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Empowering Individuals in the Community: Let Your Wishes Be Known Through Advance Healthcare Planning

Elizabeth Range Parnell

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Empowering Individuals in the Community: Let Your Wishes Be Known Through
Advance Healthcare Planning

by

Elizabeth Range Parnell

A capstone project submitted to the faculty of
Gardner-Webb University Hunt School of Nursing in
partial fulfillment of the requirements for the degree of
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Abstract

Advance healthcare planning in the community is a responsibility that requires informed decision-making, time, and individualized attention. Advance healthcare planning in the community should be an organized process of communication that is intended to assist, engage, and support individuals, their families, and friends in understanding, reflecting upon, and discussing the loved one's goals, values, and preferences for their future health care needs. The growing older adult population in the United States has increased age-related morbidities, and life-limiting chronic illnesses that increase the demand for quality, yet cost-effective end of life care. When a loved one is sick and unable to speak for himself or herself it can create an emotional turmoil, and uncertainties for family members and friends. Knowing and understanding the healthcare wishes of a loved one can provide a sense of peace for everyone involved. The purpose of this evidence-based project was to empower individuals living in a rural southeastern United States community with the knowledge to let their healthcare wishes be known. The Advance Directives Attitudes Survey was used to evaluate the project (Nolan, 1997). This project used a convenience descriptive design to provide education to 155 individuals at three senior service locations. Theoretical grounding for this study was Travelbee's (1971) Theory of the Human-to-Human Relationship Model. The role of the nurse needs to be able to relate to the patient as one human being to another human being, instead of the nurse to the patient (Butts & Rich, 2015 p283 -285; Travelbee, 1971, p61, 157). Limitations to generalization of the project includes that only adults over the age of 55 who speak, read, and write English were already attending a monthly support group to learn about different healthcare and community issues. Thus, limiting the ability to generalize the findings to all community-dwelling seniors.

Keywords: advance directive, Living Will, health care power of attorney, proxy

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SECTION I

Introduction

An estimated 1.5 million people in the United States (U.S.) die each year of a chronic illness. Of the 1.5 million people that die of a chronic illness, 70% are admitted to the hospital one or more times in the last six months of life. Studies have shown people living with chronic illnesses who have not previously discussed health care planning experience inadequately treated symptoms, fragmented healthcare, and poor communication with their providers (Gardner, 2012; Miller, 2017). Without advance healthcare planning, families and healthcare providers are left to make difficult healthcare decisions, often during emotional and traumatic times, for individuals who are no longer able to make decisions for themselves (Gardner, 2012; Miller, 2017).

Healthcare planning, especially end-of-life issues, should be discussed while individuals are still in good health. Just as individuals and families prepare for marriage and the birth of a child, it is just as important to prepare for healthcare journeys such as acute illnesses, chronic illnesses, and traumatic events. The Advance Healthcare Planning Project was developed to communicate with individuals in the community to assist, engage, and support them, their families, and friends in understanding, reflecting upon and discussing the individual's goals, values, and preferences for their future health care needs in case he or she is no longer able to make those decisions themselves (Alano et al., 2010; Davis & Panksepp, 2011; Gardner, 2012; Institute of Medicine [IOM], 2015; Miller, 2017; Patients' Rights Council, 2013; Salmond & David, 2005; United States Government Accountability Office [USGAO], 2015).

When individuals discuss their goals and preferences with family and friends, it leads to a greater satisfaction of their care and a clearer treatment plan of care (Gardner, 2012; Salmond & David, 2005). Taking the time to reflect upon what information family and healthcare providers should know before a critical situation occurs, provides vital information in the event a person is unable to speak for himself or herself (Alano et al., 2010; Davis & Panksepp, 2011; Gardner, 2012; IOM, 2015; Miller, 2017; Salmond & David, 2005; USGAO, 2015).

Background and Significance

In 2008, Medicare paid an estimated \$55 billion for doctors and hospital bills during the last two months of patients' lives. Approximately 30% of medical expenses may have had no meaningful effect on patients' outcomes. In 2013, research indicated 47% of adults over the age of 40 had an advance directive. However, this estimate varied by the type of provider and demographic characteristic. Research also indicates most people who completed an advance directive fall into specific categories such as being over the age of 65, white, female, with a higher education, or a higher income (Advance Care Planning, 2017; Davis & Panksepp, 2011; Gardner, 2012; Miller, 2017; Salmond & David, 2005).

