that it was easier for them to talk about their EOL care wishes than to put them on paper - though they also said they intended to complete written ACP documents. A Black female from FG 6 who had written out her EOL care preferences agreed that it was difficult, though important, saying the following:

> *I think that writing it out takes more thought and more planning but it prepares you for the conversation. You can say "Here, this is what I've decided and I just need you to agree to this. Look it over, so you'll know. Just follow my instructions." The hardest part. It took a lot of thinking.*

By contrast, few of those who had not talked to family members referred to EOL planning needs or obligations. Some said that it was too soon to consider such things, that if a person were not seriously ill there was no need to talk about EOL matters. As a White women from FG2 described it:

> *I think people have a hard (time) when you're healthy. I know you're supposed to think about those things way in advance, but when we're healthy, you can't think about us being not healthy. Just went to the doctor yesterday, perfect picture of health, everything is fine. Good. I'm good to go for another 20.*

Others said they never worried about the possibility of a health problem leading to incapacity. A White female participant from FG 1 who had been hospitalized for heart problems but had not engaged in a family discussion stated, "I never even thought of that when I was going under. I just figured that everything is going to be OK." A White male participant from FG4 expressed a similar feeling while describing a recent hospitalization and consideration that something might prompt the need for life support measures. "I was just confident....Just this feeling that, well, you're going to survive, you're going to be OK."

It bears noting that some participants who had not had the family discussion had undertaken other EOL and death-related planning, showing some level of proactivity. A White woman from FG1 said she had completed a living will years earlier without giving much thought to it, though the focus group discussion had piqued her interest in revisiting it:

> *Right now we're trying to finagle finances so we can, you know, get to the end. We didn't really think about this. I do think we need to get the living will out and see what it's all about again. We were probably 10 years younger, didn't think seriously about it. Now you look at it a little differently.*

Others in the non-discussion groups had gone so far as to determine how their possessions would be distributed among their children. Two were organ donors, including a Black female in FG4, who said, "I'm an organ donor. And it's easy to talk about being an organ donor, and how you want the insurance money to be spent, and having a memorial."

One of the more proactive participants, a White woman from FG7, addressed this idea when another said she thought funeral planning was easier than advance care planning. "(At the funeral) you're dead. You're gone. But if you're lying in a hospital and people have to make choices about whether you stay alive or don't stay alive, it just makes a difference." In this vein, a subtheme of awareness emerged as an activator, particularly an awareness of the consequences of others knowing or not knowing one's wishes. Another participant from FG7, a White woman who had engaged in a family discussion and completed written documents, said the following:

> *With medical technology doctors can "put parts in people and hook people up and keep this part of your body working....You want everything clear for your son, for the next generation. We didn't want to have that, 'Oh, now what do I decide.' I think that's a terrible burden to put on somebody, when you could take care of alleviating some of that burden."*

An Hispanic female participant from FG3 stated the following about the importance of understanding the need for ACP and the consequences of family members not knowing one's EOL care wishes:

> *"You must be conscious that the moment is going to arrive and motivate them (to talk) so it won't be any conflict; they need to know what is going to happen in order to avoid conflict."*

Those who had engaged in family discussions cited events that had made them aware of the need for ACP. A White female from FG 7 discussed the "very big" impact of the case of Terry Schiavo, the Florida woman whose husband and parents battled in court over her care after she suffered cardiac arrest and was diagnosed as being in a persistent vegetative state. "That was never going to happen to me. No matter what," she said.

It should be noted, however, that several participants in the non-discussion groups had experienced similar personal and family crises and not been activated to begin their own planning. A White male participant in FG2 who had lost his son after a long illness was adamant in his opposition to having a discussion with family members about his EOL care wishes, saying, "I don't want to discuss it with anybody." Some made the assumption that the discussion was not necessary because a family member would know what to do and make the right decision if the time ever came. As a White male participant from FG2 said, “There’s always someone, always someone that has the common sense (to make the decision).”

Others seemed to be in an intermediate stage of awareness. A White male participant from FG 1 said he was unaware of the need for ACP until the recent death of his mother in hospice care and a heart episode that soon followed. At the time of the focus group, he had yet to have a discussion with his family members about his EOL care wishes, or to complete ADs, but said, "It's got it going slowly back there" to explain his experiences and thoughts about ACP. Others seemed to have gained some awareness through the focus group meeting itself, such as the White woman from FG 1 who had previously completed a living will and concluded after the meeting that she needed to review it. Speaking again to the process, another White female participant in this group learned during the meeting about the "Five Wishes" AD and said that she though it could serve as an “ice breaker” for a discussion with her children.

Several of the participants mentioned religion related to ACP and proactivity, but there was no clear pattern to this. A White male participant in FG 4 who had not engaged in a family EOL care discussion said that he did not worry about any negative health consequences because of his faith. However, participants in FG6 who had engaged in discussions also brought up religion related to ACP. One Black woman noted that some Black people "don't prepare" and "don't believe in it," suggesting that religion discouraged ACP proactivity. However, she emphasized that she and others were different because they understood the burden a lack of planning placed on other family members. As another Black participant in this group said, "(God) gives you common sense."

Overall, the participants who had engaged in family EOL care discussions seemed more proactive by nature and more easily activated to have the discussion. However, their levels of activation varied, for some Black and Hispanic participants not extending to completion of a living will. Those who had not engaged in discussions had not been activated by their experiences, though many were proactive in other ways and some seemed to be moving toward ACP activation. Others, however, seemed to resist moving forward.

Theme 2: Accepting the Reality of Aging and Death

Among those who had discussed their EOL care wishes with family, several talked about accepting the reality of death. A Black female participant from FG6 said the following:

> *When you asked the question about what made you decide to discuss the issues, I think for me it was when I realized that I could go at any time… I'm a cancer survivor and survivor of a stroke. I said OK. And once I made peace with that, 'Girl you're going to leave here.'*

Another Black female in this group responded, "Yes, ma'am."

An Hispanic female participant from FG3 who had engaged in a family EOL care discussion with her family said, "I think that (there are) persons who think it is too early to think about that, but (it) comes and doesn't warn you. It's better to talk now and understand what is correct."

A White male participant from FG5 talked about getting over the fear of dying after having been a part of several death and dying discussions, including a public seminar. He and two others in his group agreed that such discussions should become "normal," like talking about car or life insurance, and should begin in young adulthood. He said, "I just have found for my own self, yes to make it normal, to be able to feel, I'm not afraid of dying now. I really am not. It's something I'm going to do."

By contrast, several of the participants who had not talked to family about their wishes expressed an aversion to the thought of dying, and this appeared to block their activation. A White female participant from FG 4 said that while she and her spouse realized ACP was important, "This is going to be the end of whatever happens, that's what it comes down to, and you don't really want to think about it." A White female participant from FG1 expressed a similar feeling: "You don't want to think about that time, so you don't talk about it."

Related to the theme of acceptance/aversion, a subtheme of the emotions connected to the planning process emerged. Among those who had discussed their wishes, one White female participant from FG7 described openly confronting and accepting the emotions:

> *When we filled out our forms, we sat there and cried. We cried. It was just an emotional thing to say, "If I'm in this position this is what I want." You think, "God, I hope I never have to face this." It's just emotional to think about your own end of life and you want it to be as easy as possible.*

Among those who had not had the discussion, the emotion most related to their death aversion was fear. A White female participant from FG2 described her mother's fear that talking about death would make it come faster. A White male participant from FG2 described his own fear stemming from his upbringing and having to withdraw life support for both his mother and father:

> *I don't like to talk about it. I had to do it with my mom. I had to do it with my dad. I had to take them off of plugs. I can't talk about it. It's something that takes me back to that time. That frightens me. Something that is inbred. I guess I am not a realist. It is a frightening thing that is a part of my psyche. I think a lot of people have that problem.*

An Hispanic participant in FG3 who had not engaged in a family EOL care discussion talked about the sadness of his mother's death. "You know, when she is sick in bed, you know that any moment she can die, but when she dies you get very depressed. It is hard. I don't like to talk about that, that is very personal and I don't like to comment on that."

Several of the other participants, White and Black expressed the apprehension that talking about their end of life would make them seem weak or vulnerable, or that it conflicted with the idea of living life. As one Black female participant from FG4 said, "We don't want our children and our husband to think of us that way."

Overall the participants' acceptance or rejection of the idea that they were aging and would one day die seemed to respectively facilitate or block their movement toward EOL care discussions and other ACP. Many seemed to equate ACP with serious illness and/or death, in particular difficult death. For some, death was too sad or difficult to discuss in any way with others.

Theme 3: The Effect of Family Dynamics

Participants in all of the groups highlighted the difficulty of talking to family members, their children in particular. Some described it as a logistical problem due to family members living in separate cities. Some were estranged from family members or didn't trust them to carry out their wishes or feared conflict among them. What distinguished those who had engaged in EOL care discussions from those who had not was the firmness of their approach. Related to the theme of proactivity, several participants who had engaged in discussions were not deterred by their children's reluctance or refusal to talk. For some, the discussion was one of multiple ACP steps, and they relied on those other steps to aid their discussion efforts. One Black participant from FG 6 described the following encounter:

> *(The children) said, "no Mama, we don't want to talk about this," and I said "you got to talk about it….I said, 'I'm just going to put it down in writing. You all do exactly what I say do. You promise you'll do what I say do.' "*

Some of these participants dealt with their concerns also by choosing the child they felt was most responsible as the primary decision maker. A White male participant in FG5 said the following:

> *We wanted to make sure that it's clearly laid out what happens with our lives now. It wasn't before. We assessed each child. They all bring different things. We felt that (our son) was the most reasonable and would act on our wishes and not force his opinion on how he feels about it.*

By contrast, some of those who had not engaged in a family EOL care discussion could not imagine how to do it. A White female participant from FG 1 described the difficulty posed by some of her children living out of town and the awkwardness of discussing EOL care long distance. In a discussion of the "Five Wishes" AD, she remarked, "I mean to call on the phone? 'I'm going to give you Five Wishes guys. Ready? Sit down.' "

Several participants had raised the topic with their children or considered raising it, but did not force the issue. They had been activated but faced a critical barrier. This was the case with 3 of the 6 Hispanic participants. As an Hispanic female from FG3 said, her children were not "ready" to talk about such things with her. An Hispanic male from the group described the following: "I spoke with (the children) a little bit and they told me 'don't do that, we don't like that'….They say 'when that happens, we know what to do, let's talk about other things, we don't want to talk about that.' "

Theme 4: The Effect of Knowledge

Many of those who had engaged in discussions had learned about EOL planning through their involvement with their parents' or others' EOL decision-making. One White female participant from FG7 who had talked to her son about her EOL care wishes recalled her father being told that he had a choice to forego food and water, and that without water he would likely die in a few days. She said, "He had never really thought about that. I had never thought about that. He decided no water or food." A White male participant from FG5 described his mother's decision to forego treatment for lung cancer as a "learning experience." This theme was less prominent among the Black participants who had engaged in EOL care discussions, though several described close family relationships and shared health care decision-making.

By comparison, many of those who had not had family discussions said they never knew what their parents had wanted. One Black female participant from FG4 said, "Our parents didn't do it to us (talk about ACP). Our grandparents didn't do it to them. Those issues never came up." This theme, however, emerged among White participants, too. A White female participant from FG2 who had not engaged in any ACP described her mother's refusal to talk about death.

> *So she, in other words, she herself didn't want to put herself there....I, I had struggled with it, do this, do that, your therapy, your this. (In the end) she says, "I'm not going to be here that much longer." She knew it was coming to an end. And that's when she said, she said "I know you'll make the right choices."*

Overall, it seemed that many of the participants who had engaged in EOL care discussions had been primed for activation through their previous experiences, while those in the non-discussion groups had not. The participants in the non-discussion groups also had some specific knowledge gaps, such as knowing the role of and how to name a health care proxy.

Several posed questions concerning when and how to start an EOL care discussion, such as this from a White female in FG2: “How can you make those choices now when in 20 years things may be entirely different?” A Black female from FG4 said the following:

> *You hear about how important it is to go to the doctor and talk about doing things to be healthy, but the issue about the living will and the other things, that part is just not discussed. You don’t hear about it. The media talks about going to the doctor and different medicines, but they don’t talk about preparing for the end.*

A subtheme to the knowledge theme is the role of doctors in providing people with the knowledge needed to undertake ACP and/or make an EOL decision. Several in the non-discussion groups said their doctors had not offered to provide or explain ACP materials, even in health care circumstances that would warrant it. A Black female from FG 4 described having received a form, but she had only partly completed it and no one asked her about it again. Several also said they would welcome a doctor providing information about written documents and initiating or facilitating a family EOL care discussion. However, a White female participant from FG 2 was strongly against doctors’ initiating a family discussion:

> *Is that a conversation that I would want with my doctor? That is the person I go to to help take care of me. He's not my BFF. He is not someone that is a family member. Does his decision or his assistance in this situation, could it be of help? Maybe to understand what your situation is. But for him to be the encourager to say “Hey go home and talk to your kids about end of life choices.” No.*

This participant believed that a doctor should get involved with ACP only with those in the last stages of an illness. Others who had not engaged in family EOL care discussions expressed a similar view, that a doctor’s involvement related to ACP meant that the patient was seriously or terminally ill. Addressing the question of whether a doctor would want to have such a discussion, a White female participant from FG2 said: “I think they would be afraid the patient would not trust them anymore. I don't think that is a good idea.”

It is also notable that many of those who had engaged in family EOL care discussions were skeptical about doctors’ involvement with ACP. Their doubts revolved around their beliefs that doctors are so strongly oriented toward keeping people alive that they would have trouble effectively talking about one’s plans to ever limit treatment. Said a White female participant from FG7: “I think so many doctors are so full of, ‘I can keep you alive and I don’t want to hear about ways to not keep you alive,’ because that’s the oath they take.”

Only one seemed to know that the federal government had started providing Medicare reimbursement to doctors for ACP consultations. This White female participant from FG7 knew this because her doctor suggested she set up a discussion appointment after she had mentioned revising her living will during a routine office visit. Despite their skepticism, however, many participants agreed that doctors were important sources of information related to ACP and EOL care. A White female from FG 7 said, “They need to tell us what will happen if I do this and what will happen if I don’t. Not just the healing part.” Several agreed that doctors needed to become a part of “normalizing” the public’s conception of death and dying. Overall, their comments suggested that doctors have a critical role to play in providing information and knowledge to facilitate one's movement toward an EOL care discussion and other ACP. However, it is questionable how well this information will be received by those who have not been initially primed or activated to undertake ACP.

Discussion

This study examined the differences between older adults who had talked to their family members about their EOL care wishes and those who had not. However, our results extended beyond this one aspect of ACP to include the other behaviors (e.g. completing a living will, naming a health care proxy) and showed that ACP is a complex and nuanced process. Previous studies have shown that the component behaviors of ACP are distinct and that there is no common sequence of steps toward comprehensive ACP (Fried et al., 2010). Overall, our results showed that older adults who had engaged in EOL care discussions were more likely to have written ACP documents than older adults who had not had such discussions. However, we found differences within the groups. Those who had talked to family about their wishes had not followed a set series of steps. With some the discussion came first, but with others it followed the written documents. Of those who had not engaged in the discussion, some seemed to be on the verge of taking planning steps, though they varied on whether they were more inclined to have the discussion or complete the documents first. By contrast, others were resistant to any form of planning, likely due to a lesser awareness of the consequences of not planning or an aversion to the topic grounded in fear. Results also indicated that people vary in what prompts them to consider ACP and what stands as a barrier.

These results have implications for anyone designing interventions to increase ACP. In support of Fried and colleagues (2010), they suggest that people are in different stages of change for ACP and for the separate behaviors of ACP (e.g. talking to family, completing a living will). They also suggest that varied approaches must be taken to accommodate differences in proactivity, acceptance of aging and death, family dynamics, and knowledge of ACP, in particular related to family experiences.

