Exploration of factors that influence advance care planning for primary care patients

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Abstract

The purpose of this exploratory descriptive research study is to explore the individual factors that influence health care decisions in a small sample of primary care patients who have received advance care planning education through the State Innovation Model Grant in Rhode Island. Both quantitative and qualitative data was gathered from a voluntary 10 question participant survey. This survey research aimed to answer the following research questions: What are the individual, environmental and behavioral factors that influence healthcare decisions at end-of-life? How do individuals, in their own words, describe the thought process used for making decisions about advance care planning? A 38% response rate was achieved. Results revealed that education about end of life care and family were the most consistently reported elements which helped make choices for preferred care at end of life. Two major themes emerged, control over self and family, and sharing of experiences that impact decision making for care at end of life. Awareness of elements that influence preferences for care provide valuable insight into the thought processes that frame healthcare choices for end of life care and identify barriers and facilitators that influence end of life planning. Knowledge of this information can guide program development, policy and procedures around advance care planning.

Keywords: advance care planning, decision making, end of life care, health behavior, communication, primary care

Copyright Page

There were no copyrighted materials utilized within this project.

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Only one in three people have discussed their preferences for serious illness care with their family and one in ten with their healthcare provider (Coalition to Transform Advanced Care, 2013). The Centers for Disease Control and Prevention (2017) report that 70% of Americans are without an advance care plan. There is a great opportunity to engage, educate and empower patients to communicate their preferences for care to their family and healthcare providers. The Institute of Medicine (IOM) report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (2014), has called for a transformation in how we care for the dying with emphasis on enhanced communication and documentation of healthcare wishes. A key recommendation is to normalize end-of-life conversations through engagement of persons and families in care planning throughout the trajectory of health (Institute for Healthcare Improvement, 2014). This responsibility falls upon all providers, including primary care clinicians, hospitalists and even specialists, in both the acute and subacute settings. Education about the importance of advance care planning (ACP), improved communication processes and documentation of wishes across the continuum can lead to care that aligns with patient's wishes improving the quality and value of care (Bernacki et al., 2015). Consumer and clinician education, as well as redesign of current workflow processes, may contribute to improved knowledge around the importance of ACP resulting in better documentation and subsequently care that aligns with patient's values and preferences.

There is limited research exploring the individual-specific factors that influence healthcare decision making at end of life. There is a need to understand how individuals formulate preferences for end of life care and identify the important elements that influence these choices. Recognizing what matters to individuals beyond the physical, disease-specific medical care can provide opportunity to align end of life care with patient's values. The purpose of this exploratory descriptive study is to understand the individual factors that influence health care decisions in a small sample of primary care patients who have received advance care planning education through the State Innovation Model Grant. The research questions are: 1) What are the individual, environmental and behavioral factors that influence healthcare decisions for end-of-life care? And 2) How do individuals, in their own words, describe the thought processes used for making decisions about advance care planning? This study aims to explore individual factors that influence decisions and preferences for end of life care. Findings from this study may offer opportunities to enhance the way we engage, educate and empower patients to communicate their preferences for care at end of life.

Literature Review

The literature search was conducted using the following databases: CINHAL, PubMed, EBSCOhost, and Cochrane Library. Search terms included: advance care planning, decision making, end of life care, health behavior, communication, primary care.

History of Advance Care Planning

The Patient Self-Determination Act (1990) was passed by the United States Congress to inform patients of their rights regarding decisions toward their own medical care, and ensure that these rights are communicated by the healthcare provider. This federal law protects individuals' right to accept or reject medical or surgical treatments as instructed by their written advance directive. Additionally, the law allows for the appointment of a durable power of attorney in the event that the individual becomes incompetent (Kelley, 1995). Despite the fact that this law was passed almost three decades ago, completion of advance directives remains considerably low. Approximately three-quarters of the population do not have an advance care plan (Centers for

Disease Control and Prevention, 2017). Rao, Anderson, Lin and Laux (2014) identify the primary reason is lack of awareness. Lack of discussion and documentation of ACP can result in care that does not align with patient wishes. A retrospective analysis of Medicare beneficiaries from the National Health and Aging Trends Study (NHATS) revealed one in eight bereaved respondents reported care in the last months of life was inconsistent with patients' wishes and was associated with worse ratings of care, pain management and communication with clinicians (Khandelwal et al., 2017). Care at the end of life is often wrought with multiple transitions and high utilization of intense treatment that is not consistent with patient's wishes. Concerns exist as to how well we are matching medical care to individual values and preferences.

Effective communication enhances, not only end of life care, but quality of life throughout the trajectory of illness (Bernacki & Block, 2014). In the past decade, there has been a wave of national attention on the importance of ACP throughout the trajectory of illness as an essential aspect of person-centered care (Institute for Healthcare Improvement, 2014). Advance care planning acknowledges that individuals' preferences often evolve as their health care status changes (Mackenzie, Smith-Howell, Bomba, & Meghani, 2018). Early goals of care conversations are associated with better quality of life, positive family outcomes and reduction in non-beneficial care at end of life resulting in reduced costs (Bernacki et al., 2015). This becomes increasingly important as we move away from fee for service and into an era of value-based care.

Definitions & Legislation

Many definitions of advance care planning exist throughout the literature. A recent Delphi survey of palliative care experts defined ACP as a process of care " that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care" (Sudore et al, 2017a, p. 821). ACP allows for patients and families to consider and express preferences for care that corresponds with their values through a facilitated discussion, by any treating clinician, intended to be updated as circumstances change (Bond et al., 2018).

While ACP speaks to the process of care, an advance directive is a legal document completed and signed which provides guidance for medical and health care decisions in the event the person becomes incompetent to make such decisions (Merriam-Webster, 2018). Appointing a durable healthcare power of attorney or proxy decision maker is an important aspect of the advance directive. The healthcare power of attorney form designates a surrogate to complete decision making in the event the individual is unable to make his or her own health decisions (Rhode Island Department of Health, § 23-4.10-2, 1986). If appropriate, a Medical Order for Life Sustaining Treatment (MOLST) document can also be completed which clarifies wishes for resuscitation, crosses home and healthcare settings and can be translated into inpatient code status orders with a patient's affirmation (Bond et al., 2018). In January 2014, the Rhode Island Department of Health passed legislation enacting the MOLST form as a portable healthcare order for terminally ill patients (Rhode Island Department of Health, R23-4.11-MOLST, 2013). The MOLST order can be used to refuse or request treatment and is completely voluntary. In the state of Rhode Island, this form can be completed by a physician, nurse practitioner or physician's assistant in any healthcare setting (Rhode Island Department of Health, R23-4.11-MOLST, 2013). This legislative change is an example of Rhode Island's commitment to honoring patient's preferences for care.

Nationally, the Centers for Medicare and Medicaid Services (CMS), reimburse clinicians for ACP documentation because these crucial conversations result in improved patient satisfaction with care, improved patient and family quality of life, and receipt of medical care that aligns with patient's wishes. (Institute of Medicine Report, 2014). Effective January 1, 2016, CMS pays for ACP under the Medicare Physician Fee Schedule (MPFS) and the Hospital Outpatient Prospective Payment System (OPPS). The Current Procedural Terminology (CPT) codes are 99497 (first 30 minutes of advance care planning, when meeting or exceeding 16 minutes) and 99498 (each additional 30 minutes of advance care planning, when meeting or exceeding 46 minutes). Medicare will pay for ACP discussions when medically necessary and as a part of the annual well visit. There are no limits on the number of times ACP can be reported for a given individual (Department of Health and Human Services, Center for Medicare & Medicaid Services, 2016). Additionally, "incident to" billing applies to ACP conversations in the outpatient setting. For example, a licensed clinician (social worker or nurse) can provide ACP education and initiate the discussion and the provider can debrief afterwards and bill for the total time spent. The CMS policy change provides incentives to clinicians from any specialty to discuss patients' views on quality of life and care preferences (Lakin et al., 2017). The importance of ACP conversations is recognized as an essential part of quality value-based care.

Barriers to Advance Care Planning

There are a number of well-documented reasons that exist as barriers to advance care planning. They include timing, age, procrastination, health status, knowledge deficits, concerns for others, ownership of who is responsible to start the discussion, appropriate setting for ACP conversations, discomfort, or expectations that family members will make end of life decisions (Crisp, 2007). Specific patient, as well as provider, reasons are responsible for the low completion rate of advance directives that exist today. A dated but pertinent study by Crisp (2007) revealed three major themes which emerged from qualitative interviews seeking to explore how healthy older adults decide to execute advance directives. The themes are: family influences, quality of life and pragmatic concerns. These themes tied into important concepts of autonomy, dignity, self-advocacy and attitudes toward death. Individuals weigh priorities about preferences for end of life care differently dependent on gender, age and family bonds. By supporting dialogue around ACP and incorporating these personal factors that influence preferences for care, there is a greater opportunity that care at end of life will match patients' wishes, enhancing person-centered care.