The average life expectancy in the U.S. increased to 78.6 years of age in 2017 (National Center for Health Statistics, 2017). By 2050, the number of people in the U.S. that will be over the age of 65 is estimated to be approximately 43.1 million (Ortman, Velkoff, & Hogan, 2014). Diseases that once took a person's life such as pneumonia, cancer, and massive heart attacks have been replaced by long-term chronic diseases, such as advanced cancers, diabetes, kidney disease, chronic obstructive pulmonary disease

(COPD), human immunodeficiency viruses (HIV), and Alzheimer's disease. In addition, as the population has grown older so has the cost of providing healthcare. Research has shown healthcare costs increased dramatically in the last six months of life due to multiple hospital admissions, tests, and treatments (Advance Care Planning, 2017; Bastable, 2019, p120; Chastek et al., 2012; Gardner, 2012).

In 1990, the Patient Self-Determination Act (PSDA) was passed to ensure that a patient's right to self-determination in health care decisions are adequately communicated, as well as protected (Duke, Yarbrough, & Pang, 2009; H.R. 4449- Patient Self Determination Act, 1990). The PSDA is a federal law that makes it easier for individuals who have an advance directive or Living Will to be able to control decisions affecting their healthcare even after they are no longer able. The PSDA was also passed to encourage people to prepare an advance directive before one is needed (Douglas & Brown, 2002; H. R. 4449- Patient Self Determination Act, 1990; Kelley, 1995; Rao, Anderson, Lin, & Laux, 2014). However, a convenience sample by Salmond and Estrella (2005) reported that although federal law requires all patients admitted to a hospital be provided information on PSDA, only 82% of the sample reported receiving information on advance directive planning.

Duke et al. (2009) stated little progress had been made over the first 20 years advance directives was in existence, which suggests the importance of enhancing the efforts to increase the awareness, education, and attitudes of advance directives completion. These discussions should occur in an appropriate setting and an optimal time for the individual. Little has been done to increase advance directives completion rates which varied between 15-20% and have remained static since its inception in 1990 (Duke

et al. 2009). A study by Waldrop and Meeker (2012), indicated that although there have been widespread and various efforts in the U.S. to promote the completion of advance directives, efforts have shown limited success ranging from 5% - 15% (Waldrop & Meeker, 2012).

Definitions

- **Advance Healthcare Planning** involves understanding the different types of decisions that may need to be made in the event an individual is no longer able to speak for himself or herself and letting your family and healthcare providers know your preferences. These preferences are often put into a legal document such as an advance directive or Living Will (National Institute on Aging, 2018).
- **Advance directive** is a legally recognized document that assists an individual to state his or her healthcare wishes in the event he or she becomes unable to make decisions for themselves. Advance directives can be broken down into two main categories: a Living Will and a Durable Power of Attorney for Health Care (Patients' Rights Council, 2013).
- **Living Will** is a signed, witnessed, and notarized document that instructs a physician to provide or withhold medical interventions if the person is in a terminal condition and unable to make decisions concerning his or her medical treatment (Patients' Rights Council, 2013).
- **Durable Power of Attorney for Health Care (HCPOA)** is also a signed, witnessed, and notarized document in which the individual designates another person or persons to make health care decisions if the individual temporarily or

permanently becomes unable to make decisions concerning his or her medical treatment (Patients' Rights Council, 2013).

- **Health care proxy** is someone an individual chooses to make health care decisions if he or she is no longer able to speak for themselves. A health care proxy is also called a health care agent or Durable Power of Attorney for Health Care (The Conversation Project, 2017).

Specific Aims

The purpose of this Advance Healthcare Planning Project was to increase the knowledge and understanding of advance directives in the community. This increase in knowledge and understanding will empower individuals to be able to make health care decisions regarding advance directives and lead to an increase in advance directives completion rate. Most agree that people who are terminally ill should be given an opportunity to discuss their healthcare wishes for future health care and treatment preferences. The purpose of having discussions with terminally ill individuals about their health care wishes assist the individual to be able to anticipate how his or her condition may affect them in the future, and allow them to verbalize their preferences, choices, and or the decisions to refuse treatment, or to have treatment withheld if their condition is terminal (Parry, Land, & Seymour 2014). However, often these discussions are difficult for the healthcare provider, nurses, family, and friends to begin when he or she knows that the individual is terminally ill.