Many of the participants who had talked to family members about their EOL care wishes had proactively planned for a broad range of life events, in addition to taking multiple ACP steps. Notably, however, several of the Black and Hispanic participants who had engaged in family discussions had not completed living wills. Such documentation differences have been found in other studies (Carr, 2011; Sanders, Robinson, & Block, 2016), with Blacks showing a preference for family discussions over written ACP documentation. The only explanations for this in our research came from one comment from a Black participant that Black people overall didn't engage in EOL care planning. Also, one Hispanic participant said that Hispanic people didn't like to fill out living wills, though he did not explain why. Further research is needed into the cultural barriers to completing living wills. It is worth noting that several of the Black participants said that they intended to complete living wills, and some had already started them.

Interestingly, many of the participants with incomplete ACP, including those who had not engaged in family discussions, had engaged in other after-death planning. It seemed the difference was that they had not dealt with the question of the actual dying process - many of them were not as aware of the eventualities of this process (e.g. the need for mechanical ventilation for life support) as others who had engaged in fuller ACP. This aligns with the TTM, as those who had not had the discussion did not perceive the risks involved, which would place them in the precontemplation stage. This suggests an avenue for intervention, such that increasing people's awareness of the importance of ACP could activate them to begin or complete the planning process. TTM addresses the value of increasing awareness as a way to move people to more advanced stages of change (Prochaska et al., 1992). Those who had already begun a family discussion or living will, who seemed to have been activated to a certain extent, would likely be the most receptive to such an approach. Some of the participants seemed to have been activated by the focus group meeting itself.

A related, though different theme was the influence of one's acceptance of aging and death. Many of those who had not talked to family about their wishes expressed fear of talking about their dying or the prospect of serious illness. Some tied this to their culture or upbringing and/or to having experienced a difficult family death. By contrast, several of those who had engaged in extensive planning talked freely of their own mortality. Some talked about the importance of making discussions of death and dying more "normal," even for young adults. Research has shown the potential for increasing ACP awareness among young adults and that this could serve an important public policy purpose by preparing them to act one day as health care surrogates (Kavalieratos, Ernecoff, Keim-Malpass, & Degenholtz, 2015).

Researchers who have recommended the use of TTM for ACP have also proposed that introducing ACP concepts early is important because ACP can be a long process involving a great deal of thought and personal preparation (Sudore, et al., 2008). The Institute of Medicine’s 2014 report on Dying in America (Meghani & Hinds, 2015) highlighted the importance of "normalizing" the death and dying conversation and called for a national dialogue on the issue (Meghani & Hinds, 2015). This could ultimately help reduce that barrier to ACP posed by many people's aversion to the topic of death and dying. Our results suggest, however, that this aversion is somewhat prevalent today. Previous research has found that those with greater death anxiety are less likely to engage in all forms of ACP (Carr & Khodyakov, 2007) suggesting that there is a population of people who currently would close themselves to a national dialogue about death and dying. More research is needed to understand this fear and aversion, including the association of ACP with ill health and weakness, so that any effort to address this important topic does not exclude a large number of people. Further research is also needed to understand the deferred autonomy displayed by many participants who assumed their family members would know their EOL care preferences, making the EOL care discussion unnecessary (Daaleman, Emmett, Dobbs, & Williams, 2008).

Concerning family dynamics, participants in all of the groups had experienced resistance to EOL care discussion from their children, another barrier to the ACP process. Several of the participants had forced the issue, some using their written documents as aids. In keeping with the idea of the TTM, these participants had developed strategies to help them undertake this behavior (Prochaska et al., 1992). By contrast, many who had not pushed the discussion also had not engaged in other ACP. Research has shown the value of using role modeling as a strategy to help people initiate and conduct a discussion concerning EOL care (Volandes, Mitchell, Gillick, Chang, & Paasche-Orlow, 2009). Such an approach may be effective with the participants having difficulty confronting their children's unwillingness to have an EOL care discussion, such as the Spanish-language participants in our study. This highlights the importance of offering multilingual resources, as some have (Sudore et al., 2014)

Many of those who had planned extensively had a greater knowledge of ACP. They recounted experiences with family members' EOL decision-making, parents in particular, and the knowledge they gained in the process, which is consistent with previous research (Carr, 2012). Also consistent with this research, many of those who had not talked with their children or other family about their EOL care wishes had witnessed the "bad" deaths of loved ones or participated in difficult EOL decisions without clear knowledge of their loved ones' wishes. This shows the priming effect of these experiences. It also shows the intergenerational impact of ACP (Carr, 2012), knowledge of which could be critical to understanding how to persuade a non-planner to take action.

It should be noted that few of the participants were opposed to ACP. The difference for some seemed to turn on the question of when. For those inclined to be proactive, the time for planning is now. Several used the phrase “you never know” or something similar to express their view that even though they were relatively healthy, they could fall ill or become incapacitated without warning. Those who were less proactive were more likely to see the discussion and ACP as actions they could undertake later. They were more vulnerable to the many obstacles and barriers, such as fear of death and family resistance.

Doctors and other health care practitioners play a central role in helping individuals and their families navigate these complex circumstances. Concerning the effect of a loved one’s death on future ACP, Carr (2012) suggested that health care practitioners have a role in helping patients understand and accept the losses, thereby moving them toward ACP. It is possible that these individuals are still grieving, which in keeping with the TTM behavioral model would stand as a barrier to stage change. This suggests a role for hospice to provide grief counseling aimed at improving ACP.

Beyond this, doctors can provide or guide people to the information they need to start a discussion and develop an advance care plan. Furthermore, they can explain why it is important. However, this is a somewhat delicate task, as seen in the participants’ conflicted views of the role the doctor should play – as revealer or as healer. More research is needed on how doctors can help the patients who need it – those facing their own or others’ resistance – to engage in ACP without compromising trust or inciting fears. This is especially important considering that doctors are now able to receive Medicare reimbursement for ACP consultations. This benefit had been available only since January 2016, so it is too soon to know whether it will improve ACP. However, the findings of the current study and others have the potential to further encourage health professional to offer ACP consultations.

Limitations

This study had some limitations. First, the study was designed to compare groups of those who had talked to their family members about their EOL care wishes and those who had not. However, some groups included both, particularly the Spanish speaking group. It is possible that the opinions of those who had engaged in discussions influenced the opinions or comments of those who had not, in that some questions related to the desirability of having such discussions. However, the majority of the groups were exclusively one or the other as intended, enabling us to see clear differences between them. In addition the sample was diverse by race, ethnicity, and income, with Hispanic, Black, and White participants among those who had had family discussions and those who had not.

Our Spanish-speaking sample was recruited from one community and likely did not encompass the diversity of Spanish speakers in Florida and the United States. Also the focus groups included no predominantly English speaking Hispanics, who may also have provided a greater diversity of responses.

Another limitation is that we recruited from sites attended by generally active older adults, all living in the community, so our sample was relatively healthy and relatively well educated. While several of our participants were in their 80s and reported at least two chronic health conditions, our results may have been different for older adults who had more serious illnesses and less education. Furthermore, we did not conduct member checking to ensure the themes from the study results were congruent with participants' experiences. However, facilitators did summarize the results of the groups with participants at the end of each group.

Conclusion

Despite these limitations, our findings show that family discussions play a central, though variable, role in ACP from one person to the next, and that the entry points to action vary by individual. Furthermore, there is potential for increasing the occurrence of such discussions and ACP overall by understanding more about the individual inclinations and attitudes that influence these differences. This knowledge could be used to develop interventions that would help reduce current barriers to ACP, as proposed by the TTM. Doctors have a role in this process because of the knowledge they have to share - about health in general, their patients' health and prognosis, and how to engage in ACP - and the information they can provide to help link patients and their families. More research, however, is needed to determine how doctors can best fulfill this critical role and improve EOL care not only for patients but the patients' families.

Table 3. Focus Group Participants' Demographic Characteristics, by Discussion Category

	Talked to family (*n* = 17)	Not talked to family (*n* = 19)
Characteristic	*n* (%)	*n* (%)
Age: Mean years (range)	73 (58-87)	67 (59-77)
Female	14 (82)	13 (68)
Race/Ethnicity		
White, Non-Hispanic	9 (53)	11 (58)
Hispanic	2 (12)	4 (21)
Black	6 (35)	4 (21)
Education		
High school or less	4 (24)	9 (47)
Some college, trade school	7 (41)	4 (21)
College or more	6 (35)	6 (32)
Married	6 (35)	11 (58)
Chronic conditions, >1	13 (76)	8 (42)
Has a living will	11 (65)	3 (16)
Has a health care proxy	15 (88)	2 (11)
Talked to doctor about EOL care	9 (53)	1 (5)

Table 4. Themes and Selected Quotations from Focus Groups, by Discussion Category

Talked to Family Member	Theme	Subtheme
	Proactivity	**Awareness**
Yes	We are very, very proactive....We've shared with our kids our decisions, and we've made appointments with our children about certain ones to do certain things. I had an Aunt Dotty. She was a planner and you did not cross her with her plans….After she had died and after my husband had died and after I had talked to my son, at one point he said, you sound just like Aunt Dotty. But he was right. I had to have it all planned out.	I wanted to be thoughtful toward others when it came to my end of life. I think some people are just more aware of these issues. It's like a problem you will face in the future and (you) are more of a problem solver. I think the times now have brought the conversation front and center to so many people, be they our age or younger. I think they understand it now that putting someone on life support is not a favor.
No	I don't get excited unless something is right at the doorstep and it's going to happen. People who get their ducks in row. I hate people like that. Plan, plan, plan....those people drive me crazy. Why can't you just have a good time and live life?	
	Acceptance of Aging, Death	**Emotions**
Yes	So if I was ready to go tomorrow or whatever, I'm comfortable with it. And every night I say "well father if I said anything wrong to anybody will you please forgive me." I do it every day because we never know. We're all going to come to an end. Everyone could say, "this pertains to me."	
No	You don't talk about it, because if you talk about it, it will happen. That sounds stupid but you have to understand that's in my psyche. That's in me. It was bred, it was taught that's there	This conversation is hard for me. It is something that is going to happen to everybody, but there are many people....they are afraid about dying, like my daughter (who had cancer) who was terrified and nobody was able to talk to her about that.

Table 3. (Continued)

Talked to Family Member	Theme	Subtheme
No	**Acceptance of Aging, Death** Q: Have you ever heard of something called Death Cafes, where people get together for dinner to talk about their wishes? [Speaker 1] Ewww. I would not be able to have dinner. [Speaker 2] That just sounds "yuk" No.No. I don't think I would go to that.	
	Family Dyanmics	
Yes	“I just told my daughter, ‘I’m not having it. This is what I want.’ ”	
	We assessed each child. They all bring different things. We felt that (this son) was the most reasonable and would act on our wishes, not force his opinion on how he feels.	
No	I think there would be disagreement because each child, they’re an individual. I have 3 children and this one might say yes, and this one might say well I don’t know and the other one might say let me think about it.	
	To me (the discussion) is a hard thing, because when my youngest son comes, his youngest comes and his wife….It's their vacation, so they're on the go.	
	Knowledge	**Doctor's Role**
Yes	(My mother) didn’t want to be on life support. She had Alzheimer’s…but (we talked) at the beginning about 5-6 years before. I know for me, my mother was diagnosed with lung cancer when she was about 84. They wanted to do surgery and she said "no. I’ve had a good life," and we took care of her. That was one learning experience.	I think is that these issues are very difficult to treat….I think the only person who can talk about this is the doctor, talk to you directly and without feeling sorry about that. Somebody has got to say how it is to the doggone doctors, that not everybody wants to hang on until the very last second and suffer.
No	I talked to my dad, he was like "whatever you have to do." He wanted nothing to do with the decisions. So it was left to me to make those decisions and I did what I had to do.	

CHAPTER FOUR:

FAMILY EOL CARE DISCUSSIONS: A MIXED METHODS STUDY

Introduction

With the aging of the population in the United States and other countries, older adults are increasingly likely to reach the end of their lives in a compromised state in which they are unable to express their health care preferences (IOM, 2014). Silveria and colleagues (2010) found that nearly 30 percent of older adults required end-of-life (EOL) decision-making but lacked the capacity. In these cases, health care providers often turn to family members to decide whether to provide, withhold, or discontinue treatment. Preparing family members is especially important in light of research questioning how well written documents ensure that patient's EOL care wishes are known and honored (Oulton et al., 2015). McMahan and colleagues (2013) suggested that ADs overall are ineffective if patients have not talked to their surrogate decision-makers with sufficient detail for the surrogates to know what to do to honor the patients' wishes. Furthermore, studies have shown that such discussions can reduce the family conflict that often accompanies EOL decision making (Kramer & Boelk, 2015).

Research has also documented, however, that whether and how these discussion occur depends largely on family dynamics (Glass & Nahapetyan, 2008). Families that function in a more positive way (e.g. solve problems collaboratively) are more likely to engage in family EOL care discussions (Boerner et al., 2013). By contrast, research has found that poor family functioning can hinder family EOL care communication (Schenker et al., 2013; Su, McMahan, Williams, Sharma, & Sudore, 2014). Parks and colleagues (2011) found that higher levels of family conflict were associated with lower levels of proxy accuracy concerning a loved one's care preferences, suggesting they also experienced lower levels of EOL care discussion.

Racial and ethnic aspects of EOL care conversations warrant special focus, given research showing that the family role in EOL care giving is particularly important among those who are Black (Bullock, 2010; Dillon, Roscoe, & Jenkins, 2012) and Latino (Cruz-Oliver, Talamantes, & Sanchez-Reilly, 2013). Exploratory results from a qualitative study suggested that Blacks and Latinos were more likely to be subject to parents' unspoken EOL care expectations and that the subject of death was a taboo in many cultures and often led to stress at EOL (Su et al., 2014).

Research concerning theoretical models has begun to view such discussions as personal and interpersonal behaviors that are subject to change. A number of these studies have used the Transtheoretical Model (TTM) of health behavior (Prochaska et al., 2008), proposing that increasing ACP requires understanding an individual's readiness to take action (e.g. Fried et al., 2009; Ramsaroop et al., 2007). Several of these studies have examined the occurrence of family EOL care discussions (e.g. Fried, 2010), however, none to our knowledge have examined the way in which family relationships may influence an individual's stage of change for having a family discussion. The TTM therefore serves as the conceptual model for the present study. Its purpose is to understand more about family relationships and EOL care discussions through a mixed methods analysis combining quantitative and qualitative date. Our research questions are as follows:

1) What is the association between family relationships and the occurrence of family EOL care discussions?

2) How do those who have engaged in family EOL care discussions differ in their family relationships from those who have not engaged in EOL care discussions?

3) What role does race or ethnicity play in family relationships as they relate to engaging in family EOL care discussions?

It should be noted that because we are presenting this study as a stand-alone paper, we have included full descriptions of the quantitative and qualitative methods. These methods, however, are largely the same as those presented in Chapters 2 and 3 of this dissertation. (They appear on pages 63-69 of this paper.) The difference in the current paper is the addition of mixed-methods descriptions. The quantitative results are also the same, though presented differently because of the focus on family relationships. The qualitative results are substantively different so as to address the research questions concerning family relationships and EOL care discussions. In addition, this paper includes an additional section describing the integrated results.

Methods

The present study used mixed-methods integrated at the design level to follow the explanatory sequential model (Creswell & Plano Clark, 2011). It began with the collection of quantitative data (questionnaires). This was followed by collection of qualitative data (focus groups) among selected participants from the quantitative phase for the purpose of explaining and expanding on the quantitative results. We chose this quantitative-qualitative approach because EOL care issues can be personal and subjective, which can limit the explanatory value of quantitative data alone. Preliminary analysis of the quantitative questionnaires helped the researchers develop research questions to explore during the qualitative phase. It also helped researchers select the appropriate participants for the qualitative phase of the study and more deeply analyze the quantitative data. The institutional review board at the University of South Florida approved the study (#Pro00023404). See Figure 2 for a depiction of the process.

Quantitative Data Collection and Analysis

The quantitative phase of the study employed a cross-sectional survey design using a structured questionnaire created by the researchers. The questionnaires were in English and Spanish, with the Spanish questionnaires developed through back-translation. (See Appendix 1 for examples of the questionnaire.)