While the traditional structure of written advance directives is currently the best means to communicate healthcare wishes, the form itself lacks the clarity required to align care with patient preference. Most standardized advance directives forms are designed to address medical needs and do not include the personal preferences that individualize care for the patient's psychosocial non-medical needs (Schellinger, Anderson, Frazer, & Cain, 2018). Advance directives do not specify what matters most to the patient in terms of values and preferences. Discussions about individuals' priorities often reveals desires beyond physical needs and includes social, ethical, familial, psychological, financial and bereavement needs (Schellinger et al., 2018). Peterson et al. (2018) conducted focus-group interviews which revealed four themes of experiences and attitudes on ACP: being proactive or passive/reactive; perceiving discussion of death as normal or abnormal; response to family resistance or disconnection; and knowledge acquired. The group of older adults who discussed their end of life wishes with family members reported the conversation as an opportunity to be proactive about their wishes. Additionally, a study using the Respecting Choices model noted key elements of successful ACP conversations included individuals' ability to share their stories about loved ones' death which allowed them to consider their own wishes and knowledge of their disease (Niranjan et al., 2018). Challenges identified were fear of dying and avoidance of preparation for death, personal discomfort around end of life conversations, difficulties in family engagement and timing of the initiation of ACP conversations with respect to an individuals' health status (Niranjan, 2018). The Respecting Choices Model shows that understanding the personal factors that influence decisions provides opportunity to tailor education tools and communication approaches to consider the variable attitudes and experiences of individuals.

Healthcare literacy, culture and language barriers surrounding advance care planning are well-documented barriers that exist in minority populations (Sudore et al., 2018). Lack of trust, concerns of racism, and complex legal language can perpetuate this concern. In response to this disparity, Sudore and colleagues created an easy-to-read advance directive (2007) and a patient directed, online advance care planning program (2014) called PREPARE For Your Care (PREPARE). It is available in both English and Spanish. A recent comparative efficacy randomized clinical trial revealed statistically significant gains, measured by documented advance care planning (43%, $p<0.01$) and patient reported engagement (98.1%, $p<0.01$) for those participants in the PREPARE arm (Sudore et. al, 2018). These findings reveal that responding to the needs of the population can enhance patient's self-advocacy and ability to express priorities and preferences.

Socioeconomic status has been related to a long history of social inequalities in healthcare. Despite the advances we have made in access to care and improved resources for the disadvantaged, financial status continues to affect care across the health span. This is true in the realm of ACP and end of life care. A recent study by Tripken, Elrod and Bills (2018) assessed the knowledge, attitudes and beliefs among older adults in two socioeconomically diverse settings about ACP utilizing the social-ecological model which incorporates the effects of personal and environmental factors that determine behavior. Results note that higher levels of knowledge and engagement in ACP were reported at higher income levels highlighting the contextual factors that influence individual health behaviors regarding ACP. There is tremendous opportunity to create a variety of tools and resources about ACP that will meet the needs of specific populations with consideration of culture, religion, finance and resources. Provision of patient-centered care at end of life is not a privilege for only the wealthy and educated. It is a human right of all.

Financial Implications of Advance Care Planning

As we move into an era of value-based medicine, communication with patients about preferences for care is not only important from a quality perspective but from a financial one as well. Cost savings were 35.7% lower among patients who reported having an end-of-life discussion, with an average cost savings of $1,041 per patient in the last week of life (Zhang et al., 2009). Temel et al. (2010b) showed early and consistent palliative care resulted in fewer interventions and less time in the hospital. Community ACP and documentation of advance directives was directly linked to decreased utilization and cost of care 12 months prior to death (Bond et al., 2018). As a result of our changing healthcare landscape, new reimbursement models are being defined. The Institute for Healthcare Improvement (2018) developed a three dimensional framework to optimize health system performance called the Triple Aim. The triads include population health, the experience of care and per capita cost. The concept design includes the following components: focus on individuals and families, redesign of primary care services and structures, population health management, cost control platform and system integration and execution (Institute for Healthcare Improvement, 2018). With focus on the Triple Aim, there is increasing pressure to improve quality while reducing costs. Advanced practice nurses (APNs) are in the perfect position to advocate and develop system level changes to make these crucial conversations the standard of care in all settings. By engaging, educating and empowering patients to discuss their preferences for care, we can improve quality by offering care that aligns with values.

National Education Efforts

Individuals lack the knowledge and understanding of the many aspects of ACP. Efforts to increase patient and community education about the importance of ACP is one method of increasing the knowledge base surrounding healthcare choices. Educational evidence-based models are available for providers to inform patients about health care decisions including the Respecting Choices Model (Gunderson Health System, 2017), the Serious Illness Guide (Ariadne Labs, 2018), the Institute for Healthcare Improvement's Conversation Starter Kit (IHI, 2018) and the PREPARE website and videos (Sudore et al., 2017b). These examples provide a brief overview of developed models that offer a framework for advance care planning discussions. To introduce the topic of advanced care planning, the provider may use open-ended questions to encourage patient reflection of values, priorities and life experiences to shape a conversation around healthcare decisions. A variety of patient engagement tools exist including self-guided questionnaires, group visit discussions, interactive exercises and video-based programs. These interventions can take place in diverse settings including community centers, libraries, and primary care practices, as well as in the acute care setting.

It is ideal when ACP conversations take place initially outside of an acute event or crisis situation. ACP conversations with a trusted, long term primary care provider may enhance greater clarity for the individual to share their preferences for end of life care. The primary care office is a setting that has great opportunity to embed ACP discussions into the routine daily workflow. Using the office team to educate patients, enhance talking points about ACP, inform them of resources and even offer group visits can encourage the standardization of healthcare planning (Sudore et al., 2017a). Normalizing the ACP discussion is a goal towards creating a change in culture about death and dying. According to the National Health Statistics Reports (2017), in 2013, 18% of office based primary care physicians worked in practices certified as patient centered medical homes (Hing, Kurtzman, Lau, Taplin & Bindman, 2017). The Agency for Healthcare Research and Quality (2018) defines the patient-centered medical home as a model of primary care that delivers comprehensive, patient-centered, coordinated, accessible and quality care. Inclusion of advance care planning into this model is a natural fit for value-based high quality care.

Recent studies by Sudore et al (2017b), Lum et al (2016), Lakin et al (2017) and Carly et al (2018) have provided novel ways to engage patients in discussions about advance care planning in a variety of settings with diverse models of implementation and documentation. Understanding what motivates individuals to participate in ACP is important for designing program outreach. Sudore et al. (2017b) highlights key strengths of the group visit model which includes high-quality education and supportive discussions, patient and provider satisfaction and improved patient self-efficacy (Lum et al., 2017). These studies demonstrate that there is not a "one size fits all" model. It requires continued research and thoughtful evaluation of best practice approaches.

Significance to Practice

The importance of ACP in providing person-centered care that aligns with patient preference has been extensively outlined above. Both on a local and national level, initiatives are being developed to educate and improve conversations about preferences for care at end of life. In 2015, Rhode Island was one of twenty four states to receive a State Innovation Model (SIM) Test Grant from the Federal Centers for Medicare and Medicaid Services (CMS). CMS developed a federally funded grant to promote innovative changes to Rhode Island's healthcare system. The vision of the Rhode Island SIM Test Grant reads "Continuously improving Rhode Islanders' experience of care (including quality and satisfaction), enhancing the physical and behavioral health of all Rhode Island's population, and reducing the per capita cost of healthcare for our residents" (Executive Offices of Health and Human Services, State of Rhode Island, 2015). SIM funds are supporting several activities that can be broken into three categories: improving the primary care and behavioral health infrastructure, engaging patients in positive health behaviors and self-advocacy, and expanding the ability of providers and policy makers to use and share data. As an arm of the patient engagement branch, group advance care planning sessions are taking place in primary care practices throughout the state of Rhode Island. The aim of the pilot project is to increase the number of patients with advanced directives in primary care. The intervention is a free 1.5 hour information session that educates participants on the importance of advance care planning and completion of advance directives. These sessions are both didactic and interactive and were designed to engage, educate and empower patients to make well informed decisions about serious illness care. The outcome measurements of the SIM pilot will be the use of advance care planning billing codes 99497 and 99498 after implementation of the educational intervention and secondary outcomes include participant knowledge and confidence in advance care planning activities.

As an educator for the SIM advance care planning sessions mentioned above, several observations have been made when participants engage in group discussion around serious illness care or end of life. The concepts of mortality and humanity consistently arise as participants reflect on past experiences and consider future healthcare preferences. Comradery develops from the human connection that is palpable in the room. Tears, laughter and emotion are shared in this intimate space. It is a reflection of humans connecting with one another about sensitive life decisions. Participants allow themselves to be vulnerable with strangers and share meaningful expression of values, culture, and faith. Based on the observations, some common factors that appear to influence healthcare decisions include past experiences surrounding healthcare decisions of a family member or loved one. Whether these experiences were positive or negative, participants verbalized the importance of ACP and seemed motivated to express their personal preferences for care. Education level, including healthcare literacy, as well as occupation were also driving factors in the documentation of wishes. Nurses who have attended the sessions shared personal stories, as well as professional experiences about end of life care which appear to influence their healthcare choices. Family support or lack thereof appeared to be motivators that have also been observed. A number of participants were single or have no siblings, and identification of a healthcare proxy was verbalized as an important aspect of advance care planning. Despite what has been observed, it remains unclear what factors have the most impact on decision making for ACP. Due to the aim and design of the SIM project, further exploration and clarification of participant statements has not been possible. Yet, as the literature revealed, it remains essential to identify factors that influence healthcare decisions. A scholarly project is proposed to explore, in participants own words, the factors that influence ACP decisions and will include documentation and robust analysis of themes that emerge from a 10 question survey given to participants. Closer evaluation of the antecedents that influence health care decisions can provide valuable insight and opportunity for enhancing the way we engage, educate and empower patients to communicate their preferences for serious illness care and promote innovative practice changes in the delivery of goal-concordant care.