There are multiple benefits for informing individuals about completing an advance directive. Patients would ideally be aware of all the rights and options surrounding medical treatment in order to make decisions before he or she is unable to

communicate their wishes to medical professionals and loved ones. In addition, family and friends would benefit by knowing what the individual wanted at the end-of-life, eliminating the pressure from family members and loved ones to make the decisions surrounding medical treatment and end-of-life decisions (Parry et al., 2014). Further, medical professionals will know in advance what the individual would want, rather than making the tough medical decisions while trying to guess what the person would want to happen.

Most people agree that individuals who are terminally ill should be provided an opportunity to discuss his or her healthcare wishes for future health care and treatment preferences. The aim would be to assist terminally ill individuals in understanding their health care wishes and to help them anticipate how their condition may affect them in the future and allow them to verbalize their preferences, choices, and the decision to refuse future treatment (Parry et al., 2014).

When individuals discuss their goals and preferences with family and friends, it leads to a greater satisfaction of their care and a clearer health care treatment plan (Gardner, 2012; Salmond & David, 2005). Taking the time to reflect upon healthcare information and sharing those wishes with family members and healthcare providers before a critical situation occurs will provide vital information in the event a person is unable to speak for himself or herself (Alano et al., 2010; Davis & Panksepp, 2011; Gardner, 2012; Miller, 2017; IOM, 2015; Salmond & David, 2005; USGAO, 2015).

Specific Project Question

Will implementing an advance healthcare planning program increase the knowledge and understanding of advanced directives and empower individuals in the community to complete an advance directive?

SECTION II

Review of Literature

A relevant review of the literature to evaluate the interventions that have been used in the past to increase advance directive completion rates in the community have shown slow progress. This review demonstrates the need for an increase in educating in the clinical and the community setting about advance healthcare planning. Providing education and support in the community may lead to an increase in the completion of advance directives. Increasing advance directive completion rates will also assist patients in receiving the end of life care they prefer and will assist providers in providing the care the patient desires.

Patient and Provider Influences

A quantitative cross-sectional pilot study by Zhou, Stoltzfus, Houldin, Parks, and Swan (2010) used a web-based survey focused on oncology advanced practice nurses (APNs) to develop a statistically reliable and valid survey tool. This tool was used to assess and obtain a preliminary understanding of APNs knowledge, attitudes, and practice behaviors toward advance health care planning, and to discover any barriers that may impede advance care planning discussions. Guided by Ajzen's Theory of Planned Behavior, a 52-item questionnaire test-retest survey tool was developed. The survey was sent to 300 oncology APN's via e-mail (SurveyMonkey). Ninety individuals responded to the initial test survey. One survey was incomplete. After 30 days a retest was sent to the 89 participants who responded to the test survey, of which 53 responded to the retest survey.

Findings from the study revealed that APNs were moderately knowledgeable about advance care planning and demonstrated positive attitudes toward advanced care planning. However, there were several limitations to this pilot survey study, such as the small sample size. This study should be further validated using a larger sample size. In addition, the study was descriptive and relied on self-reporting, which could have been subject to bias or inaccuracy because the respondent did not estimate their knowledge, attitudes, or practice behaviors concerning advance care planning. Also, the measure of data concerning the participant's knowledge and attitudes were limited in number and scope, restricting the interpretation of results. Further, the population surveyed may have been working in different practice settings which could have led to different patient care emphasis such as nurses already working in hospice which may not need to practice advanced care planning.

In conclusion, this study (Zhou et al., 2010) found that although there had been an increase attention both nationally and internationally on palliative and hospice care, many front-line oncology nurses lag behind in the knowledge, skills, and competency to address end-of-life care needs for patients with advanced cancer. Although this study sample was small, findings indicated that advance practice oncology nurses are moderately knowledgeable with positive attitudes toward advanced care planning, which is encouraging. However, perceived barriers may hinder them from routinely performing productive discussions.

Billings (2012) recommended precautions should be put into place for advance care planning to encourage physicians to err on the side of preserving life when a patient's advance care directive is unclear. The impetus to influence patients in

completing advance care planning to decline life-sustaining measures was the focus of the study (Billings, 2012). Several studies were reviewed by Billings (2012) and found that only five of ten patients who indicated the desire for aggressive treatment received treatment consistent with previously stated wishes.