Participants were recruited from a variety of settings in West Central Florida, including senior centers, senior housing apartments, community events, and service organizations. Participant eligibility criteria consisted of being age 50 or older; able to communicate in either English or Spanish; and able to understand and complete the 4-page questionnaire. Between October 2015 and May 2016 survey questionnaires were distributed at meetings with participants. A researcher was available at each meeting to explain the items as they related to EOL care and to obtain written informed consent from each participant. A native Spanish speaker who also spoke English provided translation and assistance with the questionnaires at the meetings with Spanish-speaking participants. Of the questionnaires that were originally collected, 16 (4%) were excluded because data were missing from the questionnaires, providing a final sample size of 364.

Quantitative measures

Dependent variable. The primary outcome measure in this study was stage of readiness to have an EOL care discussion with a family member. It was measured through a series of questions based on research by Fried and colleagues (2010) concerning EOL care discussions with family members. Figure 1 illustrates the specific questions. Based on their responses participants were classified as being in one of 6 stages – precontemplation, contemplation, preparation, action, relapse, and maintenance.

Independent variables

Family involvement with health care. This was the independent variable of interest in this study and was measured through a question concerning family involvement in health care decision-making. Participants were asked about the extent to which they wanted to involve family members or friends in their health care decision-making and directed to choose one from the following progression, which was scored as a Likert scale: “I make decisions without much advice from them” (= 1); “I get their advice and then make decisions” (= 2); “We make decisions together” (= 3); “I leave decisions to them” (= 4). Higher scores reflect greater family involvement. This question and the scoring approach is from the National Health and Aging Trends Study’s (NHATS) Round 2 module concerning individuals' preferences for involvement in health care decisions (Kasper & Freedman, 2015). To our knowledge, it has not been used in previous studies.

Sociodemographics. Participants recorded their age, gender, marital status (married, single, divorced, or widowed), household composition, education (highest year completed up to 16+, which was grouped as high school or less, some college, or bachelor’s or graduate degree), race (White, Black, other), and Hispanic ethnicity. They also were asked to report whether the income at their disposal was sufficient.

Health. Heath conditions included self-reports of whether participants had been medically diagnosed (yes/no) with heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, cancer, or dementia. Responses were dichotomized according to whether participants had two or more conditions. Participants were asked to rate their general health as excellent, very good, good, fair or poor, and these were dichotomized into excellent, very good, and good vs. fair and poor. Participants also were asked a yes/no question about having been hospitalized overnight in the previous 12 months.

Health literacy. Participants were asked “How confident are you filling out medical forms?" and asked to choose from 1 (low health literacy) to 4 (high health literacy). This question was based on previous literature concerning ACP (McMahan et al, 2013) and has been found to perform well as a single question to detect inadequate health literacy, with an area under the Receiver Operating Characteristic Curve (AUROC) of 0.84 based on the Rapid Estimate of Adult Literacy in Medicine (REALM) (Chew et al., 2008).

Self-efficacy. Participants’ self-efficacy related to ACP was measured with the question, “How confident are you that you could ask your doctors the right questions to get information to help you make good medical decisions?" As with the previous question, the choices ranged from 1 (low self-efficacy) to 4 (high self-efficacy). This question was based on previous ACP literature and is part of a larger validated survey that measures several aspects of ACP, one of which is self-efficacy (Chiu et al, 2016; Sudore et al., 2013) (The other aspects of ACP included in the above-mentioned survey are assessed in the present study using other measures, such as the stages of change question route.) General self-efficacy was assessed with two questions about the extent to which participants agreed that “When I really want to do something, I usually find a way to do it,” and “Other people determine most of what I can and cannot do.” Potential responses were agree not at all (=1), agree a little (=2), and agree a lot (=3). The “other people determine” question was reverse-coded and the responses were summed so that a higher score signified greater self-efficacy. These questions were based on questions from the full NHATS (Kasper & Freedman, 2015). They have been used together in previous studies measuring self-efficacy and shown to be associated with personal activity limitations (Lin & Wu, 2014). To our knowledge, they have not been used in ACP studies.

Knowledge of palliative care. Participants responded yes/no/don't know to a set of statements concerning EOL care, adapted from Schulman-Green et al. (2012). They were: 1) Palliative care includes chemotherapy and radiation; 2) Palliative care helps manage pain and other symptoms; 3) Palliative care includes psychological, social and spiritual care. A correct answer was scored as a 1, an incorrect or don't know answer was scored as a 0. Sums provided one total score. The Cronbach's alpha for this version of the Schulman-Green scale was $\alpha = .70$.

Advance Care Planning (ACP). Several questions assessed ACP. Participants were asked whether they had a living will; had named a health care proxy (yes/no); and whether they had talked to a health care provider in the past 12 months about their EOL care preferences. Participants also were given two ACP scenarios: 1) "What if you could speak, walk, and recognize others, but you were in constant, severe physical pain?" 2) "What if you were not in pain, but could not speak, walk, or recognize others?" After each scenario, they were asked to choose either 1) receive life prolonging treatments; 2) stop/reject treatments; or 3) don't know. These questions came from a module concerning ACP in Round 2 of the NHATS (Kasper & Freedman, 2015). They have not been used in previous studies, to our knowledge. Finally, participants were asked if their EOL preferences had changed in the past 12 months (yes/no).

Religion and values. Participants rated the strength of their religious or spiritual orientation from 1 (low religiosity/spirituality) to 4 (high religiosity/spirituality) with the following question: "What is the strength of your spiritual or religious orientation?" (Dobbs et al., 2012). Previous research has shown that religious and spiritual orientation are highly correlated (Garrido et al., 2012). Also participants indicated their strength of agreement, from 1 (low strength of belief) to 4 (high strength of belief) with three statements about God's role in their health and the length of one's life (Garrido et al., 2012). The statements were “It is God’s will when a person's life will end”; “The length of a person's life is determined by God”; and “I turn my health problems over to God.” The scores were summed and higher scores indicated greater strength of belief. Finally, participants were given the following statement: "The quality of a person's life is more important than duration." (Sharp et al., 2012) and asked to choose from 1 (low emphasis on quality of life) to 4 (high emphasis on quality of life).

Analysis of the questionnaire responses was conducted using SAS (Version 9.4. Cary, NC: SAS Institute Inc. 2011). We examined the univariate associations between family discussion stage and the independent variables using the Chi-square test for categorical variables, and analysis of variance for the independent continuous variables. We used a Bonferroni correction to account for multiple comparisons. Bivariate multinomial logistic regression was used to test the association between stages of discussion and a single race/ethnicity variable. Independent variables that were significantly associated with discussion stage in the analyses ($p < 0.05$) were included in a multinomial logistic regression analysis examining the associations between discussion stage and family involvement in health care and the other independent variables. The independent variables included family involvement with health care decisions, confidence talking to doctors (health care self-efficacy), and health literacy. We also included sociodemographics (e.g., sex, race, ethnicity, education) based on previous research. The reference category in the regression analysis was precontemplation.

Qualitative Data Collection and Analysis

The focus group participants were drawn from those who completed the questionnaire (*N*=364). For the purposes of this qualitative analysis, those who had engaged in EOL care discussions (from action and maintenance stages) were categorized separately from those who had not (from the precontemplation, contemplation, preparation, and relapse stages). They were recruited for the focus groups by telephone.

Based on previous research and input from geriatrics and gerontology experts, a focus group guide was developed to help explain the occurrence of family EOL care discussions. Included in the guide were questions concerning why these discussions were difficult for participants (or not), and what would encourage people to have such discussions. See Appendices 2 and 3 for the guides; they varied slightly based on whether the participants had or had not engaged in the discussion. Seven groups of 4 – 7 participants each (*N*=36) were conducted between May and June 2016. Four groups (*n*=19) involved those who reported they had not engaged in family EOL care discussions and three (*n*=17) involved those who had not. The group meetings took place in senior centers (2), libraries (4) and a senior living community (1), each in a private room and lasting from 90-120 minutes. Five of the groups were facilitated by a graduate student in aging studies with a graduate background in communication, who was assisted by a note taker for one of the groups. One was facilitated by a PhD trained gerontologist with a graduate background in public policy, who was assisted by a note taker. One group consisted of Spanish-speaking adults of Hispanic ethnicity and was recruited and facilitated by a native Spanish-speaker who also spoke English. She was assisted by a member of the research team who spoke Spanish. When there was no note-taker, the facilitator took notes. Field notes related to the participants' responses were shared and discussed after each group. The facilitators had no prior relationship with the participants, except the Spanish-speaking group, in which case the participants knew the facilitator through their association with a senior services volunteer group. At the end of each group, facilitators raffled two $25 gift certificates.

For analysis, all groups were audio-recorded and transcribed verbatim (a native Spanish speaker who also speaks English transcribed the focus group of Spanish speakers into English). The data was entered into Atlas/ti version 7 (Scientific Software, Berlin, Germany) and analyzed using a standardized, iterative framework approach. Using the software, two authors (LP, DD) developed a coding scheme through independent reading of the transcripts. One was a graduate student in aging studies with graduate experience in communication; the other was a sociology PhD, both with EOL research expertise). An "open coding" approach was used, with each code representing a distinct idea or information (Strauss & Corbin, 1998), although individual sections of data could be assigned multiple codes. The coding scheme was consistently refined using the constant comparative method (Corbin & Strauss, 2008). Coding discrepancies were discussed among the coding team of two until consensus was reached. Related codes were clustered as patterns emerged (axial coding) and axial codes were added to the list to reflect the relationships between the initial codes (Strauss & Corbin, 1998). For example, the codes of family EOL care experiences and knowledge of family EOL care wishes were found to occur together or in close proximity, such that knowledge seemed to result from these experiences. Knowledge therefore becoming an axial code reflecting a group of open codes.

Integration of Quantitative and Qualitative Data

A technique known as "following the thread" was employed in the present study. This involves using the initial results of the analyses to identify an issue for exploration across both sets of data (Moran-Ellis et al., 2006). This is in keeping with the sequential explanatory design, in which analysis of one set of data informs collection of the second set. However, after identifying the "thread" for the present study, family relationships and the occurrence of EOL care discussions with family members, we also employed a triangulation technique in which both data sets were analyzed together by way of a mixed methods matrix (Creswell & Plano Clark, 2011; O'Cathain, Murphy, & Nicholl, 2010). The relevant quantitative and qualitative data were displayed in columns and compared across rows of focus group cases to assess quantitative/qualitative concordance. Primarily, we compared each participant's stage (based on the questionnaires) to his or her comments concerning the family relationship themes that emerged during the focus group discussions. We also examined other quantitative data related to family relationships (i.e. family involvement in health care decision making) and ACP (e.g. having a living will) as they compared to the emergent themes.

Results

Quantitative Results

Descriptive sample characteristics. More than 44% of the sample was between 65-75 (*n* = 159) and 38% was older than 75 (*n*=138). Whites made up 61% (n=222), Blacks made up 26% (*n*=95), Hispanics made up 13% (*n*=46). Women made up 75% (n=273). The sample had a relatively high education level, as 32% (*n*=116) had a bachelor's degree or higher and 28% (*n*=102) had some post high school education. Nearly 62% (*n*=229) considered their disposable income to be sufficient. Nearly 40% (*n*=145) was married.

On family health care involvement, only 8 participants chose the option of leaving health decisions to family or friends, so we combined them with the next highest involvement option, making decisions together. These two combined made up 39% of the sample (*n*=142). Those who reported making decisions after getting advice made up 30% (*n*=109) and those who made decisions on their own made up 31% (*n*=113).

More than 60% (*n*=218) reported having two or more chronic conditions, though only 17% (*n*=62) reported their health as fair or poor, compared to excellent, very good, or good, and only 20% (*n*=73) had been hospitalized in the previous year. Participants reported relatively high levels of health literacy (scoring an average of 3.3 of 4), health self-efficacy (3.4 of 4), and general self-efficacy (5.5 of 6). Their palliative care knowledge was moderate (2.1 of 3).

Concerning preferences for care during serious illness, 31% (*n*=113) said they would want all available treatment if they were in severe pain though able to walk, talk, and recognize others, while 25% (*n*=87) said they would stop or reject treatment. Nearly 44% (*n*=160) reported that did not know what they would want in this scenario. In the scenario of being free of pain but unable to walk, talk, or recognize others, 19% (*n*=69) said they would want all treatment, 47% (*n*=171) said they would stop or reject care, and 34% (*n*=124) reported they did not know. Concerning advance care planning, 62% (*n*=226) reported having living wills and 68% (*n*=247) reported having named a health care proxy. Only 22% (*n*=80), however, had talked to their doctors about their EOL care wishes, and even fewer (13%, *n*=47) reported having changed their EOL care wishes in the 12 months. Participants reported high mean scores in religiosity (3.4 of 4), belief in the role of God in health and life span (9.5 of 12) and valuing the quality of life over quantity (3.6 of 4).

Sample distribution of EOL care discussions. Among the participants, 24% (*n*=86) were in the precontemplation stage (unaware or unready to have a family EOL care discussion); 6% (*n*=23) were in contemplation (thinking of having a discussion in 6 months); 1 (*n*=4) were in preparation (preparing for a discussion in 30 days); and 7% (*n*=24) were in relapse (having had the discussion more than a year ago). In addition, 27% (*n*=98) were in action (having had one discussion in the past 12 months); and 35% (*n*=129) were in maintenance (having had a discussion twice are more in the past 12 months.). Because of the low numbers of participants in the contemplation and preparation stages, these two were combined into a preparation category. In addition, they were combined with the participants in the relapse stage. Individuals who have taken action but not maintained it in a year's time are considered to have fallen out of action back into preparation. As with those in contemplation and preparation they have shown inclinations to act but cannot be considered "active" (Ernecoff et al., 2016). They would potentially need similar interventions to those in the contemplation and preparation stages. Overall, this created four discussion stages for analysis, precontemplation, preparation, action, and maintenance. Participant characteristics by stage of conversation readiness are shown in Table 1.

EOL care discussion stage and independent variables. In univariate analyses (shown in Table 1) we found that greater family involvement in general health care decisions (e.g. making decisions together) was significantly associated with higher discussion stages. Nearly 40% of those in action and 49% of those in maintenance reported that they made their health care decisions together with other family members, compared with 26% of those in precontemplation concerning family EOL care discussion stage (being unaware or unready to have the discussion). Conversely, 48% of those in precontemplation reported that they made their health care decisions with little advice from family members, while only 20% of those in maintenance reported the same family decision style.

Being Hispanic was significantly associated with lower family discussion stages, while there was no significant difference between being Black or White and discussion stage. Higher levels of education were significantly associated with higher discussion stages (e.g. action and maintenance), as was one’s assessment that his or her income was sufficient. Greater confidence in one’s ability to communicate with his or her doctor and greater confidence in one’s ability to complete medical forms was associated with higher family discussion stages. Higher knowledge of palliative care scores were significantly associated with higher discussion stage, while not knowing one's own wishes in the incapacity scenario (free of pain but unable to function) was significantly associated with being at a lower discussion stage, with half of those in precontemplation answering that they did not know what they would want. Having talked to a doctor about one's EOL care wishes, having a living will, and having a health care proxy were each significantly associated with higher discussion stages.

In the adjusted analyses we found significant associations between family EOL care discussion stage and family engagement in general health decisions. (See Table 2 for the results.) While controlling for sociodemographics, health, and other factors related to knowledge and understanding (e.g. self-efficacy and knowledge of palliative care), greater family involvement was associated with a 2.4 times higher likelihood of being in the action stage (p <.001) and 2.9 times higher likelihood of being in maintenance (p < .001). This result, combined with the unadjusted results, answered our first research question, showing that those with closer family relationships concerning health care decision-making were significantly more likely to engage in discussions about their EOL care wishes, especially multiple discussions.

With the adjustments, including the family involvement variable, there were no significant associations between race or ethnicity and discussion stage. However, women (vs. men) were 2.6 times more likely to be in the maintenance stage (p = .04). Those with greater confidence in their ability to communicate with doctors were 1.9 times more likely to be in the maintenance stage (*p* =.009). Those who had talked to their doctors about their EOL care preferences, however, were significantly more likely to be at a higher EOL-discussion stage. They were 3 times more likely to be in the action stage (*p* = .049) and 4.6 times more likely to be in the maintenance stage (*p* = .004). Those who did not know what they would want if they were incapacitated were significantly less likely to be in the action and maintenance stages (68% [*p* = .006] and 64% [*p* = .01] respectively). In addition, having named a health care proxy (the majority of whom were family members) was significantly associated with a 2.9 times greater likelihood of being in the maintenance stage (*p* = .03).