Theoretical Framework

Bandura's Social Cognitive Theory (1986) suggests that individuals are contributors to their life's circumstances, not just products of them. Humans can adapt or change their behavior after processing information they receive from the world or environment around them. Thru the lens of the Social Cognitive Theory, a triadic reciprocal relationship exists between the individual, environment and behavior (Bandura, 1986). These three elements interact to determine motivation and behavior. The elements are not of equal strength, nor do they occur concurrently (Wood & Bandura, 1989). Individuals have control over behavior, but are also in control of how they think and feel about a behavior which ultimately affects performance. Additionally, unseen cognitive process such as beliefs, attitudes and emotions can directly affect or mediate behavior (Bandura, 1986).

Bandura (1977) developed the Self-efficacy Model as part of the larger Social Cognitive Theory. He defines self-efficacy as "the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations" (Bandura, 1977, p. 193). Simply stated, it is what an individual believes he or she can accomplish using his or her own skills under certain circumstances. The theory outlines a theoretical framework in which self-efficacy is the central concept for analyzing changes in fearful and avoidant behavior. It reflects confidence in the ability to exert control over one’s own motivation, behavior and social environment. The theory takes into account a person's past experiences, which factor into whether behavioral action will occur (Bandura, 1977). These past experiences influence reinforcements, expectations, and expectancies, all of which shape whether a person will engage in a specific behavior and the reasons why a person engages in that behavior (Badura, 1986).

Bandura goes on to name four sources of efficacy beliefs: performance outcomes, vicarious experiences, verbal persuasion and physiological feedback (Bandura, 1977). *Performance outcomes* include positive and negative experiences that can influence the ability of an individual to perform a given task (Badura, 1977). *Vicarious experiences* reflects the evaluation of other’s actions and outcomes in comparison to ones’ own (Bandura, 1977). *Verbal persuasion* is influenced by the encouragement or discouragement pertaining to an individuals’ ability for behavioral change (Bandura, 1977). Lastly, *physiological feedback* pertains to emotional arousal and its influence on an individuals’ self-efficacy (Bandura, 1977). Self-efficacy beliefs are created by observation of behavior or consequences of similar behavior, emotional arousal which can be interpreted as enthusiasm or anxiety, verbal persuasion as defined as encouraging or discouraging messages from others, and previous successful or failure experiences (Pajares, 2009).

The Self-efficacy Model has been used as a tool in a number of health promotion and health maintenance behaviors including self-management of chronic disease, smoking cessation and pain control (Badura, 1997). Use of this model as a framework for the concept of ACP creates opportunity for empowerment and confidence in voicing individual preferences for care at end of life. Individuals make choices about their preferences for end of life care based on a number of influences. They draw upon past experiences at end of life (*performance outcomes*) or experiences of friends or colleagues (*vicarious experiences*) to frame decisions and choices about desired care. Culture, religion, education, support systems, and family (*physiological feedback*), influence opinions surrounding end of life care. There is a nationwide movement to increase education about advance care planning which has been shown to improve the documentation of healthcare wishes (*verbal persuasion*). Patients place value on what is important based upon the elements of self-efficacy. As noted above, a number of factors influence the thought process around ACP and health care choices. Awareness of personal stories and experiences that guide health care decision making are important to healthcare providers in order to deliver care that aligns with patient's wishes.

Methodology

The DNP scholarly project will examine the individual factors that influence decisions and preferences for care at end of life. An exploratory descriptive design will be used to collect both quantitative and qualitative data gathered thru participant survey responses. This survey research will aim to answer the following research questions: What are the individual, environmental and behavioral factors that influence healthcare decisions at end-of-life? How do individuals, in their own words, describe the thought process used for making decisions about advance care planning? Project design was submitted to both Salve Regina University (SRU) and Care New England (CNE) Institutional Review Boards for approval. Project submitted to CNE on October 29, 2018 and approved for Exempt status on December 14, 2018. Project submitted to SRU on October 19, 2018 and approved January 3, 2019.

Participants: The participants will be a convenience sample of English speaking individuals who are 18 years or older from primary care practices within an accountable care organization in

Rhode Island. There are no limitations due to gender, ethnicity or culture. Inclusion criteria includes the individuals who have attended a group advance care planning session at their primary care office as part of the State Innovation Model (SIM) pilot project "Increasing patient engagement through advance care planning in primary care". Exclusion criteria are those < 18 years of age and non-English speaking. Goal sample size is 30 participants. This number was determined based on a reasonable sample size to conduct both qualitative and quantitative analysis of a small purposive sample.

Setting: There are multiple practice sites that have provided advance care planning education through the State Innovation Model Grant. Collaborating practice sites include Rhode Island Primary Care, Care New England Medical Group and South County Health. Practice sites are located throughout the state of Rhode Island.

Tools: Attendees of the ACP education class will be asked at the end of the session if they would be willing to participate in a voluntary 10 question written survey. The intent of this survey is to explore factors that influence individual's decisions regarding advance care planning. The individuals who agree to participate will be given a numbered survey with a return self-addressed envelope to de-identify data. Completion of the survey is voluntary and all responses will remain confidential as outlined in the survey letter. Return of the survey will imply consent. See Appendix A for Participant Letter and Survey.

The Intervention and Data Collection: Study participants will be identified as those who have completed the ACP education session. At completion of the session, individuals will be asked to participate in a 10 question written survey that is intended to explore factors that influence decisions regarding advance care planning**.** If agreeable, they will be given a numbered survey with stamped, self-addressed return envelope. This process will be used for de-identification.

Participants will be asked to complete and return the survey within 2-3 weeks. Returned surveys will serve as implied consent for study participation.

Outcome measurements will include both nominal and categorical data. Descriptive statistics were collected to describe the participant's characteristics. Analysis of individual, environmental and behavioral factors that influence healthcare decisions at end of life will be explored thru comparison of responses in Questions 1-7. Demographic data will be used to calculate the mean of each category. In addition, data frequency will be evaluated. Each demographic response will be compared to the responses of questions 1-7 to explore relationships between variables. For example, female and male responses will be compared for questions 1-7, age range differences will be compared for questions 1-7, similarly with education level, culture and religion. Qualitative content will be gathered in questions 8-10. The responses will be analyzed using Tesch's Eight Steps in the Coding Process (1990). The eight steps include: 1) Get a sense of the whole. Read all the transcriptions carefully. Perhaps jot some ideas as they come to mind as you read. 2) Pick one document. Go through it asking yourself "What is this about?" Think about its underlying meaning. 3) After completing this process with several responses, make a list of all the topics. Cluster together similar topics. Form these topics into columns. 4) Take these topics and go back to your data. Abbreviate the topics as codes and write next to appropriate segments of the text. Use this organizing scheme to see if new categories of codes emerge. 5) Find the most descriptive wording for your topics and turn them into categories. Reduce your total list by grouping topics that relate to one another (data reduction). 6) Make a final decision for each category. 7) Assemble the data material belonging to each category in one place and perform a preliminary analysis. 8) If necessary, recode your existing data (Tesch, 1990). Further qualitative content analysis will be done by review with a doctorally-prepared committee member with experience in qualitative analysis. To increase confirmability and dependability, the qualitative expert read data separately and then we will meet until we reach a consensus on coding categories and themes.

Risks: There are very little anticipated risks associated with completion of the survey. Inconvenience may include the time spent in completion of the survey.

Protection of Subjects: All data collected will be kept confidential and anonymity will be protected by de-identification of responses.

Confidentiality: All participants who agreed to participate were given a numbered survey along with a self-addressed stamped envelope in which to return the survey. This will be held confidential by the primary investigator. Number assignment is for de-identification purposes. Participant responses will be kept confidential and anonymous. All files will be kept in a locked file cabinet within a locked office after the completion of the project for a total of five years at which time they will be destroyed by shredding.

Benefits: Identification of the preferences and values that influence an individual's healthcare decisions provides valuable insight to the ways in which patients process and evaluate choices for serious illness care. Exploration of the factors that influence advance care planning choices can guide practice changes that align care with patient preference improving the value and quality of care.

Analysis

Findings from Quantitative Analysis

A total of 82 surveys were handed out and 31 were returned, 38% response rate, within the time frame of January 7, 2019 through February 26, 2019. Eight ACP classes were taught during this time frame. Table 1 shows the characteristics of the 31 participants who responded. 87% of the respondents were female, 57% between the ages of 51-90. 93% were Caucasian and 54% had an education level of Bachelor's degree or higher. 47% were married and 60% Catholic.