The goal of advance directive planning is to provide patients the autonomy to make decisions when they are no longer able. Billings (2012) states that previous drives to increase completion rates of advance directives with patients who were on Medicare led to feelings of “death panels”. The push for health care regulation requiring physicians to offer advance care planning during annual visits was sometimes construed as an attempt to sentence seniors and the disabled to a premature death rather than promoting autonomy within the age group. Further, the changes in healthcare cost reductions that limit access to expensive test and treatments only increase such concerns for the elderly. Billings (2012) also states that finding the right balance between respecting patient wishes and making decisions that may be construed as undermining the patient’s autonomy could be challenging. Providing clinicians with education concerning the apprehensions of older adults’ views on advance healthcare planning would help alleviate fear and promote patient autonomy.

Spoelhof and Elliott (2012) focused on improving advance directive completion rates through repeated conversation with patients in the clinical arena. Physician and patient barriers were identified. Physicians’ barriers included the lack of time, billing for service, meeting with proxy and family members, as well as feeling uncomfortable with the topic, preferring the patient initiate the conversation on advance directives. Identified patient barriers included the lack of interest or knowledge concerning advance directives,

the fear of burdening family or friends, the feeling that current health status did not correlate with the need to complete an advance directive, and the expectation that the physician would bring up the topic. Additional patient barriers included social isolation and lack of an available proxy.

Spoelhof and Elliott (2012) also identified cultural, racial, and ethnic factors which could affect advance directive completion rates. Traditional and spiritual beliefs may overlap in attitudes among ethnic and racial groups. Other barriers identified to implementing advance directives were the language using words that could be misleading such as “terminal, no hope of recovery, and no heroics”.

Spoelhof and Elliott (2012) completed two systematic reviews on how to increase advance directive completion rates which lead to the conclusion that involving the patient, the family, and the proxy decision maker early was the key to success. A three-phase clinical approach was used based on the patient’s life stage fostered effective and interactive discussions concerning completing an advance directive and updating as appropriate. Phase one occurred between 50-65 years old in the physician’s office during a routine checkup and be readdressed subsequently during annual visits. Phase two occurred when the patient experienced a chronic and progressive illness and updated if needed. The third and last phase occurred when the patient becomes frail or needs long-term care. The semblance of this three-phase model is to start the conversation concerning advance directives completion while an individual is healthy and to update as appropriate when health status changes. The three-phase model allows for open, honest discussion between the physician, patient, family, and healthcare proxy. Limitations to this study included conversations concerning healthcare planning, and waiting until a

person is between 50-65 years old, which does not address advance directive completion rates at an earlier age. Another limitation was the yearly evaluation and updating if needed which would add time to a physician's already conceived lack of time.

A cross-sectional analytical study by O'Sullivan, Mailo, Angeles, and Agarwal (2015) revealed that advance directives are underused in primary care practices. A self-administered patient questionnaire was used on a convenience sample of 1,104 adult patients in an urban family medicine teaching clinic during a one-week period in Hamilton, Ontario. Of the total 800 participants who completed the survey, 19.7% had previously completed advance directives, and 43.8% had previously discussed advance directives.

Of the participants surveyed, 21.4% rated advance directives as not important, 37.9% as somewhat important, 26.0% as quite important, and 14.7% as extremely important. The study indicated that only 5.7% of physicians initiated the topic with the patient. Participants (72.3%) indicated that patients should initiate the subject of advance directives where another 28.1% indicated they thought the family physician should bring up the topic (O'Sullivan et al., 2015).

Limitation of the study included it was conducted at one urban teaching clinic near an impoverished inner-city neighborhood of low socioeconomic status, new immigrants, and refugees, as well as university students, and associated professionals (O'Sullivan et al., 2015). Also, the study was completed during a one-week period. The authors stated that it would be difficult to generalize the results to a patient population that did not attend the clinic, citing they may not require medical services, may be institutionalized, or may receive care at home. The authors also concluded that advance

directives were not widely discussed with patients in this one practice. However, recommendations for future studies should include identified barriers to discussing advance directives, and the correlation of patient perspectives with physicians' beliefs and expectations.

Miller, Morris, Files, Gower, and Young (2016) conducted an eight-month study to determine if family members who faced making end-of-life decisions for loved ones in an intensive care unit (ICU) experienced a higher level of decisional conflict and greater decision regret than other decisions they had to make. Eligibility criteria for this study included that patients must be at least 18 years old, received mechanical ventilation longer than 96 hours, and had a surrogate (proxy) decision maker. Surrogates were required to identify a decision (end-of-life decisions or non-end-of-life decisions) made on behalf of the patient. If the surrogate was unable to identify any decisions, he or she was excluded from the study.