Qualitative Results

The mean age of the participants was 70 (ranging from 58-87) and three-fourths were female (*n*=27). More than half were White, non-Hispanic (*n*=20), six were Hispanic, and 10 were Black. About two thirds had come college or more (*n*=23) and more than half (*n*=21) had two or more chronic conditions.

Participants who had talked to family members about their EOL care wishes were on average older (mean age=73) compared to those who had not talked to family (mean age=67). Of those who had engaged in family discussions, more than 80% (*n* = 14) were female. In addition about half were White-non-Hispanic (*n*=9); two were Hispanic, and six were Black. Nearly 70% (*n* = 13) of those who had not engaged in discussions were female. More than half were White, non-Hispanic (*n*=11); four were Hispanic and four were Black.

More than three-fourths of those who had engaged in EOL care discussions reported have two or more chronic conditions (*n*=13), while of those who had not engaged in discussions less than half reported two or more chronic conditions (*n*=8). See Table 3 for more detail on the demographic and ACP characteristics of those who had and had not engaged in family discussion.

Of those who had talked to their family about their EOL care wishes, about half (*n*=9) indicated in the questionnaires that family members were highly involved in their health care decision-making (that they and family members made decisions together); about a fourth (*n*=4) indicated moderate involvement (they discussed their health care with family then made their own decisions); and about a fourth (*n*=4) indicated that they were at the lowest level of family involvement (they made their health decisions independently from their families). Of those who had not talked to family about their EOL care, only about one fifth (*n*=4) indicated that they were highly involved, while seven of the 19 were at a moderate level and eight were at the lowest level, a greater proportion than those who had engaged in family discussions.

Examination of the focus group data revealed three overall themes concerning how those who had engaged in family EOL care discussions differed in their family relationships from those who had not engaged in EOL care discussions 1) family interdependence and EOL care discussions; 2) being proactive regarding family involvement in EOL care discussions; and 3) knowledge of others' wishes related to EOL care discussions.

Theme 1: Family interdependence. Among those who had and had not engaged in family EOL care discussions there were distinct differences in their reliance on other family members to make general health care decisions. Many of those who had engaged in the discussions described close, cooperative relationships. One White female from FG 5 described her daughter as her "boon companion," saying the following:

> *My daughter is my main confidante. My daughter is 55 and she, her and I talk. And I'm her confidante also because of her work situation (with a retirement community). My*

> *family knows my medical background, and I know theirs…. My son is in North Port, but he is also involved. As soon as he finds out there is a doctor's appointment, he wants to know what it's for, what it's about.*

A Black female in FG 6 who had suffered from serious health problems said she and her daughters talked every day, "They're always calling to ask me how I'm doing." Another Black female in FG 6 who lived independently in overall good health said she and her daughter shared so much that her daughter made some of her doctor's appointments for her. She described a recent telephone conversation: "She says 'it's time for your check up.' I say, 'how do you know that' and she say, 'I'm looking right at it (on the calendar).'"

Others who had engaged in EOL discussions described relationships that were not as involved but were open and cooperative. A White female participant in FG 7 said that she made her own health care decisions, but added, "I make sure my family knows, but we're so much on the same page, it's a very easy and comfortable thing. I could ask them if I wanted input and I would listen to what they had to say.

A White male in FG 7 who lived alone and said he made his own health care decisions added that family members who lived out of town kept a close eye on him. "If they think there's something wrong, there's no hesitation on their part" to get involved.

Others who also described themselves as independent in their health care decision making emphasized that they sought the opinions of family members. An Hispanic female from FG 3 said, "I make my own decisions, but I listen to my kids, listen to my family because sometimes you make mistakes…The communication, I am reinforcing a lot. It is very important to me, the communication."

By contrast, several of the participants who had not engaged in EOL care conversations with family members described much less involved, even disconnected relationships. Commenting on involving others in her general health care discussions, a White female from FG 1 said, “They don’t really want to hear.” A White male participant from FG 1 said he talked to his wife though not his three sons about his general health care. “It’s just hard to discuss health,” he explained, suggesting that part of the problem was that two of his three children lived elsewhere.

> *It’s tough because nobody lives together like they used to. When I was younger it seemed like everybody lived in the same area. Today, California, New York, Texas. It makes it more difficult.*

Others who had not had a family EOL care discussion described relationships and communication patterns that could be characterized as unidirectional. A White female from FG 2 said, "Having worked in the health care profession, I get phone calls from everybody (seeking advice).” Another White female from FG 2 said, “People in the family are asking me, they’re asking me first” for advice before going to the doctor. Neither, however, relied on others to make their health care decisions. In a similar vein, a White male from FG 4 said the following:

> *I’ve been on my own pretty much since I was 18, travelling around a lot, doing things totally on my own. Don’t really have a lot of family around me, well here. There’s just a cousin, though I seldom see her. And so everything’s like on my own as far as making decisions and things. Also quite a few years ago, 40 years ago now, I got a license to be a licensed practical nurse, so I relied on my own medical knowledge. I had that. I’ve always made my own decisions. I’ve found I’m the best person to rely on.*

Other participants who had not had EOL care discussions described a similar self-reliance stemming from being on their own earlier in life. A Black female participant from FG 4 said the following concerning involving others in her general health care: “I’ve always been independent. You had to take care of yourself growing up. You had to fend for yourself….No one did everything for you.” Another Black female from this group explained that she was one of 18 children with an alcoholic mother, and that early on she learned "independency." An Hispanic participant from FG 3 described having only her partner to talk to because her son "is far."

A Black female from FG 4 related her reluctance to tell her children about anything concerning her future care. She said, "When you talk about it they’re like, 'Oh, mama, the doctor told you something? You dying? You sick? You got some new aches and pains?' I gotta go through 50 questions, saying no, no, no."

Theme 2: Being proactive regarding family involvement. Many of those who had engaged in EOL care discussions described ACP as a family obligation. As a Black female participant from FG 6 said, "I owe it to my family" to ensure they know what to do. A White female participant from FG 5 explained that her parents instilled in her the importance of being responsible, and that this entailed planning of all kinds, including multiple types of ACP.

Similarly, participants described the importance of choosing a responsible son or daughter to be their decision makers. A White male participant from FG 5 said the following about the choice of his youngest son:

> *We assessed each child. They all bring different things. We felt that (he) was the most reasonable and would act on our wishes not force his opinion on how he feels about it, because if you don’t have it in writing, it’s a mess. One child could say "I don’t want mom to have another surgery and the other is well, I think we should," and you’re stuck.*

He added that he and his wife took this son with them to the lawyer where they discussed and signed the couple's ADs, in order to ensure that he understood their EOL care wishes. A Black female participant from FG 6 described why she chose her oldest son.

> *My youngest son, I can't (pause), I don't feel real comfortable leaving him with that responsibility because of his wife. She's the type that just kind of does what she wants. And I want what I want.*

An Hispanic female from FG 3 who had engaged in multiple family EOL discussions described her choice of her oldest son. "I have three children and my kids know when I cannot decide they know perfectly what to do. The three of them are my kids, but the oldest is the one who decides. Maybe I am wrong but that is the way I raised them."

Participants from all the groups, those who had and had not engaged in EOL care discussions, brought up the problem of family members' reluctance to participate in such a discussion, in particular their children's reluctance. A typical comment came from an Hispanic male from FG 3, who described the following: "I spoke with (the children) a little bit and they told me 'don't do that, we don't like that....when that happens, we know what to do, let's talk about other things, we don't want to talk about that.'"

The participants who had engaged in discussions, however, took steps to make sure their children understood and would comply. As a Black female participant from FG 6 put it, "I just told my daughter, 'I'm not having it. This is what I want.' " A White female participant from FG 7 said she would "force" the topic on her children, who would never initiate the discussion, but would listen. "They don't add anything to it. But they listen."

For some the discussion followed creation of a written document. One Black female participant from FG 6 described the following encounter:

> *My sons, they didn't want to talk about it, especially the oldest one. I said 'That's fine. I'm writing it down. You don't have to talk about it. And all you have to do is follow the directions. If you follow these directions you'll be fine.' 'OK ma, I'll do that.'*

For several of those who had engaged in family discussions, their proactivity seemed to stem from an awareness of the consequences of family members not knowing one's wishes. A white female from FG7 who had engaged in extensive ACP discussions and written documents, said, "To me, you can make it a real gift for your family or it can be a terrible burden and they can have awful guilt about making these decisions but now knowing what you want ." Others who had engaged in family EOL care discussions mentioned the burden of not knowing a loved one's EOL care wishes, as exemplified by this comment from a Black female participant in FG 6. "We don't want to put that burden on our family, on our husbands, on our kids. We don't want to put that burden on them."

By contrast, many of those who had not talked to their family about their EOL care seemed unaware of the need to have an EOL care discussion. A male participant in FG 1 said that it had never occurred to him and his wife to talk about their EOL care wishes, even though she had heart problems: "We never thought about it….We never bring it up with our kids." Like those who had engaged in discussions, many faced their children's reluctance to talk, but they did not seem able to overcome it. Some worried about the conflict or emotion that it might provoke. A Black female from FG 4 said, "You're thinking that they're not going to agree with you….That they won't respect your wishes." A White female from this group interjected, "And they won't." In this same vein, an Hispanic female from FG 3 said she didn't want to cause her son any "worry."

Participants also minimized the importance of such discussions, saying that family members would know their wishes without being told. These comments represented a subtheme of deferred autonomy, exemplified by this comment from an Hispanic female participant from FG 3. “My son knows, they know that whatever they determine it is going to be OK.” Discussing her spouse, a Black female from FG 4 said she and had not talked specifically to him about her EOL care wishes, but she trusted him to make the right decision when the time came. “I’m confident he would know. He doesn’t know what I want. We haven’t really talked about it,” but if he needed to make an EOL care decision for her, “he would know.” A White female participant said she believed her son would take over as decision maker and the other children would go along. "Yeah, I think they would because they are far away and if they can't find us, they would automatically call him. So they do revert to him. I would think."

Theme 3: Knowledge of others’ EOL care wishes. Many of the participants who had engaged in EOL discussions with family members had learned about EOL matters through their involvement with their parents’ or others’ EOL decision-making. One White female from FG7 had seen her husband through a long illness, which ended with his decision to stop treatment. She said she harkened to this when she talked to her son.

> *Shortly after my husband died, we talked, and I said, "You know, Dad, I had to ask him things about what he wanted, what we should do, and, and it made it much easier for me, knowing that I was doing what he wanted. So we need to do the same thing so you will know what I want."*

A White female participant from FG 5 described having learned early in life how to be a caregiver to family members at the end of their lives, then to care for her husband:

> *My mother was ill when I was a teenager in school, so I have always had obligations. And then I helped my sister with her mother-in-law. She had Parkinson's and dementia, so I helped with her and I even helped my brother with his mother in law. And then my husband became ill....he had a cerebral hemorrhage and he got to the point where he wasn't doing too well and he had the last (stroke). There was no way I was going to put him on life support. Same with my mother. The doctor said "We can do this and she will live a little longer." I said "What about the quality of her life," and he said "It wouldn't change," and I said "Don't you dare."*

An Hispanic female in FG 3 who had engaged in EOL care discussions with her children described a pattern of EOL care discussions with her parents, saying the following:

> *Years ago we have talked in my house because we had good and bad experiences. I have seen negative experiences, but not in my house, thanks God. I had a good experience in my family, like when my mom (died), we did everything on time and we didn't have any bad situation. The same with my father. I want the same for me. I already told them what I want. Everybody knows how I want things done. I have talked to my family many times about this in a nice way, because I don't know for how long I will be clear in my mind and thanks God they never told me "don't talk about that."*

Some participants learned through a combination of experiences with others and with their parents. A Black female participant from FG 6 described working in a doctor's office and observing the experiences of other families who had not engaged in any ACP. She then helped her parents make plans, as she described:

> *"I saw so many who didn't have it. I didn't want to be like that. And I told my mom and we got that all straightened out....She didn't want to be on life support. You know. She*

> *had Alzheimer's near the end, but at the beginning what about 5-6 years before the Alzheimer's....she had all that."*

Interestingly a White male participant from FG 1 who said he had never before thought about having an EOL care talk with family said he was preparing to do so now because of two recent awareness-raising events. One was his mother's decision to forego treatment after a cancer diagnosis (which she met with every family member to explain) and his own heart attack.

By contrast, many of those who had not had family discussions said they never knew what their parents EOL care preferences. One Black female participant from FG4 said the following about her experience with her mother:

> *She got sick, I said "mama what's wrong?" Never did tell me. She had the 4th stage (lung cancer) and it was incurable....Our parents didn't do it to us (talk about ACP). Our grandparents didn't do it to them. For whatever dysfunctional reasons, a lot of us grew up in single-parent homes. A lot of us grew up in broken homes, alcoholic homes, abusive homes, whatever, and those issues never came up.*

A White female participant from FG 2 who had not talked to her family about her EOL care wishes described having to make decisions for her parents without knowing what they wanted. She said the following:

> *It's not like I ever had that conversation with (my mother), like "what do you want, what do you think you want, blah blah blah." I mean, I talked to my dad; he was like "whatever you have to do." He wanted nothing to do with the decisions. So it was left to me to make those decisions for them, and I did what I had to do.*

Another White female participant from FG2 who had not engaged in an EOL care discussion said that her mother refused to talk about death and left her with the decision.

> *So she, in other words, she herself didn't want to put herself there....I, I had struggled with it, do this, do that, your therapy, your this. (In the end) she says, "I'm not going to be here that much longer." She knew it was coming to an end. And that's when she said, she said "I know you'll make the right choices."*

A White female participant from FG 1, who had said she never thought about talking to her family about her EOL care wishes, described the difficult weeks leading up to her mother's death in another state and discord with her mother's doctor over her treatment.

> *My mom was in the hospital and they had to give her a feeding tube and my sister was the only one there in charge. She called me. I said "I'm against it." She called my brother. He was against it.... (The doctor) says, "Well there's no decision to be made. She has to be on the feeding tube. I can't give her medicine any other way." So she got the feeding tube. When she left hospital and went to a home they were trying to rehabilitate her and the nurse said to (my sister), "Your mother is not responding, we can reverse the feeding tube." So she had to call us all, because I was down here and they're up (north). So I said "You know how I feel." I was against it from the beginning and my brother was against it. So they reversed that feeding tube and told us that she would only make it a couple of weeks.*

Participants had lost other loved ones to extended illnesses without knowing their EOL care wishes. An Hispanic male in FG 3 who had not discussed his own EOL care wishes talked about losing his daughter. “She died last year with cancer but she always avoided the conversation….Nobody was able to talk to her about that.”

The participants in the non-discussion groups had other knowledge gaps, such as knowing the role of and how to name a health care proxy. Several posed questions concerning when and how to start an EOL care discussion, such as this from a White female in FG2: “How can you make those choices now when in 20 years things may be entirely different?” A Black female from FG4 said the following:

> *You hear about how important it is to go to the doctor and talk about doing things to be healthy, but the issue about the living will and the other things, that part is just not discussed. You don’t hear about it. The media talks about going to the doctor and different medicines, but they don’t talk about preparing for the end.*

One participant, a Black female from FG 4, brought up the need for doctors to link people with their families to have EOL care discussions. She said the following:

> *It would need to be a doctor and a doctor I trust or course. It has to be very serious, and the question I would have for the doctor is, "if you can explain to me, I’m having problems explaining to my children. Could you take time," which they never can, "but can you take time to explain this to me so I can explain it to my children, because I’m having problems explaining to them.*

When asked about the role of doctors and other health care providers concerning ACP, an Hispanic female from FG 3 said they should provide ACP information in their offices. "I believe they should unite to facilitate the people...and this is what will help us to avoid problems when the time comes."