Education about end of life care and family were the most consistently reported elements which helped make choices for EOL care (Q1). This was true among males and females, as well as across all age groups, followed by finances. No differences were noted in regards to level of education, marital status, race or religion. 100% of respondents felt it was important to make their own choices about how to live and be cared for at end of life (Q2). Collectively, participants chose themselves as the BEST person to make decisions for end of life care 68% followed by their spouse 35% (Q3). Other options mentioned, which were not included in the standard survey responses, were a sibling or parent, as well as input from all 26%. 77% of females had a conversation with their families while only 50% of males did so. Interestingly, age groups of 18-31 and 71-90 were 83% more likely to talk to family vs. ages 31-70 (64-67%). Those in a relationship, married or widowed were more likely to have conversations with family (71-100%) vs. single participants (56%).

In regards to discussions with healthcare providers, 25% of male participants spoke with their providers about their wishes vs. 19% of the female participants. No one from the youngest age group (18-31) spoke with their provider about their wishes vs. 50% of the age group 71-90 did have a conversation with their healthcare provider. 45% of all respondents completed an advance directive (25% male, 19% female). 66% of completed ADs where > 50 years of age. No ADs were completed between 18-30 years of age. Reasons for not completing an advance directive included needed more time to complete and plan (69%), followed by uncertainty (19%)

and need for more info or help from family/friends (13%). A select few responses noted age (namely <30 years of age) as a reason for not completing an AD. Refer to Figure 1 for quantitative results categorized by question.

Findings from Qualitative Analysis

The survey included three open-ended qualitative questions which were: 1) What were you thinking about when you were making choices about your end of life care, 2) If you have had a past experience with death and dying, please share how this affected your personal wishes for care, and 3) Please feel free to share any additional information that you feel was important to the process of preparing for your end of life care. The aim of these questions were to support the quantitative findings as well as to explore alternative explanations (Creswell & Creswell, 2018). Participants did not consistently answer each question in entirety. There were 29 responses to question 8 (94%), 23 responses to question 9 (74%) and 12 responses to question 10 (39%). The survey responses were analyzed by use of Tesch's Eight Steps in the Coding Process (1990).

During initial review of the data, the survey responses were read multiple times while taking detailed notes on the elements that presented themselves over and over. A few poignant responses were chosen and explored critically to get a sense of the deeper meaning behind the statements. Next, a list was made of all the topics that were presented and participant responses were added to support each. Ten coding categories were initially identified through multiple rounds of comparing answers for each question and across questions. Next, the data was reduced and some coding categories were eliminated or adopted within others. Responses based on gender and age were color coded to compare against the whole. Finally, the data was reviewed with a qualitative expert over the course of multiple sessions. Robust analysis of survey responses allowed for identification of themes. Data was reassembled and analyzed within these themes. The two major themes that emerged were control over self and family, and sharing of experiences that impact decision making for care at end of life. Refer to Table 2 for Coding Categories and Description of Themes.

Control over self and family. This theme presented itself most prominently within the qualitative responses. Participants repeatedly echoed statements such as, “respect my decisions” (52), “stand by my choices” (3) and “make my wishes known” (10), In other words, do what I say reflecting an element of self-advocacy. This desire for control was an opportunity for the participant to make personal decisions for end of life care as a means to maintain control and exercise autonomy until the final days. In addition, many of the responses that reflected this desired control also exhibited a secondary intention which was protecting family and friends from burden and suffering. The participants looked at advance care planning as an opportunity to control or manipulate the situation in order to lessen the grief for family and alleviate burden. Responses such as “I did not want to burden my family with these decisions and I wanted to make sure that my wishes alone would be binding” (12) support this category of avoidance of burden. Participants also made statements such as, “I was thinking of my parents. Being young, I would not want them to have to deal with hard decisions during an already hard time. I never want to be a personal or financial burden” (50).

Decision making for care at end of life. The second major theme was experiences that impact decision making for care at end of life. The participants reflected on past personal and professional experiences that guided decision making. Experiences with death and dying seemed to be a strong predictor for decisions surrounding preferences for care at end of life. Categories within this theme included positive and negative past experiences. Participants shared more negative experiences of death which influenced their personal decisions for care. Some examples of personal responses are “After seeing family pass without arranging everything, I will make sure my wishes and financials are clear” (21). “I watched a cousin bury her child (25 years) with a brain stem injury. No one was prepared and she struggled with end of life decisions” (60).

A smaller percentage of responses reflected on positive end of life experiences as influencing decision making. A participant shared “My mom passed away…and she died in the privacy of our home and she looked so peaceful that I want to possibly go how she did” (52). “I was with my mother and father while they were passing. I felt it was a great honor to be there and was completely humbled by the experience. This has informed some of my decisions and thoughts regarding what I may wish for at end of life” (74).

Additionally, professional experiences in healthcare also appeared to affect personal decisions for care. One participant shared “Having worked in long-term care for 25 years, I have seen many residents have a long, drawn out death experience either because they never created advance directives for themselves while they were capable of doing so or because the family couldn’t let go and insisted that everything medically possible be done. By sharing my wishes and different scenarios with my husband and grown children, we all known the wishes of each other” (57). Qualitative responses were stratified by age and gender. Eighty-three percent of qualitative responses were female, as compared to 17% male. Ages 51-90 represented 59% of the qualitative responses, 41% ages 18-50. Ninety-three of respondents were Caucasian and 60% Catholic. There were no major differences for married participants.

Discussion

The results of this exploratory descriptive survey research study note that education about advance care planning and family influence are primary factors in making decisions about end of life care. Participants expressed importance of being in control of their decisions and relieving burden on family. The majority of participants identified past experiences, often negative ones, influenced their decisions for care at end of life. Most participants have had discussions with their family about preferences for care (71%); however only 19% have communicated wishes to their healthcare provider. Despite the expressed importance of this topic, 55% have not completed an advance directive.

The findings are consistent with prior pertinent studies that explored advance care planning. In a dated but relevant study, Crisp (2007) noted the influence of family death contributed to individual's self-advocacy and desire for ease of burden at end of life. Similarly, Carr (2012) reported that those witnessing death were more apt to make end of life preparations for themselves. Additionally, key elements of successful ACP conversations included individuals' ability to share their stories about loved ones' death and use of past experiences which allowed them to consider their own wishes and knowledge of their disease (Niranjan et al., 2018). Identifying goals within the context of past experiences has empowered individuals to engage in discussions about ACP (McMahan, Knight, Fried, & Sudore, 2013).

Themes of autonomy and self-advocacy have been identified as facilitators in communicating wishes for care. Some viewed advance directives as a vehicle for a "good death" and a way to gain mastery over their dying experience (Crisp, 2007), while others noted advance care planning as a reflection of their self-efficacy (Fried, Bullock, Iannone & O'Leary, 2009). As the Social Cognitive Theory suggests a triadic reciprocal relationship exists between the individual, environment and behavior (Bandura, 1986). Self-efficacy is the central concept within the theory which reflects confidence in the ability to exert control over one's own motivation, behavior and social environment. The theory takes into account a person's past experiences, which factor into whether behavioral action will occur (Bandura, 1977). These past experiences influence reinforcements and expectations, all of which shape whether a person will engage in a specific behavior and the reasons why a person engages in that behavior (Badura, 1986). Framing the research from this perspective creates opportunity for empowerment and confidence in voicing individual preferences for care at end of life. Individuals make choices about their preferences for end of life care based on a number of influences which was supported by the study findings. They draw upon past experiences at end of life to frame decisions and choices about desired care. Desire for control of end of care influences decisions about preferences for care. Education about advance care planning has enhanced engagement in discussions about advance care planning. Patients place value on what is important based upon the elements of self-efficacy. As noted above, a number of factors influence the thought process around ACP and health care choices. Awareness of personal stories and experiences that guide health care decision making are important to healthcare providers in order to deliver care that aligns with patient's wishes.

Limitations

There were a number of limitations within this study. The population was a convenience sample of participants who had completed a group ACP education session through their primary care practice. This may suggest that the attendants were self-motivated by attending the session or encouraged to attend by recommendation/offering from their primary care provider. The sample population was narrow as noted by the demographics results primarily females, ages 51-90, and Catholic. The results are not generalizable, as a diverse population was not captured. The time from survey administration to completion did not allow for clinician follow-up or official completion of the AD which may have led to a high % no responses (81% no to MD discussion; 55% no to AD completion.

Attempts were taken to account for bias as the educator for the ACP classes was also the researcher. In preparation of the study, a detailed plan for analysis of the qualitative data was developed and followed systematically throughout the research process. This prevented the researcher from seeing what they wanted to or expected to. Participant recruitment was encouraged as a means to increase representativeness. An audit trail of qualitative data was clear, organized and transparent. To increase confirmability and dependability, an expert in qualitative research read the data separately and then met multiple times with the researcher until a consensus on coding categories and themes was reached. Additionally, surveys were anonymous in an attempt to prevent identification of participants.