Two separate questionnaires were used, the open-ended Decision Conflict Scale (DCS) (16-item, on a 5-point Likert scale), and the Decision Regret Scale (DRS) (5-question scale, on a 5-point Likert scale). The DCS was given to the surrogate during his or her family member's ICU admission and was contacted again 30 to 60 days after the initial contact to respond to the DRS questionnaire.

Forty-two surrogates (mean age 40 years old, 70% female) of patients (mean age 58 years old, 45% female) who met criteria agreed to participate in the study. Forty surrogates were able to identify a decision they made on behalf of the patient and complete the DCS. Thirty-four surrogates responded to the follow-up DRS questionnaire. Surrogates in this study consisted of the patient's spouse (33%),

son/daughter (30%), parents (15%), siblings (13%), and other relatives (9%). Forty-eight percent of the decisions identified were end-of-life decisions. Fifty-two percent made decisions such as intubation (23%), tracheostomy (10%), dialysis (5%), and other decisions (14%). The DCS results indicated low to moderate levels of decisional conflict, and overall decisional regret scores were low.

Miller et al. (2016) identified several limitations to this study such as having a small sample size, and the study was conducted at one medical intensive care unit. The DRS indicated that evaluating surrogates at 30-60 days may have been a poor metric to evaluate decisional regrets and should be evaluated at the time the decision is made. The results of this study adds to the body of knowledge on appointing a surrogate, and the effect decision making has on a person.

Educational Influences

Dobbs, Park, Jang, and Meng (2015) focused on racial and ethnic disparities in advance directives completion rates in the community-dwelling older adult population. Prior research has been on non-Hispanic whites and African Americans; however, minimal research was identified regarding advance directive completion rates for other groups of ethnic minorities. Research has shown that advance directive completion rates among the older population are as high as 70% when admitted to a hospital. However, for the general population living in assisted living, nursing homes, and other community-dwelling facilities, the completion rate is only 36%. The focus of this study was to examine the effect of acculturation on awareness of advanced directives and completions rates in older Korean-American adults living in community-dwelling facilities.

This cross-sectional study consisted of 675 participants and used Andersen's Behavioral Health Model to assess participants' knowledge of, and completion of advance directives (Dobbs et al., 2015). The study was conducted over six months in 2008 in west-central Florida. Criteria for participation consisted of the following: participants had to be 60 years old or older, able to read and understand the Korean language, as well as complete the survey in Korean.

The study (Dobbs et al., 2015) results supported the authors' hypothesis that the higher the level of acculturation in older Korean-American adults, the more likely there would be an awareness and completion of advance directives. Approximately 82% of participants in this study reported previous knowledge concerning advance directives, and yet only 18.6% reported that they had completed an advance directive, which highlighted the authors hypothesis that the two outcome variables (acculturation on awareness of advance directives and completions rates) were highly correlated (Spearman correlation coefficient = 0.53, $p < .001$). Dobbs et al. (2015) indicated that awareness without acculturation does not promote completion rates of advance directives in Korean-American older adults.

This study (Dobbs et al., 2015) had several limitations including drawing causal inferences regarding the relationship between predictors and outcomes and using simple descriptive questions regarding awareness and completion of advance directives which did not address more complex issues within the culture. This study provides important findings for future research concerning the end of life care and education of advance directives in ethnic minority populations. Further, this study was generalizable and

would be more effective using a longitudinal study design to address questions on how awareness of advance directives affects completion rates in Korean-American adults.

A study by Boucher, Guadalupe, Lara, and Alejandro (2014) focused on East Harlem, New York City older Hispanic populations to evaluate the health care decision-making process with a focus on end-of-life decisions. The qualitative study was completed at two senior centers. Criteria of the study included men and women 40 years old or older who had the ability to communicate in English or Spanish. Two-hour focus groups were conducted over three days using English and Spanish speaking moderators and research assistant. Each session was recorded. A convenience sample of 21 participants who self-identified as Hispanic or Latino were included in the study. The average age of the two focus groups was 65 years and eight months.

There were multiple common themes that emerged from this study (Boucher et al., 2014). A common thread throughout the groups was the need for control of healthcare decisions that were affecting them, expressing the need for a physician-patient relationship, and of patient empowerment. Although the study provided added information for future research in culturally diverse populations, it was limited in several aspects, such as a small sample size and unknown health literacy. Although the sample size (21) was small, the authors stated the model used in this study was a successful community-based partnership that could be used in future research to educate, support, and empower individuals in similar populations.