However, a White female participant from FG 2 was strongly against doctors’ initiating or being involved in a family discussion in any way other than providing information about a person's condition when they are seriously ill. She said the following:

> *Is that a conversation that I would want with my doctor? That is the person I go to to help take care of me. He's not my BFF. He is not someone that is a family member. Does*

> *his decision or his assistance in this situation, could it be of help? Maybe to understand what your situation is. But for him to be the encourager to say "Hey go home and talk to your kids about end of life choices." No.*

Integrated Results

Family interdependence. Analysis of a matrix combining the quantitative and qualitative data showed high concordance between the two sets of results concerning family interdependence and EOL care discussions. Of those whose quantitative results showed they had engaged in EOL care discussions (*n*=17), all but 3 participants described close and/or open communication with family members concerning their general health care. Among the 3 exceptions, one said that her family members were out of the country and she tried not to worry them with her health problems when they talked, but she talked intimately with her friends. Another said that she was having difficulty talking with her son about her worsening health, but that she was close to her son's partner and confided in him.

Our integrated analysis included another quantitative measure. That was a questionnaire item that measured the extent to which participants involved family members or close friends in their general health care decision-making. Of the 17 participants who had engaged in EOL care discussions, all but four indicated in the questionnaires that they made decisions cooperatively or consulted others before making health care decisions. The focus groups responses shed light on these four by showing that while they considered themselves independent decision makers, they all took steps to ensure that family members understood their health care circumstances and their EOL care preferences.

Of those whose questionnaires indicated they had not engaged in EOL care discussions (*n*=19), all but two described relationships that involved barriers to discussing general health care. Those barriers varied, but they all involved a general disconnection, including apprehension related to past discord, a need to be self-reliant, to not reveal illness or weakness, or a sense that others did not want to know. However, discordance emerged when comparing the questionnaire results concerning family involvement in health care with focus group comments of these participants. Of the 19, nine described problematic family relationships, but reported on the questionnaires higher levels of family health care involvement. Analysis of these results showed that in six cases, the participants were Black or Hispanic. This suggests that the effect of family dynamics on EOL care discussions is different for minority families compared with White non-Hispanic families.

Proactive family involvement. The results showed a high level of concordance between the quantitative and qualitative data concerning proactivity related to family involvement in EOL care discussions. Of those who had engaged in EOL care discussions, each displayed a moderate to high level of proactivity in the focus groups. All but one showed in their comments that they were aware of either the chances that they would need EOL care and/or the negative consequences of family members not knowing one's EOL care wishes. Several talked about their children's reluctance to have the discussion but described responding with firmness and/or an involved, proactive attitude toward communication.

Among the participants who had not engaged in EOL care discussions, all but 1 were passive or resistant in some way. Several talked about never having considered or seen the need for such a discussion, some saying it was necessary only if one were seriously ill or near death. Some said it would be too painful. Like those who had engaged in EOL care discussions, some said that their children didn't want to participate, but unlike those in the other groups, they accepted the refusal.

The quantitative data also included whether participants had living wills and health care proxies, which would indicate a level of proactivity. Concordance here was mixed. As expected the majority of those who did not have living wills (as indicated on the questionnaires) expressed a lack of awareness concerning EOL matters or an aversion to the subject (14 of 22). However, six of those who lacked living wills had engaged in EOL care discussions and talked in the focus groups about the importance of communicating one's preferences. All six of these participants were either Black (*n*=3) or Hispanic (*n*=2). One of the Black participants addressed the issue, saying that it was easier for her to talk about her preferences than to write them down, though she added that she was "working on it." She was waiting for her son to come for a visit to help her. Another black participant who did have a living will suggested that ACP was not as common for Black people as for others, that many didn't "believe in it." Another potential explanation is that some of these participants did not know what a living will was. Two of them who indicated on their questionnaires that they did not have living wills discussed in focus groups having written down their wishes, and these two did have health care proxies.

Knowledge of others' wishes. The quantitative and qualitative data showed some concordance concerning knowledge of others' wishes and EOL care discussions. Among those who had engaged in EOL care discussions, 11 talked about experiences with parents or other close relatives who died, and all but one of the 11 clearly knew their wishes when the death occurred. Several discussed what they learned through the process and the value of communication concerning dying.

The story was different for those who had not engaged in EOL care discussions with family. Most talked about experiences with loved ones who had died (16 of 19), but only two expressed having known the loved ones' wishes at the time. In both cases it was their mothers. In one, the participant's mother reversed a previously expressed desire to forego care and "fought" her death. In the other, the death occurred under hospice care, and interestingly, this participant seemed to be on the verge of having an EOL conversation with his children.

There was little concordance on the related issue of doctors helping people understand ACP and how to discuss it with their families. Those who had talked to their family members about their EOL care wishes were mixed in their assessments of doctors' involvement. They all believed that doctors had a role, and most (9 of the 17) had also talked to doctors about their wishes). However, 8 of the 17 expressed doubtful or mixed views, primarily concerning doctors' willingness to be involved in these discussions or the success they would have with those who are resistant to such discussions.

Those who had not discussed EOL care preferences with family were also mixed in their views concerning doctors' roles in the discussion, with 8 of the 19 expressing doubts or unsatisfactory experiences of some kind, including feelings of distrust. It is notable that all of the Hispanic participants expressed generally positive views of doctors helping people with the EOL care discussion and ACP.

Research questions. Concerning the first of our three research questions, these results show that there was an association between family relationships and the occurrence of family EOL care discussions. It was evident in the quantitative (questionnaire) results showing a significant association between greater involvement with family in general health care decision-making and higher discussion stage.

Concerning our second question, the quantitative and qualitative results also showed distinct differences between those who had and had not engaged in family EOL care discussions. The interactions of those who had engaged in discussions were generally more cooperative and interdependent, while those who had not had such discussions faced barriers that interfered with communication.

Those who had engaged in EOL care discussions also were more proactive, particularly concerning children's reluctance to talk, and they were more aware of the consequences of not having EOL plans in place. In addition, they were more likely to have had positive EOL discussion models in their parents and others who shared with them their preferences before they died.

Concerning our third question on role of race or ethnicity, the unadjusted quantitative results suggested that Hispanics were significantly less likely than non-Hispanics to engage in such EOL care discussion, though the differences were not significant in the adjusted analysis. The qualitative data suggested more complex family relationships among some Hispanics and Blacks. Many of those who had not engaged in EOL care discussions described conflict or communication barriers, nevertheless they saw a role for family members in their health care decision-making. In addition, among those who had engaged in EOL care discussions, there seemed to be a reluctance to take other important ACP steps, such as completing a living will.

Discussion

This study aimed to quantitatively and qualitatively explore the factors related with having an EOL care discussion with family members, using a racially and ethnically diverse sample of older adults. The analyses together showed that those with closer family relationships were more likely to have engaged in EOL care discussions. Also, relationships were weaker or more difficult among those who had not engaged in family EOL care discussions. These findings align with recent research showing that better overall family functioning increases one's odds of discussing EOL care wishes with a loved one (Boerner et al., 2013). They also support research indicating that long-standing family dynamics in decision making, positive and negative, play out in EOL care planning (van Eechoud et al., 2014). The present results further support the need to involve family members in both general health care and EOL care decision making, and to consider family difficulties before the later stages of an illness, after which ACP barriers are likely to worsen.

The results also showed that there are racial and ethnic differences in family relationships and EOL care discussions, such that increasing EOL care discussions among minority families may require efforts aimed at families as well as individuals. This is consistent with research showing the desire for family-centered decision-making among Blacks and Hispanics (Bullock, 2010; Kelley, Wenger, & Sarkisian, 2010; Kwak & Haley, 2005). Our study suggests this may be a more of an issue for Hispanics than for Blacks. We found no significant EOL discussion differences between Black and White families, but in the uncontrolled analyses Hispanics were significantly less likely than non-Hispanics to engage in discussions.

The combined results also show the differences in how individuals address their children's reluctance to discuss their EOL care preferences. Those who had engaged in discussions were more proactive overall, planning for a range of life events. This included taking multiple ACP steps, completing living wills and naming health care proxies. Several also discussed being firm with their children concerning their wishes, some highlighting their decisions to choose one child as decision maker.

Many of those who had not engaged in the discussion had not overcome their children's reluctance to participate. This ties to the family health care involvement theme in that lack of communication at an earlier phase of an illness would likely complicate any later discussions. It also seemed that those who had not talked about their EOL care wishes with family members had not thought through the consequences as those in the other groups had.

Many of those who had engaged in family discussions and other ACP recounted experiences with their parents' EOL decision making and the knowledge they gained in the process. This is consistent with previous research (Carr, 2012). By comparison, our results also showed that many who had not engaged in EOL care discussions had witnessed the "bad" deaths of loved ones, also consistent with Carr's 2012 research. This shows the intergenerational impact of ACP. While both Black and White participants in the non-discussion groups lacked this knowledge, this theme seemed more prevalent among the Hispanic participants. Only one highlighted her knowledge of her parents' EOL wishes and the impression it made on her regarding EOL care discussions.

Our qualitative findings also suggest a role for doctors, as other research has (e.g., Carr, 2012; Su et al., 2014). Among those who had not engaged in family EOL care discussions, some said they would welcome a doctor's help to understand more about their own health and ACP, and to initiate a family discussion concerning their EOL care preferences. However, this is a delicate task, with results suggesting that many people may be resistant to change. More research is needed into the factors and characteristics that give rise to such resistance related to ACP and how doctors could help patients facing their own or others' resistance. This is especially important considering that doctors are now able to receive Medicare reimbursement for ACP consultations. It is too soon to know how many doctors are having these consultations, as the benefit has been available only since January 2016. However, it is hoped that research findings will lead to a better understanding of the factors that promote ACP for some but stand as a barrier for others.

Limitations

This study has some limitations. The quantitative sample was relatively small for a study examining multiple groups. Participation was voluntary, so it may have left out many who were averse to EOL discussions. Being cross-sectional it limited our ability to see causal relationships. Further, it did not measure all aspects of the TTM. Further research is needed to understand the processes that could lead to increased family EOL care discussions, particularly processes that relate to personality factors, which may be less susceptible to change or require approaches that take personality into account.

The qualitative sample was limited to those who agreed to participate in the focus groups and may have left out those who are reluctant to discuss family relationships. Also, the groups were intended to be divided between those who had engaged in EOL care discussions and those who had not. However, some groups included both. It is possible that the opinions of those who had talked to family influenced the opinions of those who had not. The Spanish speakers in our focus group sample came from one community and likely did not encompass the diversity of Spanish speakers in Florida and the United States. Furthermore, we had no predominantly English speaking Hispanics, whose responses may have differed from those of the Spanish speakers.

Because of where we recruited our sample was relatively healthy and well educated. Many participants were in their 80s and 90s and reported multiple chronic health conditions, but our results may have been different for older adults who were sicker and with less education.

Conclusion

Despite these limitations, our findings suggest that there is potential for increasing the occurrence of such family EOL care discussions and ACP overall by understanding more about the family relationships and attitudes that influence these differences. This knowledge could be incorporated into an assessment of how to influence behavior change related to engaging in EOL discussions with family members, in keeping with the TTM. Doctors have a role in this process because of their ability to link patients and their families and the knowledge they have to share - about health in general, their patients' health and prognosis, and how to engage in ACP.

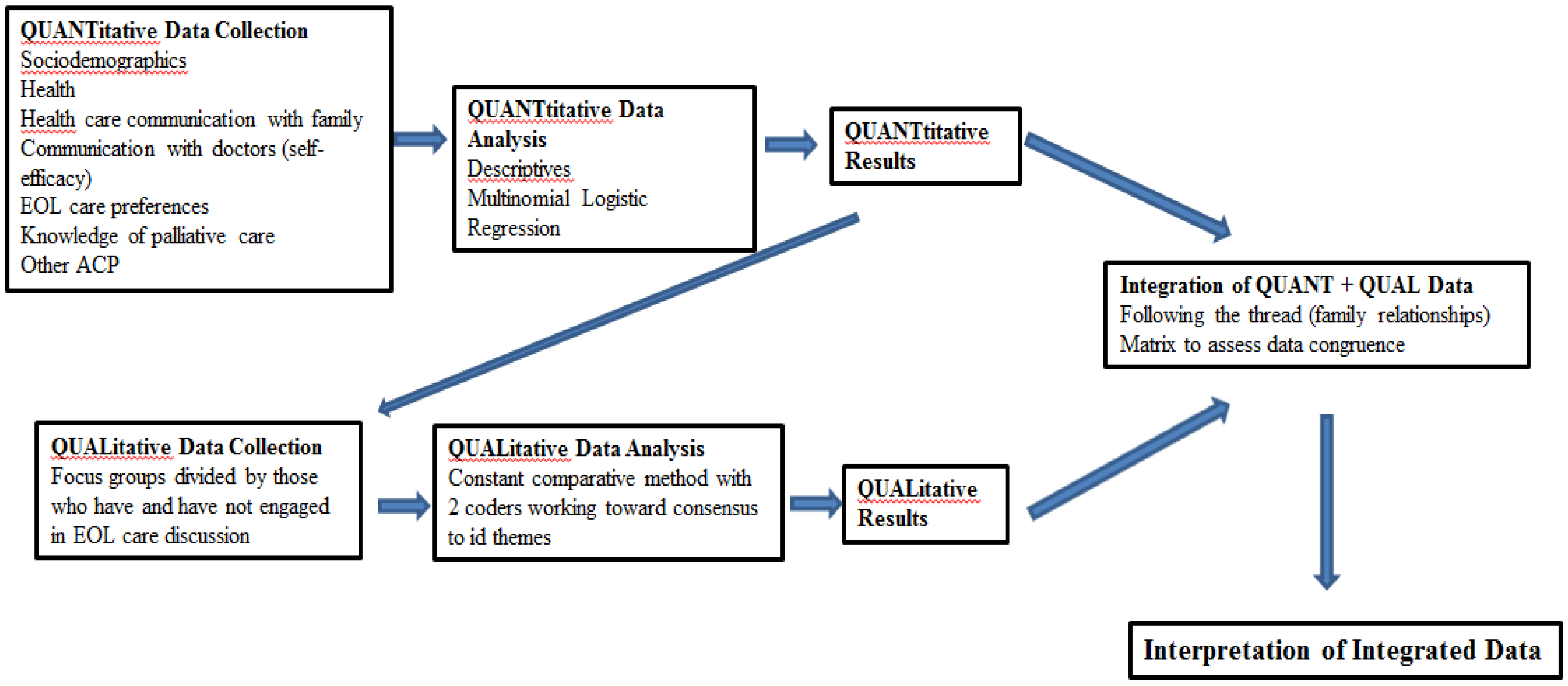


Figure 2. Sequential explanatory mixed methods design with integration

CHAPTER FIVE:

CONCLUDING REMARKS

Despite advancements in developing and promoting written ADs, research shows that many families still face difficulties at EOL, largely because those who are surrogate decision-makers do not know that to do to honor their loved one's wishes. This problem may only worsen with the rising numbers of adults with complicating chronic illnesses at EOL. This highlights the importance of understanding whether families engage in these discussions and how to increase the occurrence of discussions – as supplements to ADs. This dissertation consisted of three studies of the occurrence of family EOL care discussions, the findings of which are summarized as follows:

The first study used a racially and ethnically diverse sample of older adults from West Central Florida (*N*=364) who completed a questionnaire that measured their "stage of change" to engage in family EOL care discussions and a range of other factors. The stage approach was based on the TTM, which proposes that people are at different stages (or levels) of readiness to engage in a behavior, and that any effort to change behavior needs to be adapted to the individual's readiness stage. It focused on the question of whether there were significant discussion-stage differences by race or ethnicity, finding that in uncontrolled analysis there were for Hispanics. However, these differences were no longer significant after covariate adjustment. The results did, however, show significant associations between discussion stage and higher levels of several other factors - the extent to which individuals involved family members in general health care decisions; their ability to communicate with their doctors; knowledge of whether they would want life-supporting treatment if they were physical and mentally incapacitated; having talked to a doctor about their EOL care wishes; and having named a health care proxy. These results pointed to key areas of focus for efforts to increase the occurrence of EOL care discussions.