Despite these attempts, it was not possible to remove all sources of bias. Participants knew the researcher as the educator of the class and may have wanted to provide socially acceptable answers to please me. Those that completed the surveys may have been more impacted by an experience that they wanted to share and those that did not complete surveys may not have had similar experiences. Focus groups or interviews may have offered richer reflection of the personal process when making decisions about care at end of life. This type of design would allow for the opportunity to use open ended questions such as “tell me more” and “can you expand on that feeling”. The survey responses do not capture the energy or emotion of real-time discussions about advance care planning. Additionally, expansion to a broader and more diverse population may highlight additional influences or barriers which were not revealed in this limited representative population.

Significance and/or implications

ACP is a highly individualized process that is influenced by many variables. Identification of the preferences and values that shape healthcare decisions, provides valuable insight to the ways in which patients process and evaluate choices for care at end of life. It was clear in the study findings that control and self-advocacy were important to most respondents when it came to making decisions about care at end of life. This desire for power or command was sought most often in an attempt to manipulate the end of life experiences and alleviate stress and burden on family. Preferences for care were discussed as a means to protect loved ones and minimize grief or suffering.

Understanding what leads a person to make decisions about end of life care is an important element which can be used to design program outreach strategies that will enhance discussions about preferences. For example, education about end of life and family were the most consistently reported elements which helped make choices for EOL care. Offering education sessions that include family members may offer improved communication about preferences for care and subsequently lead to improved AD documentation and end of life care that is person-centered. Identification of facilitators and barriers play an important role in the development of process changes that can improve communication and care at end of life. For instance, males were less likely to talk with their families but more likely to discuss wishes with their healthcare provider. Exploration of gender differences surrounding engagement and communication of ACP may offer additional insight to curtail communication approaches about end of life to select participants based on their preferred style of communication.

Consumer engagement about the importance of advance care planning offers opportunity to educate and empower individuals to make well informed healthcare decisions. Accountable Care Organizations (ACOs) may benefit from implementation of consistent processes for ACP. ACOs seek to improve quality and reduce costs for a defined population of patients, and palliative care offers value on both the quality and cost sides of the equation (Block, Jackson, & Lee, 2014). Palliative care has become vital to the success of ACOs because of the high concentration of healthcare spending among seriously ill patients and palliative care's ability to improve value (i.e., raise quality and reduce costs) for this group (Kelley & Meier, 2015). A cornerstone of palliative care is advanced care planning and serious illness conversations that incorporate the values and preferences of the patient. Zhang et al (2009) investigated expenses and end-of-life discussions yielding that costs were 35.7% lower among patients who reported having an end-of-life discussion. An additional strength includes the recent policy change by the Centers for Medicare and Medicaid Services (CMS) which reimburse clinicians for ACP documentation because these crucial conversations result in improved patient satisfaction with care, improved patient and family quality of life, and receipt of medical care that aligns with patient's wishes. (Institute of Medicine Report, 2014). The policy change provides incentive to clinicians from any specialty to discuss patients' views on quality of life and care preferences (Lakin et al., 2016). Identified strengths of ACP and completion of advance directives includes awareness on person-centered care that aligns with values and preferences.

For hundreds of years, nurses have had a primary role in the care of individuals across the life trajectory. We are educators, advocates, counselors, translators, detectives, protectors and often friends. The nurse-patient relationship is a sacred bond. Just as important in times of health, nurses are obliged to provide comprehensive, compassionate care at end of life. Nurses have the responsibility to establish decision-making processes that support individual preferences and encourage patient and family participation on healthcare decisions, including advance directives and durable power of attorney. They are perfectly positioned to contribute to conversations about end of life care and decisions, focusing on individual preferences and maintaining respect for patient autonomy (American Nurses Association, Position Statement, 2016). APNs are in a prime position to develop best practices to provide person-centered quality care across the dimensions of end of life care and to promote work environments which adopt excellent standards of care for advance care planning. The doctoral prepared nurse can develop programs, policies and procedures that enhance advance care planning and contribute to its sustainability.

Goals for future research

There is tremendous opportunity to engage, educate and empower individuals to participate in discussions about advance care planning. Advanced practice nurses are in a perfect position to lead these healthcare improvement initiatives. Knowledge of the existing literature and identifications of gaps that are present enhance future opportunities to develop and implement quality research projects. In regards to advance care planning, development of new care models that integrate patient-centered conversations into the routine workflow of care settings is essential. Furthermore, exploration of factors that influence advance care planning decisions can provide valuable insight into the processes that frame healthcare choices at end of life care.

The design of communication tools and educational programs that incorporate the important factors that individuals attribute towards making end of life health care decisions, creates opportunity to enhance the relationship between patient and provider with a better understanding personal values and wishes, as well as preferred communication styles. The development of new care models that integrate advance care planning into the routine workflow within primary care practices and other healthcare organizations could normalize the discussion of advance care planning and add to sustainability. Additionally, improvement of current advance care planning documents and advance directives to include non-medical and global goals, could enable health systems and communities to better support personal preferences for care that align with values.

A multitude of opportunities exist to enhance communication, education and documentation of individualized preferences of care at end of life. As our nation faces the future challenges of an aging population, rising health care costs, and the growing burden of chronic disease, advanced practice nurses play a vital role in development of innovative processes that deliver high-quality, patient-centered healthcare.

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Appendix A: Participant Letter

As a participant in the recent Advance Care Planning education sessions that took place at your primary care office, you are being asked to participate in a brief research survey. The purpose of this research is to learn more about how people make decisions for end of life care. Closer evaluation of the personal reasons that guide health care decisions can provide important information about the way we deliver care at end of life. With this valuable information, we hope to improve care and honor personal wishes.

Your participation in this survey is voluntary. Any information you share will be kept confidential. Lack of participation in this research will not impact the care you may be receiving from, or your relationship with, your healthcare provider. You do not need to answer any questions with which you feel uncomfortable responding. Please answer the questions openly and honestly. When completed please return in the pre-paid envelope that has been provided.

If you have any questions about how your answers will be used, feel free to contact me personally (401) 737-7000, x35456. Any questions that you may have about your rights as a research participant should be directed to the Kent IRB (401) 737-7000, x31879. Thank you kindly for your completion of this survey.

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Survey Questions

Reflecting on the recent advance care planning session you attended, please answer the following questions about your thoughts and choices for care that you would prefer at end of life.

1. What helped you make choices about your wishes for end of life care?

   (Check all that apply)

   a. Family
   b. Friends
   c. Culture
   d. Finances
   e. Spirituality
   f. Personal health status
   g. Education about preparing for end of life care

2. Is it important to you to make your own choices about how you would want to live and be cared for at end of life?

   a. Yes
   b. No

3. Who would be the BEST person to make decisions for your end of life care?

   a. Myself
   b. Spouse
   c. Children

    d. Friend
    e. Doctor
    f. Lawyer
    g. Other____________

4. As a result of the advance care planning group visit, did you have a conversation with your family about your end of life wishes?

    a. Yes
    b. No

5. As a result of the advance care planning group visit, did you have a conversation with your healthcare provider about your end of life wishes?

    a. Yes
    b. No

6. As a result of your advance care planning group visit, did you complete an advance directive?

    a. Yes
    b. No

7. If you did not complete an advance directive, what kept you from finalizing your wishes for care?
   (Check all that apply)

    a. Needed more information to make decisions
    b. Needed more help from family or friends
    c. Needed more guidance from healthcare provider
    d. Fear of your wishes not being carried out
    e. Uncertainty
    f. Other________

8. What were you thinking about when you were making choices about your end of life care?
9. If you have had a past experience with death and dying, please share how this affected your personal wishes for care.
10. Please feel free to share any additional information that you feel was important to the process of preparing for your end of life care. Please write freely.