The second study added to these findings with a qualitative analysis using racially and ethnically diverse focus groups (*n*=36) drawn from the first study sample. Groups were segregated based on whether the participants had or had not engaged in an EOL care discussion with family members. Results showed distinct differences between these two groups in several areas related to the ACP process Those who had engaged in discussions were more proactive overall, including in ACP; more likely to accept the realities of aging and death; more able to deal with their children's reluctance to discuss EOL matters; and had more knowledge of ACP, largely it seemed based on experiences with family members. There were, however, differences within the groups in their ACP behaviors (e.g. not all of those who had engaged in discussions had completed living wills, including some Black and Hispanic participants). It was notable that several of those who had not engaged in EOL care discussions seemed to be on the verge of taking further ACP steps, in support of the TTM and the use of stage knowledge to develop interventions. However, it was also clear from the focus groups that some people are resistant to the idea of any ACP, associating it negatively with illness and death. Any intervention would have to deal carefully with these barriers.

The quantitative and qualitative results were mixed in the third study to focus on family dynamics, which studies show influences family engagement in EOL care discussions. It showed that those who engage in discussions have more interconnected relationships in general. Results overlapped with the second study to highlight how proactivity enables some to overcome their children's objections to talking about EOL matters. It also revealed the importance of people knowing their own parents' EOL care wishes and the consequences of having to make decisions without that knowledge. Racial and ethnic differences emerged somewhat more prominently in this study than in the other two, with the indication that many of the Black and Hispanic participants who had not engaged in EOL care discussions maintained close family ties. This was not the case with many of the White participants in the non-discussion groups, who seemed more disconnected from their families. This suggests that efforts to increase the occurrence of EOL discussions and other ACP should take into account the role of Black and Hispanic families, a finding that aligns with other research.

All three studies pointed to the role that doctors and other health care professionals can play overall in ACP and the family EOL care discussion. This is particularly important with the new Medicare benefit that will pay for ACP consultations, which went into effect in January 2016. The results suggested that doctors hold a unique position in their ability to provide patients with knowledge and support to engage in EOL discussions and other ACP. The quantitative findings, however, suggested that this task will be complicated by individuals' varied levels of discussion readiness, particularly the resistance of some. Participants' experiences with doctors also suggest that doctors themselves may have difficulty undertaking these consultations.

Limitations

Several study limitations should be noted. The quantitative analysis was cross-sectional, limiting our ability to see causal relationships. Also it used multinomial logistic regression, involving multiple groups, and therefore would have performed more effectively with a larger sample. Another limitation is that it did not measure all the constructs of the TTM, focusing mostly on stages of change. Our study did include health self-efficacy, but this measure was part of a larger measure of ACP (we could not use other elements of this larger measure because they would have duplicated measures we were already using). Further, our measure did not specifically measure self-efficacy for having an EOL care discussion. Our quantitative analysis also would have benefited from some measures of personality that seem to influence ACP.

The qualitative analysis was designed to compare those who had and had not engaged in EOL care discussions, but some groups included both. It is possible that comments from some of those who had engaged in discussions influenced the comments of the others. Also our sample was relatively healthy and well educated and our results may have been different for older adults with more serious illnesses and less education. Furthermore, we did not use member checking to ensure that the themes from the study results were congruent with participants' experiences. Facilitators did, however, summarize the results of the groups with participants at the focus group meetings.

Future Research

These studies point toward several opportunities for future research. First we need to understand more about the differences between those who are on the verge of engaging in ACP and those who are resistant. It is possible that relatively uncomplicated interventions, such as providing usable ACP documents, videos, or other instructional material, could move them into action, as proposed by the TTM. Related to this, there are multiple tools available, and more research is needed on their effectiveness and how to distribute those that are the most effective. Few participants of the focus groups were aware of two of the more common tools (the Conversation Project Starter Kit [which is provided in multiple languages] and Five Wishes)

Other techniques or tools may be required for those who are resistant, and these would have to be more carefully administered, given the emotions that seem to be related to the resistance of some. It is important to reach this population because our findings suggest that EOL care discussions and ACP are intergenerational behaviors, so those who do not communicate with their children and other loved ones are likely to set their children up for similar communication problems with their loved ones.

There are also opportunities for further work toward "normalizing" the EOL care discussion, as suggested by the IOM's "Dying in America." This would involve finding ways to reach people who are healthy and far from conceiving of the end of their lives. This is important because many of them will be called on to be surrogate decisions makers. Furthermore, our results show that EOL care discussions are often thwarted by adult children who will not engage in EOL discussions with their parents. This may be more of an issue in Hispanic families, which warrants further research. Finding ways to open the death and dying discussion between generations could go far toward reducing some barriers to family EOL care discussions and ACP overall.

Finally, a great deal of research could be conducted concerning the role of doctors and other health care providers in EOL care discussions and ACP. As the Medicare ACP consultation benefit becomes more widely known and used, we need to understand what kind of effect it is having, including the elements of effective consultations. This could be accomplished through surveys with doctors and other providers who are conducting these consultations, and surveys with patients. In addition, the present study suggests that approaches need to be adapted to the discussion stage of the patient, and its results could be used to develop stage-based approaches.

At the same time, however, it would be important to work out the logistics of such an approach, to answer the question, for instance, of how to efficiently determine a patients’ discussion stage.

Much of this depends on the health care providers’ desire and willingness to engage patients concerning ACP. The current study suggests that in the absence of the Medicare benefit, they do not wish to have these discussions with patients. Simply offering this benefit will not eliminate this reluctance, which is rooted in many ways in the culture of health care. More needs to be learned about health care providers’ attitudes toward “normalizing” the death and dying conversation and their role in that process.

REFERENCES

Abadir, P. M., Finucane, T. E., & McNabney, M. K. (2011). When doctors and daughters disagree: Twenty-two days and two blinks of an eye. *Journal of the American Geriatrics Society*, *59*(12), 2337-2340.

Abba, K., Byrne, P., Horton, S., & Lloyd-Williams, M. (2013). Interventions to encourage discussion of end-of-life preferences between members of the general population and the people closest to them-a systematic literature review. *BMC Palliative Care*, *12*(40), 1-12. doi: 10.1186/1472-684X-12-40

Bischoff, K. E., Sudore, R., Miao, Y., Boscardin, W. J., & Smith, A. K. (2013). Advance care planning and the quality of end-of-life care in older adults. *Journal of the American Geriatrics Society, 61*(2), 209-214. doi: 10.1111/jgs.12105

Boerner, K., Carr, D., & Moorman, S. (2013). Family relationships and advance care planning: Do supportive and critical relations encourage or hinder planning? *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 68 (2), 246-256.doi: 10.1093/geronb/gbs161.

Brown, B. A. (2003). The history of advance directives A literature review. *Journal of Gerontological Nursing*, *29*(9), 4-9. doi: 10.3928/0098-9134-20030901-04

Bullock, K. (2010). The influence of culture on end-of-life decision making. *Journal of Social Work in End-of-Life and Palliative Care, 7*(1), 83-98.

Butler, M., Ratner, E., McCreedy, E., Shippee, N., & Kane, R.L. (2014). Decision aids for advance care planning: An overview of the state of the science. *Annals of Internal Medicine, 161*(6), 408-418. doi:10.7326/M14-0644

Carr, D. (2011). Racial differences in end-of-life planning: Why don't Blacks and Latinos prepare for the inevitable? *Omega, 62*(1), 1-20. doi: 10.2190/OM.63.1.a

Carr, D. (2012). “I Don’t Want to Die Like That…”: The impact of significant others’ death quality on advance care planning. *The Gerontologist*, *52*(6), 770-781. doi: 10.1093/geront/gns051

Carr, D., & Khodyakov, D. (2007). End-of-life health care planning among young-old adults: An assessment of psychosocial influences. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences,62*(2), S135-S141. doi:10.1093/ geronb/62.2.S135

Carr, D., Moorman, S. M., & Boerner, K. (2013). End-of-life planning in a family context: Does relationship quality affect whether (and with whom) older adults plan?. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, gbt034.

Chew, L. D., Griffin, J. M., Partin, M. R., Noorbaloochi, S., Grill, J. P., Snyder, A., ... & VanRyn, M. (2008). Validation of screening questions for limited health literacy in a large VA outpatient population. *Journal of general internal medicine*, *23*(5), 561-566. doi: 10.1007/s11606-008-0520-5

Chiu, C., Feuz, M. A., McMahan, R. D., Miao, Y., & Sudore, R. L. (2016). “Doctor, make my decisions”: Decision control preferences, advance care planning, and satisfaction with communication among diverse older adults. *Journal of Pain and Symptom Management*, *51*(1), 33-40. doiI: 10.1016/j.jpainsymman.2015.07.018

Conner, N. E., & Chase, S. K. (2014). Decisions and caregiving end of life among blacks from the perspective of informal caregivers and decision makers. *American Journal of Hospice and Palliative Medicine*, doi: 1049909114529013.

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks, CA: Sage.

Cruz-Oliver, D.M., Talamantes, M., & Sanchez-Reilly, S. (2013). What evidence is available on end-of-life (EOL) care and Latino elders. *American Journal Hospice and Palliative Medicine, 31*(1), 87-97.

Daaleman, T. P., Emmett, C. P., Dobbs, D. & Williams, S. W. (2008). An exploratory study of advance care planning in seriously ill African American elders. *Journal of the National Medical Association, 100*(12), 1457-1462.

DiClemente, C. C., J. O. Prochaska, and M. Gibertini. (1985). Self-efficacy and the stages of self-change of smoking. *Cognitive Therapy and Research 9*(2), 181–200. doi:10.1007/BF01204849

Dillon, P. J., Roscoe, L. A., & Jenkins, J. J. . (2012). African Americans and decisions about hospice care: implications for health message design. *Howard Journal of Communications, 23*(2), 175-194.

Dobbs, D, Emmett, C. P., Hammarth, A., & Daaleman, T. P. (2012). Religiosity and death attitudes and engagement of advance care planning among chronically ill older adults. *Research on Aging, 34*(113-130). doi:10.1177/0164027511423259

Ernecoff, N. C., Keane, C. R., & Albert, S. M. (2016). Health behavior change in advance care planning: an agent-based model. *BMC Public Health, 16*(1). doi: 10.1186/s12889-016-2872-9

Fried, T. R., Bullock, K., Iannone, L., & O'Leary, J. R. (2009). Understanding advance care planning as a process of health behavior change. *Journal of the American Geriatrics Society, 57*(9), 1547-1555. doi: 10.1111/j.1532-5415.2009.02396.x

Fried, T. R., Redding, C. A., Robbins, M. L., Paiva, A., O'Leary, J. R., & Iannone, L. (2010). Stages of change for the component behaviors of advance care planning. *Journal of the American Geriatrics Society, 58*(12), 2329-2336. doi: 10.1111/j.1532-5415.2010.03184.x

Fried, T. R., Redding, C. A., Robbins, M. L., Paiva, A., O'Leary, J. R., & Iannone, L. (2012). Promoting advance care planning as health behavior change: Development of scales to assess decisional balance, medical and religious beliefs, and processes of change. *Patient Education and Counseling, 86*(1), 25-32. doi:10.1016/j.pec.2011.04.035

Garrido, M.M., Leventhal, H., & Carr, D. (2012). Pathways from religion to advance care planning: Beliefs about control over length of life and end-of-life values. *The Gerontologist*, *53*(5), 801-816. doi:10.1093/geront/gns128

Glass, A. P., & Nahapetyan, L. . (2008). Discussions by elders and adult children about end-of-life preparation and preferences. *Preventing Chronic Disease*, *5*(1), 1-8.

Greene, J. C., & McClintock, C. (1985). Triangulation in evaluation: Design and analysis issues. *Evaluation Review*, *9*, 523–545.

Hawkins, N.A., Ditto, P. H., Danks, J. H., & Smucker, W. D. (2005). Micromanaging death: Process preferences, values, and goals in end-of-life medical decision making. *The Gerontologist*, *45*(1), 107-117.

Institute of Medicine (IOM). (2014). Dying in America: Improving quality and honoring individual preferences near the end of life. Washington, D.C: The National Academies Press.

Kasper, J.D., & Freedman, V.A. (2015). *National Health and Aging Trends Study user guide: Rounds 1, 2, 3 & 4 final release*. Baltimore, MD: Johns Hopkins University School of Public Health.

Kavalieratos, D., Ernecoff, N. C., Keim-Malpass, J., & Degenholtz, H. B. (2015). Knowledge, attitudes, and preferences of healthy young adults regarding advance care planning: a focus group study of university students in Pittsburgh, USA. *BMC Public Health*, *15*(1), 1-7. doi: 10.1186/s12889-015-1575-y

Keary, S., & Moorman, S. M. (2015). Patient–Physician End-of-Life Discussions in the Routine Care of Medicare Beneficiaries. *Journal of Aging and Health*, *27*(6), 983-1002. doi:10.1177/0898264315569458

Kelley, A. S., Wenger, N. S., & Sarkisian, C. A. (2010). Opiniones: End-of-Life Care Preferences and Planning of Older Latinos. *Journal of the American Geriatrics Society, 58*(6), 1109-1116. doi**:** 10.1111/j.1532-5415.2010.02853.x

Kramer, B. J., & Boelk, A. Z. (2015). Correlates and predictors of conflict at the end of life among families enrolled in hospice. *Journal of pain and symptom management*, *50*(2), 155-162. doi:10.1016/j.jpainsymman.2015.02.026

Kwak, J., & Haley, W. E. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist*, *45*(5), 634-641. doi: 10.1093/geront/45.5.634

Lee, J. J., Long, A. C., Curtis, J. R., & Engelberg, R. A. (2016). The influence of race/ethnicity and education on family ratings of the quality of dying in the ICU. *Journal of Pain and Symptom Management*, *51*(1), 9-16. doi: 10.1016/j.jpainsymman.2015.08.008

Levesque, D. A., Cummins, C. O., Prochaska, J. M., & Prochaska, J. O. (2006). Stage of change for making an informed decision about Medicare health plans. *Health Services Research*, *41*(4p1), 1372-1391. doi: 10.1111/j.1475-6773.2006.00547.x

Lin, I. F., & Wu, H. S. (2014). Activity limitations, use of assistive devices or personal help, and well-being: Variation by education. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*,*69*(Suppl 1), S16-S25. doi: 10.1093/geronb/gbu115

Loggers, E. T., Maciejewski, P. K., Paulk, E., DeSanto-Madeya, S., Nilsson, M., Viswanath, K., ... & Block, S. (2009). Racial differences in predictors of intensive end-of-life care in patients with advanced cancer. *Journal of Clinical Oncology*, *27*(33), 5559-5564. doi:10.1200/JCO.2009.22.4733

McMahan, R. D., Knight, S. J., Fried, T. R., & Sudore, R. L. (2013). Advance care planning beyond advance directives: perspectives from patients and surrogates. *Journal of Pain and Symptom Management*,, *46*(3), 355-365. doi: 10.1016/j.jpainsymman.2012.09.006

Meghani, S. H., & Hinds, P. S. (2015). Policy brief: The Institute of Medicine report Dying in America: Improving quality and honoring individual preferences near the end of life. *Nursing outlook*, *63*(1), 51-59. http://dx.doi.org/10.1016/j.outlook.2014.11.007

Moorman, S. M., & Inoue, M. (2012). Persistent problems in end-of-life planning among young- and middle-aged American couples. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, , *68*(1), 97-106. doi: 10.1093/geronb/gbs103

Moran-Ellis, J., Alexander, V. D., Cronin, A., Dickinson, M., Fielding, J., Sleney, J., & Thomas, H. (2006). Triangulation and integration: processes, claims and implications. *Qualitative Research*, *6*(1), 45-59. doi: 10.1177/1468794106058870

O'Cathain, A., Murphy, E., & Nicholl, J. (2010). Three techniques for integrating data in mixed methods studies. BMJ, 341. doi:10.1136/bmj.c4587

Oulton, J., Rhodes, S. M., Howe, C., Fain, M. J., & Mohler, M. J. (2015). Advance directives for older adults in the emergency department: a systematic review. *Journal of Palliative Medicine*, *18*(6), 500-505. doi:10.1089/jpm.2014.0368

Pearlman, R.A., Cole, W.G., Patrick, D.L., Starks, H.E., & Cain, K.C. (1995). Advance care planning: Eliciting patient preferences for life-sustaining treatment. *Patient Education and Counseling*, *26*(1), 353-361. doi:.10.1016/0738-3991(95)00739-M

Pearlman, R.A., Starks, H.E., Cain, K.C., & Cole, W.G. (2005). Improvements in advance care planning in the Veterans Affairs system. *Archives of Internal Medicine*, *165*(6), 667-674.