Demographics:

Age

a. 18-30 years old
b. 31-50 years old
c. 51-70 years old
d. 71-90 years old
e. >90 years old

Gender

a. Male
b. Female
c. Identifies as______

Highest Level of Education

a. Less than high school
b. High School/GED
c. Associates/Trade School
d. Bachelors
e. Masters or higher

Marital Status

a. Single
b. Committed relationship
c. Married
d. Divorced
e. Widow

Race

a. Asian/Pacific Islander
b. Black/African American
c. Caucasian
d. Hispanic/Latino
e. Native American/Alaska Native
f. Other________

Religion

a. Protestant
b. Catholic
c. Jewish
d. Buddhist
e. Spiritually engaged without formalized religion
f. No formalized religion or spiritual beliefs
g. Other_________

Table 1

Participant Characteristics

Age, years
- 18-30 (33%)
- 31-50 (10%)
- 51-70 (37%)
- 71-90 (20%)
- >90 (0%)

Gender
- Male (13%)
- Female (87%)
- Identifies as (0%)

Level of Education
- Less than High School (0%)
- High School/GED (30%)
- Associates/Trade School (17%)
- Bachelors (37%)
- Masters or Higher (17%)

Marital Status
- Single (30%)
- Committed Relationship (17%)
- Married (47%)
- Divorced (3%)
- Widow (7%)

Race
- Asian/Pacific Islander (0%)
- Black (3%)

Caucasian (93%)

Latino (7%)

Native American (3%)

Religion

Protestant (0%)

Catholic (60%)

Jewish (0%)

Buddhist (0%)

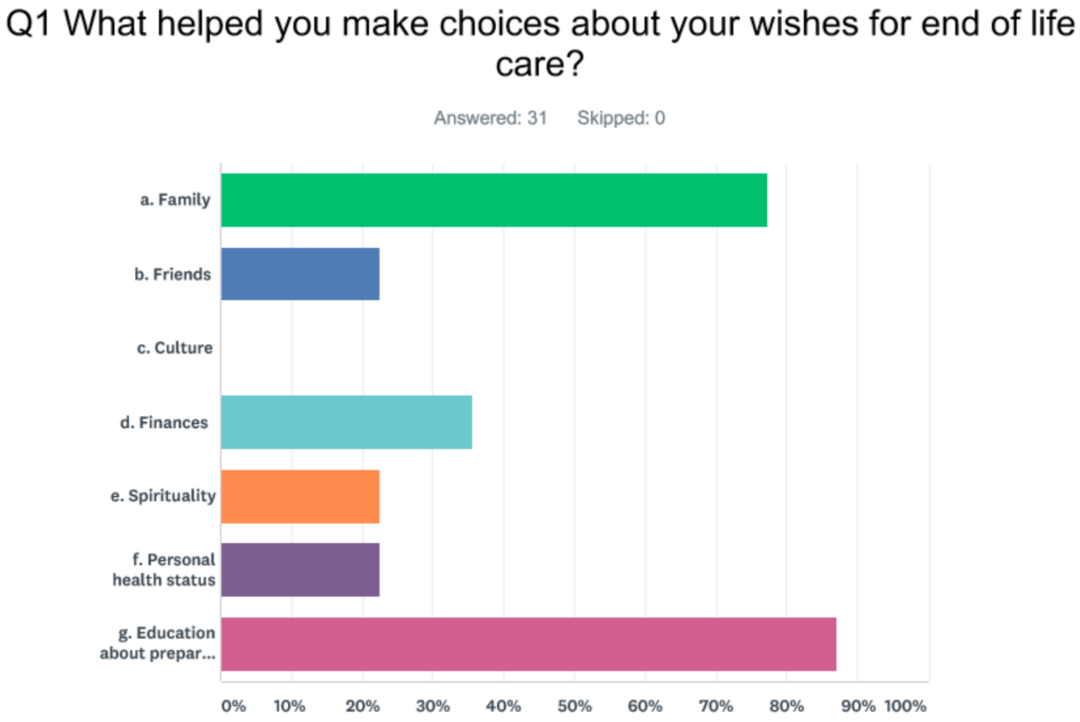
Spiritually engaged without formalized religion (28%)

No formalized religion or spiritual beliefs (12%)

Note. Participant Characteristics of those who completed survey. N=31

Figure 1

Quantitative Results by Question

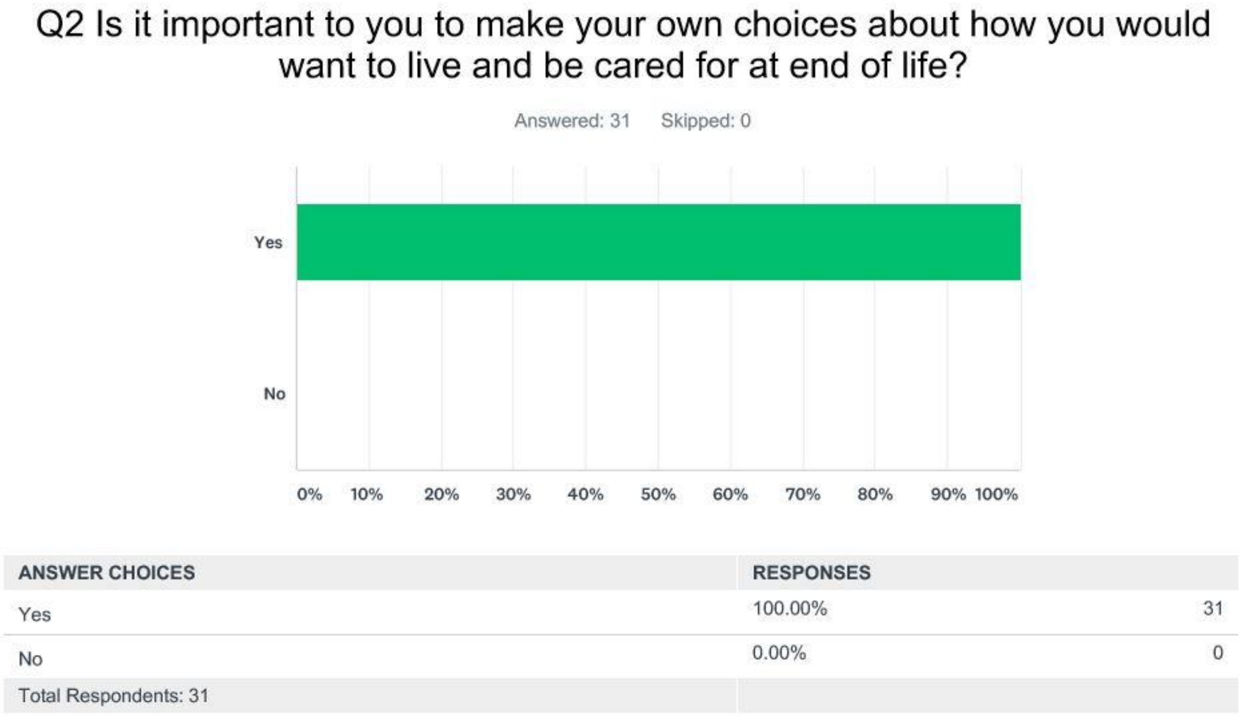


ANSWER CHOICES	RESPONSES	
a. Family	77.42%	24
b. Friends	22.58%	7
c. Culture	0.00%	0
d. Finances	35.48%	11
e. Spirituality	22.58%	7
f. Personal health status	22.58%	7
g. Education about preparing for end of life care	87.10%	27
Total Respondents: 31		

Note. Graph reflects participants responses regarding factors that influence choices for care at end of life. Participants were allowed to choose all responses that apply. Lower graph notes specific precentages and total number of responses per response choice.

Figure 2

Quantitative Results by Question



Q2 Is it important to you to make your own choices about how you would want to live and be cared for at end of life?

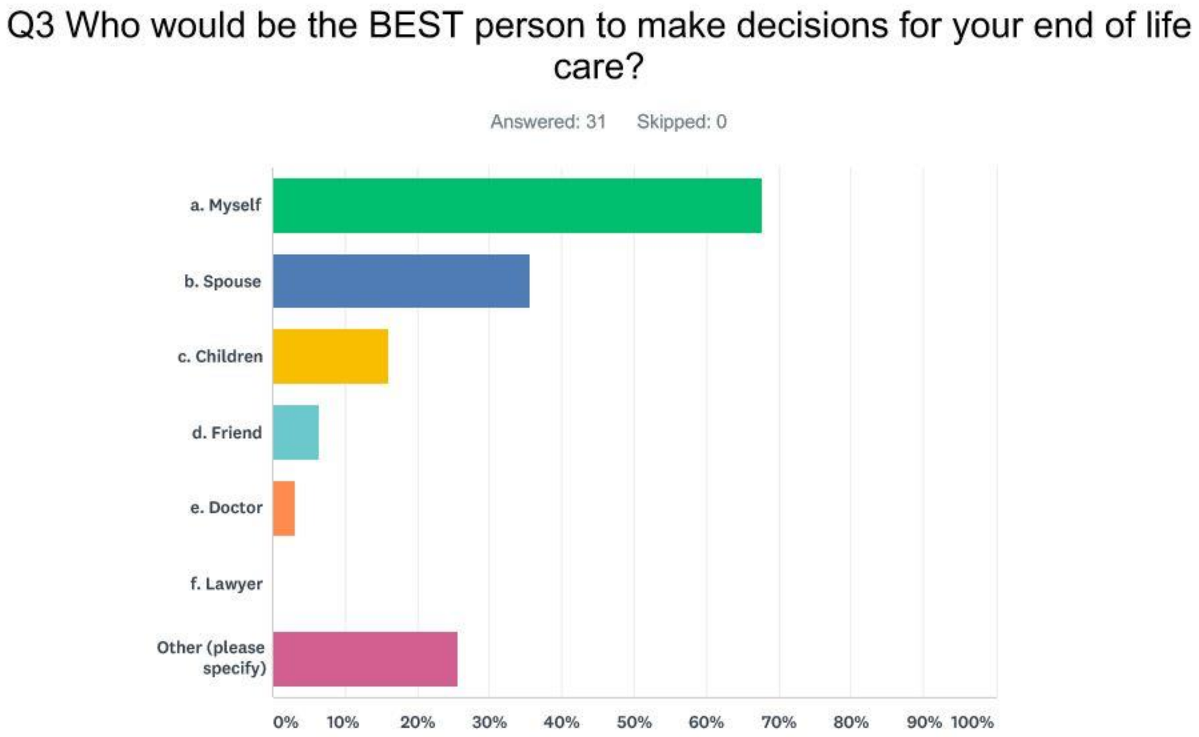
Answered: 31 Skipped: 0

ANSWER CHOICES	RESPONSES	
Yes	100.00%	31
No	0.00%	0
Total Respondents: 31		

Note. Graph reflects participants responses regarding importance of making own choices about care at end of life. Lower graph notes specific precentages and total number of responses to this question.

Figure 3

Quantitative Results by Question


Q3 Who would be the BEST person to make decisions for your end of life care?

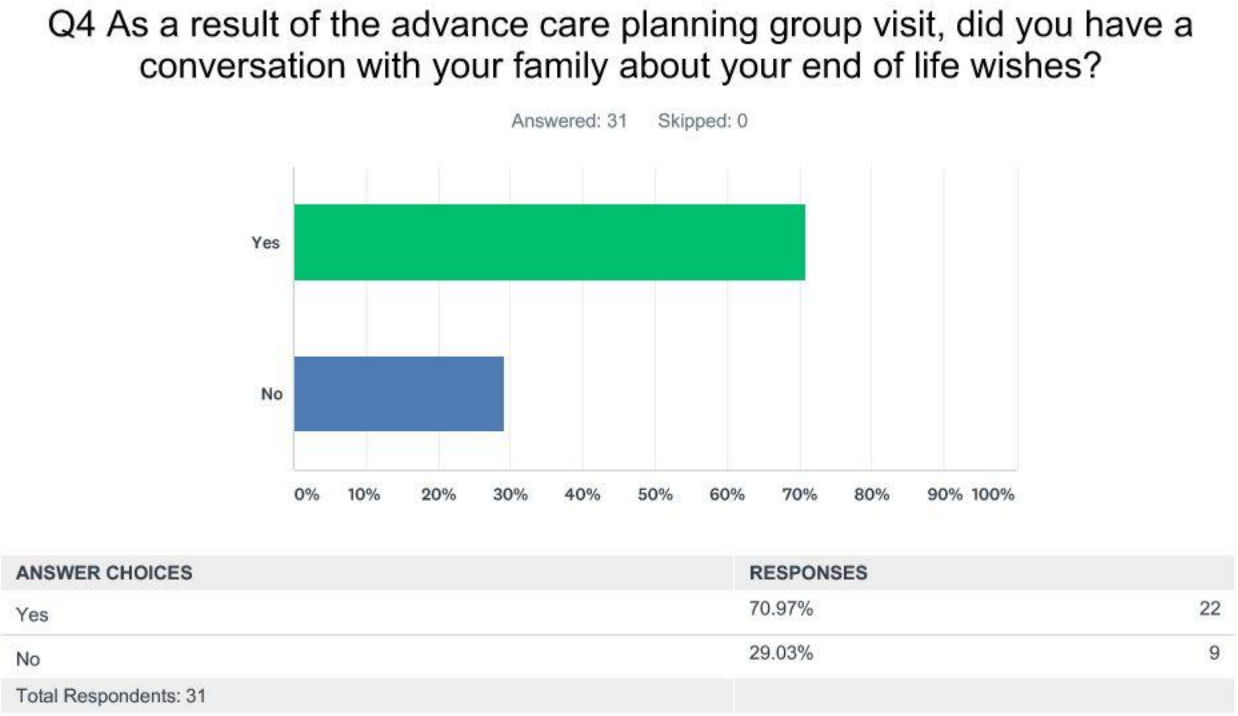
Answered: 31 Skipped: 0

ANSWER CHOICES	RESPONSES	
a. Myself	67.74%	21
b. Spouse	35.48%	11
c. Children	16.13%	5
d. Friend	6.45%	2
e. Doctor	3.23%	1
f. Lawyer	0.00%	0
Other (please specify)	25.81%	8
Total Respondents: 31		

Note. Graph reflects participants responses regarding BEST person to make decisions for participant's end of life care. Lower graph notes specific precentages and total number of responses to each choice. Some participants chose more than one choice.

Figure 4

Quantitative Results by Question



Q4 As a result of the advance care planning group visit, did you have a conversation with your family about your end of life wishes?

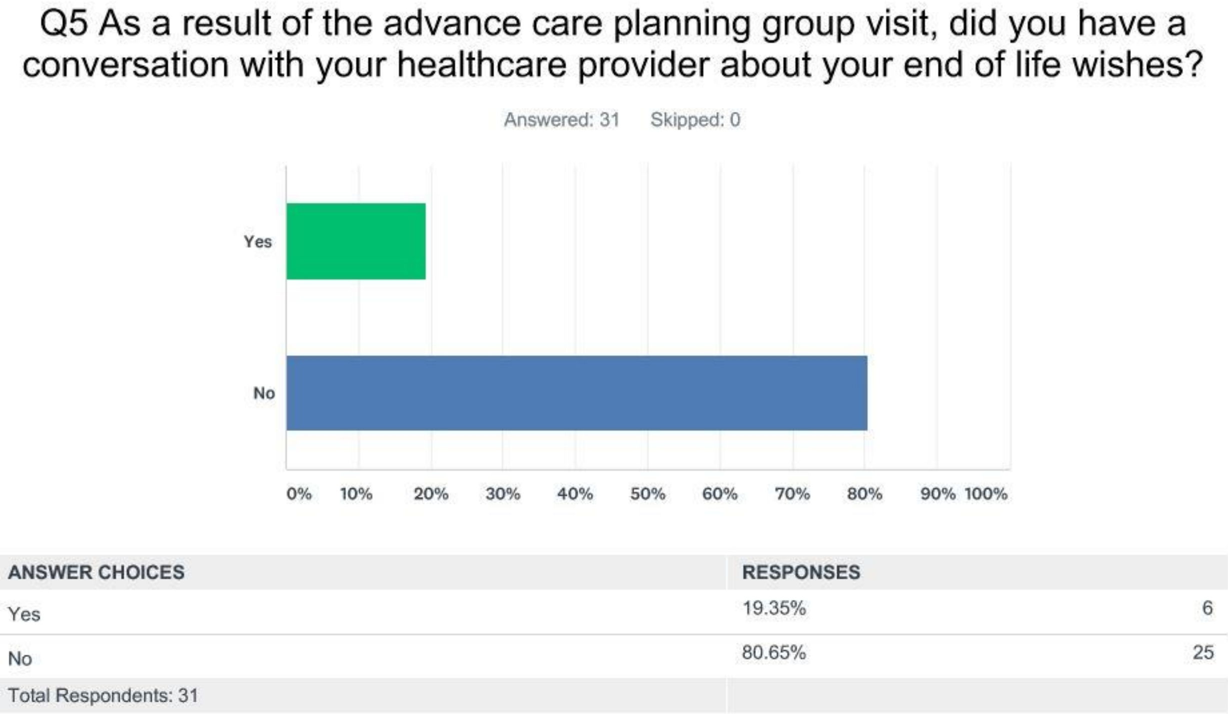
Answered: 31 Skipped: 0

ANSWER CHOICES	RESPONSES	
Yes	70.97%	22
No	29.03%	9
Total Respondents: 31		

Note. Graph reflects whether participants engaged in conversations with their family about their end of life wishes following the ACP session. Lower graph notes specific precentages and total number of responses.

Figure 5

Quantitative Results by Question



Q5 As a result of the advance care planning group visit, did you have a conversation with your healthcare provider about your end of life wishes?