Pew Research Center, Religion & Public Life Project. (2013). Views on end-of-life medical treatments. Retrieved from http://www.pewforum.org/2013/11/21/views-on-end-of-lifemedical-treatments

Prochaska, J. O., DiClemente, C. C. & Norcross, J. C. (1992). In search of how people change. *American Psychologist*, *47*(9), 1102-1114. doi:10.1037/0003-066X.47.9.1102

Prochaska, J.O., Redding, C. A., & Evers, K. (2008). The transtheoretical model and stages of change. In K. Glanz, B. K. Rimer & K. V. Viswanath (Eds.), *Health Behavior and Health Education: Theory, Research, and Practice* (4th ed., pp. 170-222). San Francisco, CA: Jossey-Bass.

Ramsaroop, S. D., Reid, M. C., & Adelman, R. D. (2007). Completing an advance directive in the primary care setting: What do we need for success? *Journal of the American Geriatrics Society, 55*(2), 277-283. doi: 10.1111/j.1532-5415.2007.01065.x

Sanders, J. J., Robinson, M. T., & Block, S. D. (2016). Factors impacting advance care planning among African Americans: results of a systematic integrated review. *Journal of Palliative Medicine*, *19*(2), 202-227. doi:10.1089/jpm.2015.0325

Schenker, Y., Crowley-Matoka, M., Dohan, D., Tiver, G. A., Arnold, R. M., & White, D. B. . (2012). I don’t want to be the one saying ‘we should just let him die’: Intrapersonal tensions experienced by surrogate decision makers in the ICU. *Journal of General Internal Medicine, 27*(12), 1657-1665. doi: 10.1007/s11606-012-2129-y

Schickedanz, A. D., Schillinger, D., Landefeld, C. S., Knight, S. J., Williams, B. A., & Sudore, R. L. (2009). A clinical framework for improving the advance care planning process: Start with patients' self-identified barriers. *Journal of the American Geriatrics Society, 51*(1), 31-39. doi: 10.1111/j.1532-5415.2008.02093.x

Schulman-Green, D., Ercolano, E., Jeon, S., & Dixon, J. (2012). Validation of the knowledge of care options instrument to measure knowledge of curative, palliative, and hospice care. *Journal of Palliative Medicine, 15*(10), 1091-1099. doi: 10.1089/jpm.2011.0514

Shalowitz, D.I., Garrett-Mayer, E., & Wendler, D. (2006). The accuracy of surrogate decision makers: A systematic review. *Archives of Internal Medicine, 166*(5), 493-497. doi:10.1001/archinte.166.5.493

Sharp, S., Carr, D., & Macdonald, C. (2012). Religion and end-of-life treatment preferences: Assessing the effects of religious denomination and beliefs. *Social Forces*, *91*(1), 275-298. doi: 10.1093/sf/sos061

Silveira, M. J., Kim, S. Y., & Langa, K. M. (2010). Advance directives and outcomes of surrogate decision making before death. *New England Journal of Medicine*, *362*(13), 1211-1218. doi: 10.1056/NEJMsa0907901

Silveira, M. J., Wiitala, W., & Piette, J. . (2014). Advance directive completion by elderly Americans: A decade of change. *Journal of the American Geriatrics Society, 62*(4), 706-710. doi: 10.1111/jgs.12736

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage

Su, C. T., McMahan, R. D., Williams, B. A., Sharma, R. K., & Sudore, R. L. (2014). Family Matters: Effects of Birth Order, Culture, and Family Dynamics on Surrogate Decision-Making. *Journal of the American Geriatrics Society*,*62*(1), 175-182. doi: 10.1111/jgs.12610

Sudore, R. L., & Fried, T.R. (2010). Redefining the "planning" in advance care planning: Preparing for end-of-life decision making. *Annals of Internal Medicine, 153*(4), 256-261. doi: 10.1059/0003-4819-153-4-201008170-00008

Sudore, R. L., Knight, S. J., McMahan, R. D., Feuz, M., Farrell, D., Miao, Y., & Barnes, D. E. (2014). A novel website to prepare diverse older adults for decision-making and advance care planning: a pilot study. *Journal of pain and symptom management*, *47*(4), 674-686. http://dx.doi.org/10.1016/j.jpainsymman.2013.05.023

Sudore, R. L., Schickedanz, A. D., Landefeld, C. S., Williams, B. A., Lindquist, K., Pantilat, S.Z., & Schillinger, D. (2008). Engagement in multiple steps of the advance care planning process: A descriptive study of diverse older adults. *Journal of the American Geriatrics Society, 56*(6), 1006-1013. doi: 10.1111/j.1532-5415.2008.01701.x

Teno, J. M., Gruneir, A., Schwartz, Z., Nanda, A., & Wetle, T. (2007). Association between advance directives and quality of end-of-life care: A national study. *Journal of the American Geriatrics Society, 55*(2), 189-194. doi: 10.1111/j.1532-5415.2007.01045.x

Teno, J.M., Gozalo, P.L, Bynum, J.P., Leland, N.E., Miller, S.C., Morden, N. E., . . . Mor, V. . (2013). Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA, 309*(5), 470-477.

Tulsky, J. A. (2005). Beyond advance directives: importance of communication skills at the end of life. *JAMA, 294*(3), 359-365. doi:10.1001/jama.2012.207624

van Eechoud, I. J., Piers, R. D., Van Camp, S., Grypdonck, M., Van Den Noortgate, N. J., Deveugele, M., ... & Verhaeghe, S. (2014). Perspectives of family members on planning end-of-life care for terminally ill and frail older people. *Journal of Pain and Symptom Management*, *47*(5), 876-886. doi: 10.1016/j.jpainsymman.2013.06.007

Volandes, A. E., Mitchell, S. L., Gillick, M. R., Chang, Y., & Paasche-Orlow, M. K. (2009). Using video images to improve the accuracy of surrogate decision-making: a randomized controlled trial. *Journal of the American Medical Directors Association, 10*(8), 575-580. dOI:10.1016/j.jamda.2009.05.006

Waldrop, D. P., & Meeker, M. A. (2012). Communication and advanced care planning in palliative and end-of-life care. *Nursing Outlook, 60*(6), 365-369. doi: 10.1016/j.outlook.2012.08.012

Wallace, C.L. (2014). Family communication and decision making at the end of life: A literature review. *Palliative and Supportive Care, 13*(3), 815-825. doi: 10.1017/S1478951514000388

Welch, L. C., Teno, J. M., & Mor, V. (2005). End-of-Life Care in Black and White: Race Matters for Medical Care of Dying Patients and their Families. *Journal of the American Geriatrics Society, 53*(7), 1145-1153. doi: 10.1111/j.1532-5415.2005.53357.x

Wendler, D., & Rid, A. (2011). Systematic review: the effect on surrogates of making treatment decisions for others. *Annals of Internal Medicine*, *154*(5), 336-346.

Wilper, A. P., Woolhandler, S., Lasser, K. E., McCormick, D., Bor, D. H., & Himmelstein, D. U. (2008). A national study of chronic disease prevalence and access to care in uninsured US adults. *Annals of Internal Medicine*,*149*(3), 170-176.

Wright, J. A., Velicer, W. F., & Prochaska, J. O. (2009). Testing the predictive power of the transtheoretical model of behavior change applied to dietary fat intake. *Health Education Research*, *24*(2), 224-236. doi:10.1093/her/cyn014

APPENDICES

Appendix 1: EOL Care Discussion Questionnaire

Family Conversations about Health Care Preferences

Please read each of the following questions and give us your best possible answer. Your responses will help with a University of South Florida research project on advance care planning and family communication. Thank you for your time and consideration.

1. Thinking about your health care decisions, how involved do you want family members or close friends to be? (Please check only one)

☐ I leave decisions up to them
☐ We make decision together
☐ I get their advice and then make decisions
☐ I make decisions without much advice from them

2. Are you aware that people sometimes talk to their family members about the health care they would want (or not) if they were seriously ill and unable to speak for themselves? ☐yes ☐no

If you answered "no" please skip to question 5 below
If you answered "yes" please answer the next question.

3. Have you thought about having this conversation with family members? ☐yes ☐no

If you answered "no" please skip to question 5 below
If you answered "yes" please answer the next question.

4. Have you talked with family members about the care you would want if you were seriously ill and could not speak for yourself?

4a. ☐ Yes **If you answered yes, how many times have you had the conversation in the past 12 months**?
☐0 ☐1 ☐2 or more

4b. ☐ No **If you answered no, please choose one of the following:**
☐ I'm preparing to have this talk in 30 days
☐ I'm thinking of having this talk in 6 mos.
☐ I am not ready to have this talk

Background

5. Gender ☐male ☐female

6. Month and year of birth ____/______

Appendix 1 (Continued)

7. Please circle the highest year of school completed

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 16+

(elementary) (middle/high school) (college/university)

8. How many people do you share your household with?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ more than 4

9. Are you currently (please choose one) ☐ married ☐ single ☐ divorced ☐ widowed

10. Ethnic origin (please check one)

☐ White, not Hispanic ☐ Black, not Hispanic ☐ Hispanic ☐ Other

11. How sufficient do you rate the income you currently have at your disposal (Is it enough)?

☐ not sufficient ☐ sufficient

12. How confident are you filling out medical forms? (choose one from 1-4; 1 is not confident; 4 is very confident.) ☐ 1 ☐ 2 ☐ 3 ☐ 4

13. How confident are you that you could ask your doctors the right questions to get information to help you make good medical decisions? (choose one from 1-4; 1 is not confident; 4 is very confident)

☐ 1 ☐ 2 ☐ 3 ☐ 4

Health and Well-being

14. Please mark the conditions you have been diagnosed with by your doctor (Please mark all that apply)

☐ High blood pressure ☐ Arthritis ☐ Osteoporosis ☐ Lung disease

☐ Heart disease ☐ Cancer ☐ Diabetes ☐ Stroke ☐ Dementia

15. In general, would you say your health is (Please check only one)

☐ excellent ☐ very good ☐ good ☐ fair ☐ poor

16. Have you been hospitalized overnight in the past year? ☐ yes ☐ no

How much do you agree with the following two statements?

17. Other people determine most of what I can and cannot do.

☐ Agree a lot ☐ Agree a little ☐ Do not agree

18. When I really want to do something, I usually find a way to do it.

☐ Agree a lot ☐ Agree a little ☐ Do not agree

The next few questions are about planning for care at the end of life

19. Do you have a living will? ☐ yes ☐ no ☐ do not know

20. Have you signed documents naming one or more persons to make health care decisions for you if you were seriously ill and could not speak for yourself? ☐ yes ☐ no

21. IF you have done so, the person(s) you chose is your: (please check all that apply)

☐ spouse/partner ☐ son ☐ grandchild

☐ daughter ☐ other relative ☐ friend/other

22. Have you talked with a doctor or other health care provider in the past year about the health care you would want if you became seriously ill and could not speak for yourself? ☐ yes ☐ no

In the next 2 questions, please imagine a situation in which you are seriously ill

23. What if you could speak, walk, and recognize others, but you were in constant, severe physical pain? Would you want to receive life-prolonging treatments or stop all treatments?

☐ Receive all treatments ☐ Stop/reject all treatments ☐ Don't know

24. What if you were not in pain, but could not speak, walk, or recognize others? Would you want to receive life- prolonging treatments or stop all treatments?

☐ Receive all treatments ☐ Stop/reject all treatments ☐ Don't know

25. In the past year, have your preferences changed concerning the type of treatment you would want if you were seriously ill and unable to speak for yourself? ☐ yes ☐ no

Please answer the next 5 questions based on what you think is true concerning care for people at the end of life

26. Palliative care includes chemotherapy and radiation ☐ yes ☐ no ☐ don't know

27. Palliative care helps manage pain and other symptoms ☐ yes ☐ no ☐ don't know

28. Palliative care includes psychological, social and spiritual care

☐yes ☐no ☐ don't know

29. Hospice is for patients expected to live 6 months or less

☐ yes ☐ no ☐ don't know

30. Hospice care makes death happen faster ☐yes ☐ no ☐don't know

Please answer the following questions concerning your beliefs and values

31. What is the strength of your spiritual or religious orientation?
(choose one from 1-4; 4 is very high) ☐1 ☐ 2 ☐ 3 ☐ 4

32. The quality of a person's life is more important than its duration.
(choose one from 1-4; 1 is strongly disagree; 4 is strongly agree)
☐1 ☐2 ☐3 ☐4

33. It is God's will when a person's life will end.
(1 is strongly disagree; 4 is strongly agree) ☐1 ☐2 ☐3 ☐4

34. The length of a person's life is determined by God.
(1 is strongly disagree; 4 is strongly agree) ☐1 ☐2 ☐3 ☐4

35. I turn my health problems over to God.
(1 is strongly disagree; 4 is strongly agree) ☐1 ☐2 ☐3 ☐4

<u>Thank you very much for your participation! You have helped us understand an important topic</u>.

Appendix 1 (Continued)

Conversaciones de la Familia sobre las preferencias del cuidado de su salud

Por favor, lea cada una de las siguientes preguntas, y nos dan su mejor respuesta. Su respuesta ayudará a la Universidad del Sur de la Florida con un estudio sobre el cuidado de las personas que están gravemente enfermos. Gracias por su tiempo y consideracion.

1. ¿Que tan involucrados le gustaría que los miembros de su familia o amigos cercanos para estar en sus decisiones de atención médica? (Marque sólo una)

☐ Dejo decisiones depende de ellos
☐ Hacemos decisión juntos
☐ Tengo su consejo y luego tomar decisiones
☐ Tomo decisiones sin mucho consejo de ellos

2. ¿Es usted consciente de que a veces la gente habla con sus familias acerca de los cuidados y tratamientos que se quieren (o no) si estaban gravemente enfermo e incapaz de hablar por sí mismos? ☐ sí ☐ no

Si su respuesta es "no", por favor pase a la pregunta 5 a continuación
Si su respuesta es "sí", por favor conteste la siguiente pregunta

3. ¿Has pensado en tener esta conversación con miembros de la familia? ☐ sí ☐ no

Si su respuesta es "no", por favor pase a la pregunta 5 a continuación
Si su respuesta es "sí", por favor conteste la siguiente pregunta

4. ¿Has hablado con los miembros de la familia sobre el cuidado que usted quiere si usted fuera gravemente enfermo y no podía hablar por sí mismo?

4a. ☐ sí **Si su respuesta es sí, ¿cuántas veces ha tenido la conversación en los últimos 12 meses?**

☐ 0 ☐ 1 ☐ 2 or mas

4b. ☐ no **Si su respuesta es no, por favor elija uno de los siguientes:**

☐ Me estoy preparando para tener esta conversación en 30 días
☐ Estoy pensando en tener esta charla conversación en 6 meses
☐ No estoy listo para tener esta charla

Historial

5. Género ☐ hombre ☐ mujer

6. Mes y ano de año de nacimiento ____/______

Appendix 1 (Continued)

7. ¿Cuál es el más alto grado de la escuela que completó

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 16+
(escuela primaria) (secondaria) (universidad)

8. ¿Cuántas personas usted comparte su hogar con?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ more than 4

9. ¿Está usted actualmente (por favor elija uno)

☐ married ☐ single ☐ divorced ☐ widowed

10. Origen (por favor elija uno)

☐ White, not Hispanic ☐ Black, not Hispanic ☐ Hispanic ☐ Other

11. ¿Es el ingreso de su disponible es suficiente?

☐ no suficiente ☐ suficiente

12. Que tan seguro de sí mismo se siente al llenar formularios médicos (1 - no seguro de sí mismo; 4 - seguro de sí mismo. Por favor haga una opción) ☐ 1 ☐ 2 ☐ 3 ☐ 4

13. ¿Si siente seguro de obtener la informacion necesaria de su doctor para hacer las decisiones medicas que necesita? (1 - no seguro de sí mismo; 4 - seguro de sí mismo)

☐ 1 ☐ 2 ☐ 3 ☐ 4

Salud

14. Por favor, marque las condiciones que le han diagnosticado por su médico (Por favor marque todo lo que corresponda)

☐ Alta presion sanguínea ☐ Artritis ☐ Osteoporosis ☐ Enfermedad de pulmón
☐ Problemas del corazon ☐ Cancer ☐ Diabetes ☐ Stroke ☐ Demencia

15. En general, ¿diría que su salud es (Por favor, marque sólo una)

☐ excelent ☐ muy buena ☐ buena ☐ moderado ☐ pobre

16. ¿Ha estado hospitalizado durante la noche en el último año? ☐ sí ☐ no

¿Cuánto estás de acuerdo con las siguientes dos declaraciones?

17. Otras personas determinan la mayor parte de lo que puedo y no puedo hacer.

☐ muy de acuerdo ☐ un poco de acuerdo ☐ no estoy de acuerdo

18. Cuando Tengo muchas ganas de hacer algo, normalmente encontrar una manera de hacerlo.

☐ muy de acuerdo ☐ un poco de acuerdo ☐ no estoy de acuerdo

Las siguientes preguntas son acerca de la planificación de deseos final de la vidas

19. ¿Tiene un testamento vital ☐ sí ☐ no ☐ do not know

20. ¿Ha firmado los documentos de nomenclatura una o más personas a tomar decisiones de atención médica por usted si estuviera gravemente enfermo y no podía hablar por sí mismo?
☐ sí ☐ no

21. Si usted lo ha hecho, la persona (s) que usted eligió es tu: (marque todo lo que corresponda) ☐ esposo/pareja ☐ hijo ☐ hija
☐ nieto/nieta ☐ otro pariente ☐ amigo/amiga

22. ¿Has hablado con un médico u otro proveedor de atención de salud en el último año sobre el cuidado de la salud que usted quiere, si usted se convirtió gravemente enfermo y no podía hablar por sí mismo? ☐ sí ☐ no

En las próximas 2 preguntas, por favor, imaginar una situación en la que usted está gravemente enfermo

23. ¿Si pudiera hablar, caminar, y reconocer a otros, pero usted estaba en, dolor físico severo constante? ¿Le gustaría recibir tratamientos que prolongan la vida o detener todos los tratamientos?

☐ Recibir todos los tratamientos ☐ Terminar o rechazar todos los tratamientos ☐ No lo sé

24. ¿Qué pasa si usted no estuviera en el dolor, pero no podía hablar, caminar, o reconocer a los otros? ¿Le gustaría recibir tratamientos que prolongan la vida o detener todos los tratamientos?
☐ Recibir todos los tratamientos ☐ Terminar o rechazar todos los tratamientos ☐ No lo sé

25. En el último año, han cambiado sus preferencias sobre el tipo de tratamiento que usted querría si estuviera gravemente enfermo e incapaz de hablar por sí mismo? ☐ sí ☐ no

Por favor conteste las siguientes 5 preguntas en base a su conocimiento de la atención a las personas al final de la vida

26. Los cuidados paliativos incluye quimioterapia y la radiación ☐ sí ☐ no ☐ No lo sé

27. Los cuidados paliativos ayuda a controlar el dolor y otros síntomas ☐ sí ☐ no ☐ No lo sé

28. Los cuidados paliativos incluye atención psicológica, social y espiritual

☐ sí ☐ no ☐ No lo sé

29. El hospicio es para los pacientes que se espera que vivan 6 meses o menos

☐ sí ☐ no ☐ No lo sé

30. El cuidado de hospicio hace que la muerte ocurra más rápido ☐ sí ☐ no ☐ No lo sé

Por favor, conteste las siguientes preguntas sobre sus creencias y valores

31. ¿Cuál es la fuerza de su orientacion espiritual o religioso?
(1 - baja; 4 - alta) ☐ 1 ☐ 2 ☐ 3 ☐ 4

32. Es la voluntad de Dios cuando la vida de una persona va a terminar.
(1 – no esta de acuerdo; 4 – es muy de acuerdo) ☐ 1 ☐ 2 ☐ 3 ☐ 4

33. La duración de la vida de una persona se determina por Dios.
(1 – no esta de acuerdo; 4 – es muy de acuerdo) ☐ 1 ☐ 2 ☐ 3 ☐ 4

34. Doy mis problemas de salud a Dios
(1 – no esta de acuerdo; 4 – es muy de acuerdo) ☐ 1 ☐ 2 ☐ 3 ☐ 4

35. La calidad de vida de una persona es más importante que la duración.
(1 – no esta de acuerdo; 4 – es muy de acuerdo) ☐ 1 ☐ 2 ☐ 3 ☐ 4

Muchas gracias por su participación! Usted ha ayudado a entender un tema importante.

Appendix 2: Focus Group Discussion Guide 1.

Care Planning Communication Focus Group Guide

Introduction

We are with the School of Aging Studies at the University of South Florida. We are gathering information to understand how people talk to their families about the health care they would want if they were seriously ill with an advanced disease. To learn about this we are talking to groups of people like yourselves. We are here to listen and are interested in all your thoughts and suggestions; there are no right or wrong answers.

Please feel free to speak up at any time, even if it is about something we have already discussed. We want you to know that everything you say is confidential and should not be shared outside this room. Please turn off or mute your cell phones. Please feel free to leave the room if you need to. There are restrooms outside the door.

Can I answer any questions for you? Any time you have a question or comment, feel free to speak?

Opening question: We would like to understand how people share information about their health, not just with their doctors but other people, too. Who do you talk to most often about your health?

Probe: How much do you rely on family or friends to make your health care decisions?

Probe: If you are more independent in how you make decisions, why is that?

Now I'd like to talk about how people plan for the time when they may be seriously ill but aren't able to speak for themselves. Like a lot of people, many of you here today have not had a conversation with a friend or family member about what you would want if you could not speak for yourself, but a serious decision had to be made concerning your care.

Questions:

1. What do you believe makes this conversation difficult?

Probe: Are others reluctant to have this discussion with you? If so, why is that?

Probe: For you, what makes this conversation difficult?

Probe: Many people believe that a conversation is not necessary because family members just know what you would want. Do you believe that family members already know this? If so, how would you deal with disagreement among family members about what kind of care to provide to you?

2. What do you think would encourage you or someone else to have this conversation?

Probe: Who are the best people to have this conversation with, family or friends?

Probe: What do you think people need to know, that would encourage them to have these conversations?

Probe: How should the information be delivered, about the importance of having these conversations?

Probe: What role do you believe health care providers can play in encouraging these family discussions?

3. Have you heard of programs to guide people in these conversations?

Probe: Do you believe they are effective?

Probe: What would you recommend for such a program?

4. As we wrap up, I'd like to ask what you believe is the benefit of telling family members or friends about your health care wishes?

5. Would you like to share anything else? Any other ideas?

You have helped us understand a complex and difficult topic. Thank you.

Appendix 3: Focus Group Discussion Guide 2

Care Planning Communication Focus Group Guide

Introduction

We are with the School of Aging Studies at the University of South Florida. We are gathering information to understand how people talk to their families about the health care they would want if they were seriously ill with an advanced disease. To learn about this we are talking to groups of people like yourselves. We are here to listen and are interested in all your thoughts and suggestions; there are no right or wrong answers.

Please feel free to speak up at any time, even if it is about something we have already discussed. We want you to know that everything you say is confidential and should not be shared outside this room. Please turn off or mute your cell phones. Please feel free to leave the room if you need to. There are restrooms outside the door.

Can I answer any questions for you? Any time you have a question or comment, feel free to speak?

Opening question: We would like to understand how people share information about their health, not just with their doctors but other people, too. Who do you talk to most often about your health?

> Probe: How much do you rely on family or friends to make your health care decisions?
>
> Probe: If you do involve family or friends, even somewhat, in your health care decision, why is that?

Now I'd like to talk about how people plan for the time when they may be seriously ill but aren't able to speak for themselves. Like a lot of people, many of you here today have had a conversation with a friend or family member about what you would want if you could not speak for yourself, but a serious decision had to be made concerning your care.

Questions:

1. What prompted you to begin this conversation?

> Probe: Was it a personal experience or an experience with someone else?
>
> Probe: What, if any, difficulties did you encounter?

Probe: How did you deal with those difficulties?

Probe: What helped you deal with those difficulties?

Probe: Have living will? Know of the Polst – Physicians orders for life sustaining treatment?

2. What do you think would encourage others to have this conversation?

Probe: Who are the best people to have this conversation with, family or friends?

Probe: What do you think people need to know, that would encourage them to have these conversations?

Probe: How should the information be delivered, about the importance of having these conversations?

Probe: What role do you believe health care providers can play in encouraging these family discussions?

3. Have you heard of programs to guide people in these conversations?

Probe: Do you believe they are effective?

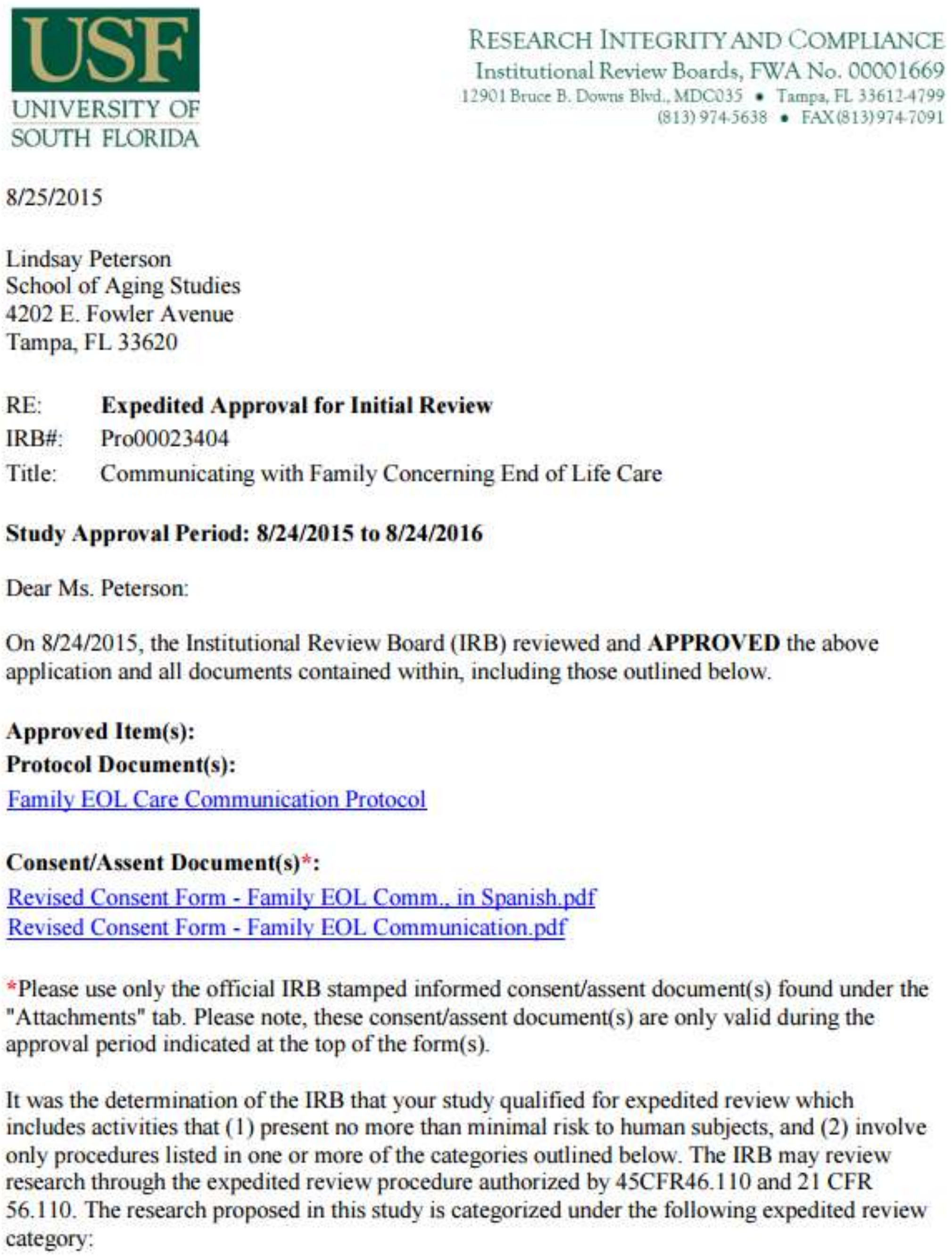
Probe: What would you recommend for such a program?

4. As we wrap up, I'd like to ask what you believe is the benefit of telling family members or friends about your health care wishes?

5. Would you like to share anything else? Any other ideas?

You have helped us understand a complex and difficult topic. Thank you.

Appendix 4: IRB Letter



USF
UNIVERSITY OF
SOUTH FLORIDA

RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX(813)974-7091

8/25/2015

Lindsay Peterson
School of Aging Studies
4202 E. Fowler Avenue
Tampa, FL 33620

RE: **Expedited Approval for Initial Review**
IRB#: Pro00023404
Title: Communicating with Family Concerning End of Life Care

Study Approval Period: 8/24/2015 to 8/24/2016

Dear Ms. Peterson:

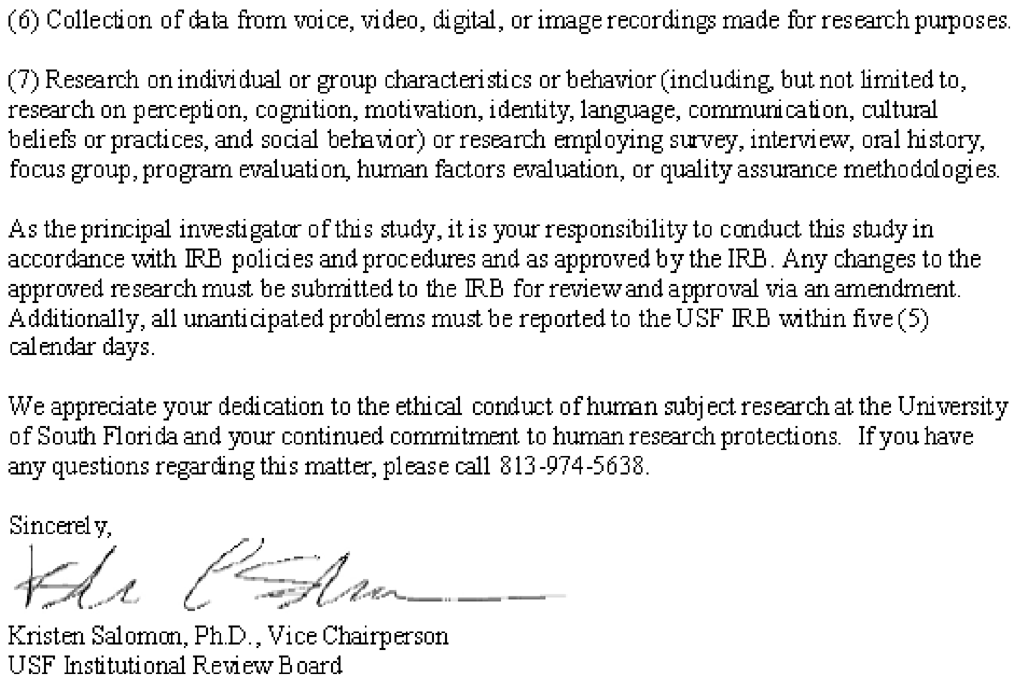
On 8/24/2015, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within, including those outlined below.

Approved Item(s):
Protocol Document(s):
Family EOL Care Communication Protocol

Consent/Assent Document(s)*:
Revised Consent Form - Family EOL Comm., in Spanish.pdf
Revised Consent Form - Family EOL Communication.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:



(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

Kristen Salomon, Ph.D., Vice Chairperson
USF Institutional Review Board