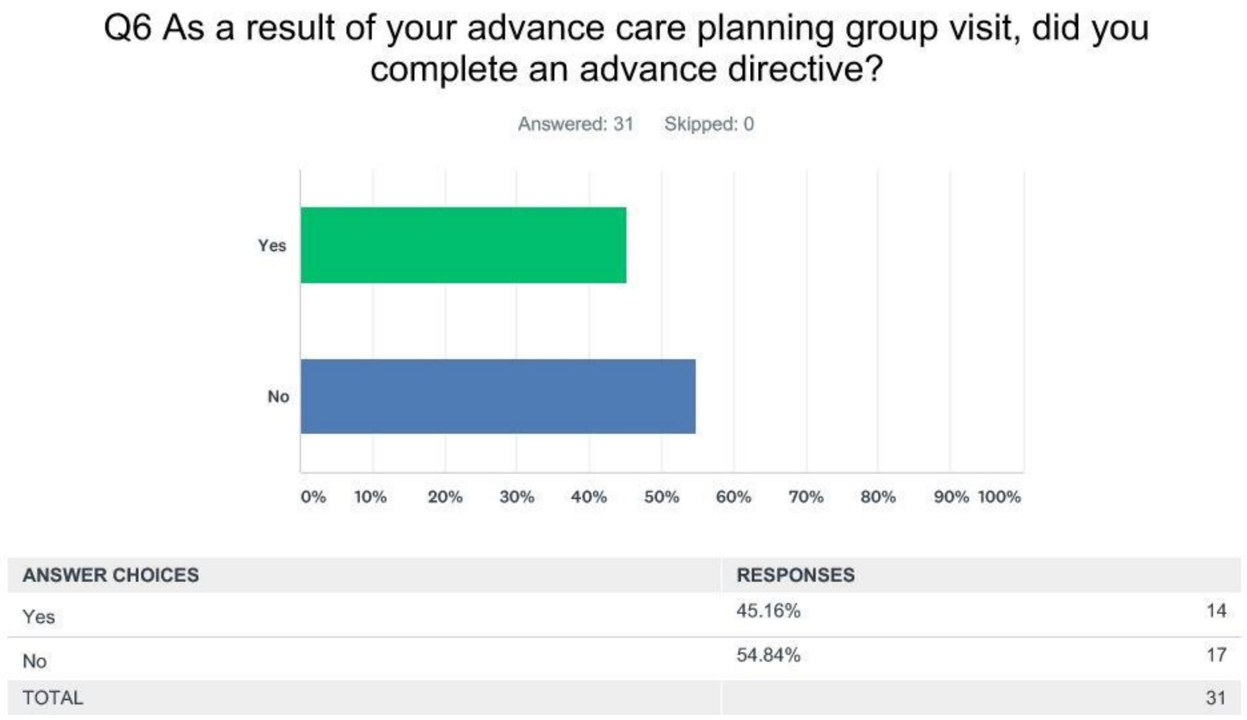
Answered: 31 Skipped: 0

ANSWER CHOICES	RESPONSES	
Yes	19.35%	6
No	80.65%	25
Total Respondents: 31		

Note. Graph reflects whether participants engaged in conversations with their health care provider about their end of life wishes following the ACP session. Lower graph notes specific precentages and total number of responses.

Figure 6

Quantitative Results by Question



Q6 As a result of your advance care planning group visit, did you complete an advance directive?

Answered: 31 Skipped: 0

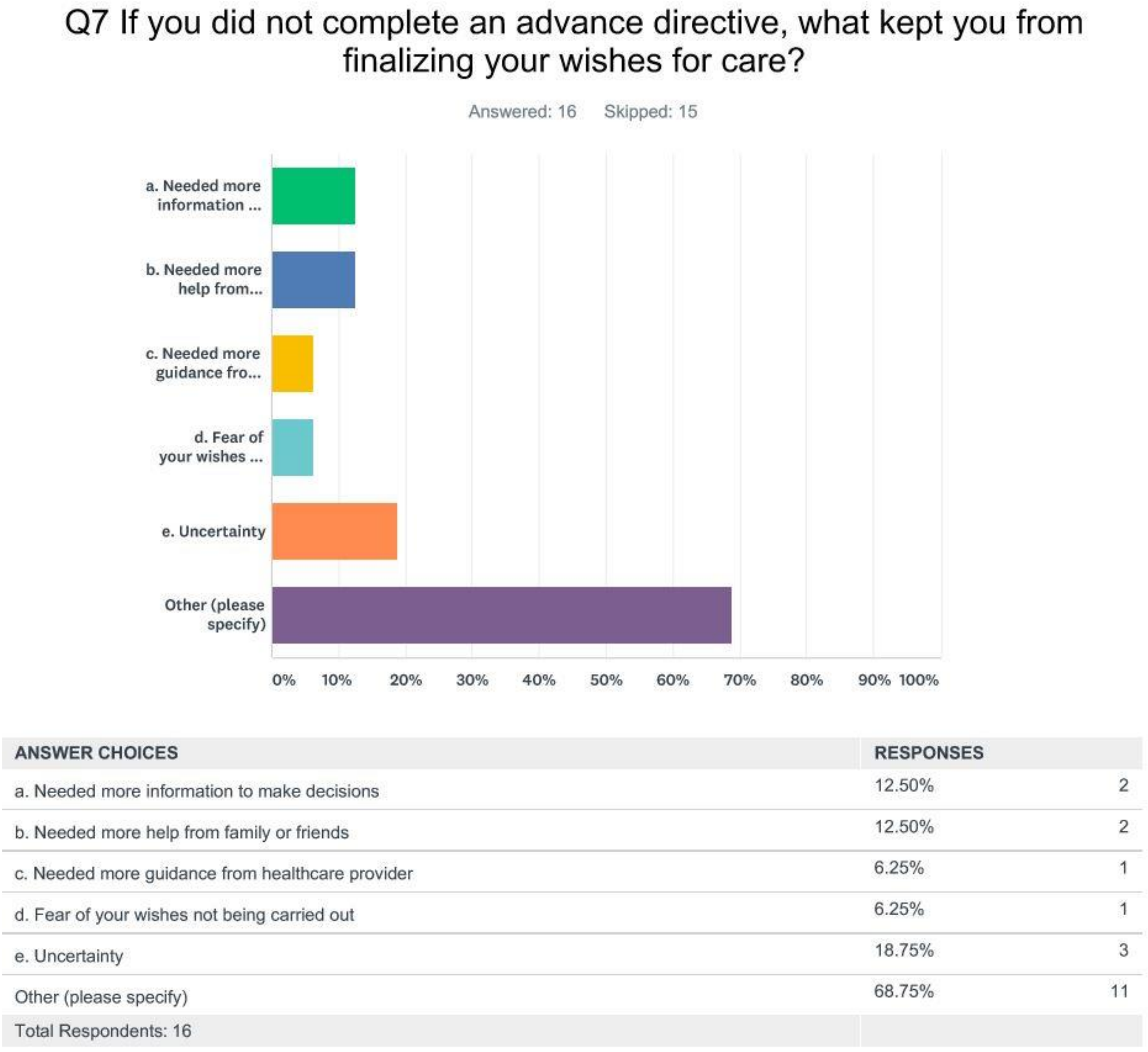
ANSWER CHOICES	RESPONSES	
Yes	45.16%	14
No	54.84%	17
TOTAL		31

Note. Graph reflects whether participants completed an advance directive following the ACP session.

Lower graph notes specific precentages and total number of responses.

Figure 7

Quantitative Results by Question



Q7 If you did not complete an advance directive, what kept you from finalizing your wishes for care?

Answered: 16 Skipped: 15

ANSWER CHOICES	RESPONSES	
a. Needed more information to make decisions	12.50%	2
b. Needed more help from family or friends	12.50%	2
c. Needed more guidance from healthcare provider	6.25%	1
d. Fear of your wishes not being carried out	6.25%	1
e. Uncertainty	18.75%	3
Other (please specify)	68.75%	11
Total Respondents: 16		

Note. Graph reflects factors that kept the participant from completing an advance directive. Lower graph notes specific precentages and total number of responses per choice. Some participants chose more than one choice.

Table 2

Qualitative Data: Coding Categories and Description of Themes

Research Question One: What are the individual, environmental and behavioral factors that influence healthcare decisions for end of life care?	**Research Question Two:** How do individuals, in their own words, describe the thought processes used for making decisions about advance care planning?
Survey question 8: *What were you thinking about when you were making choices about your end of life care?*	Survey question 9: *If you have had a past experience with death and dying, please share how this affected your personal wishes for care.* Survey question 10: *Please feel free to share any additional information that you feel was important to the process of preparing for your end of life care.*
Major Theme/Categories: Control over self and family • Do as I say • Avoiding burden	Major Theme/Categories: Experiences that impact decision making for care at end of life • Positive past experiences • Negative past experiences
Responses: *Do as I say* “Respect my decisions” (52) “Stand by my choices” (3) “Make my wishes known” (10) *Avoiding burden* “I did not want to burden my family with these decisions and I wanted to make sure that my wishes alone would be binding” (12)	Responses: *Positive past experiences* “My mom passed away…and she died in the privacy of our home and she looked so peaceful that I want to possibly go how she did” (52) “I was with my mother and father while they were passing. I felt it was a great honor to be there and was completely humbled by the experience. This has informed some of my decisions and thoughts regarding what I may wish for at end of life” (74)

“I was thinking of my parents. Being young, I would not want them to have to deal with hard decisions during an already hard time. I never want to be a personal or financial burden” (50) “That my family knows my wishes for care, not to be a burden” (10) “Understanding that those you love cannot always carry out your wishes. One needs to be very clear what you want to be done” (10) “That my wishes are known and to make things easier for my family when the time comes” (46) “My desire to have the least restricted environment and the least stress on my family” (74)	*Negative past experiences* “After seeing family pass without arranging everything, I will make sure my wishes and financials are clear” (21) “I watched a cousin bury her child (25 years) with a brain stem injury. No one was prepared and she struggled with end of life decisions” (60) “My husband died with a supraventricular aortic valve. As he struggled to breathe and filled up with blood thru aorta, heart and lungs, struggling for each breathe, my heart was literally breaking. I felt helpless. Only my promise to allow him to pass at home kept me from hospitalizing him. I don’t want my sons to experience a similar situation” (11) “Having worked in long-term care for 25 years, I have seen many residents have a long, drawn out death experience either because they never created advance directives for themselves while they were capable of doing so or because the family couldn’t let go and insisted that everything medically possible be done. By sharing my wishes and different scenarios with my husband and grown children, we all know the wishes of each other” (57)