A study conducted by Volandes et al. (2012) explored whether an educational video about life-prolonging, basic, or comfort care would make an impact preference for resuscitation in patients with advanced cancer. Eighty patients diagnosed with advanced

cancer from an ambulatory oncology practice affiliated with Memorial Sloan-Kettering Comprehensive Cancer Center completed a verbal pre- and post-survey before and after viewing the video. Eligibility criteria included patients with terminal, progressive cancer with poor prognosis and whose treatment plan was palliative.

Compared to baseline (pre-survey) there was not a significant ($p=0.28$) change after viewing the video on life-prolonging care, basic care, or comfort care. However, after viewing the video more patients did not want cardiopulmonary resuscitation (CPR) (71% vs. 61%, $p=0.03$). There was also a significant ($p<.001$) increase in goals of care and the likelihood of resuscitation. There was no correlation between expressed wishes and documented code status. Of the patients who did not want CPR or ventilation, only four (5%) had a do not resuscitate (DNR) order in their medical record.

Results of the study (Vollandes et al., 2012) indicated viewing an educational video on life-prolonging, basic, or comfort care did not change the patient's preference. The video was highly acceptable by the patients (80%) and significantly increased a patient's knowledge ($p<.001$) by visualization of goals of care, thus promoting more informed health care decisions. Findings indicated that using support tools such as a video could supplement patient-physician discussions concerning advance directive planning.

Vollandes et al. (2012) stated there were limitations to the study such as visual images may bias patients in certain decisions. Another limitation of the study was that it was completed in one New York City location mostly with highly educated (83.7%), white (91.3%), male (72.5%) patients with prostate (45%) cancer. Additionally, the study population already had an advanced directive (75.0%) and may have already

considered decisions on overall goals of care. This study was generalizable; however future research should be done in multiple settings to include a diverse culture and ethnic backgrounds, as well as the socio-economic arena.

Detering, Hancock, Reade, and Silvester (2010) studied the impact of advance care planning on end of life care in elderly patients in Melbourne, Australia. A randomized controlled trial was conducted on 309 competent medical inpatients who were ≥ 80 years old and spoke English. Patients were followed for six months or until death. Patients were randomized to receive traditional care or traditional care plus facilitated advance healthcare planning. Facilitators were trained using the Respecting Patient Choices Model. The facilitation of advance healthcare planning aimed to support patients in reflecting on their own goals, values, and belief, and to consider future healthcare preferences. Patients were also assisted in appointing a surrogate/proxy as well as having their wishes documented.

The aim of the study (Detering et al., 2010) was to see if participants completed advance directives prior to a hospital discharge and to evaluate if the facilitated intervention assisted in whether a patient's end of life wishes was known and respected. Participants were contacted by phone immediately after hospital discharge, and again at three and six months. If a participant had died, the appointed family member was contacted and interviewed about three months after the participant's date of death. Of the 309 participants recruited for the study, 154 were randomly chosen to receive facilitated healthcare planning. In the intervention group, 125 (81%) received advance care planning, and 108 (84%) expressed their wishes and appointed a surrogate/proxy ($P < .001$). Fifty-six participants died within six months of entering the study and showed

that the intervention group (86%) end of life wishes was more likely known than the intervention group (30%). The family members of the intervention group reported significantly less stress, anxiety, and depression than the family members of the control group. This study showed that advance care planning carried out by trained facilitators improved end of life care by enabling patient's wishes to be determined, documented, and respected. Results showed that 92% of the participants whose wishes were known were honored. This study was generalizable for future research.

Leung et al. (2016) performed a prospective cohort study on homeless men living in Toronto, Canada. The goal of the study was to determine if a shelter-based intervention to assist homeless individuals in completing their advance directive are more likely to have information documented and utilized during future hospitalizations. Of the 205 homeless men enrolled in the study, 104 completed an advance directive. Participants who completed an advance directive were provided copies, and a copy was electronically stored in an advance directive database. Hospitals within a one-mile radius of the shelters were provided access to the advanced directive database. A one-year follow up chart review found that 38 participants who completed an advance directive and 37 participants who did not complete an advance directive had at least one hospitalization. Of the individuals who completed an advance directive and were hospitalized, it was found that the information was referenced in the chart (26%). It was determined that the advance directive had a direct impact on their treatment decisions (5.3%). Leung et al. (2016) reported the finding demonstrated that when homeless individuals can prepare advance directives identifying a proxy decision maker, it allowed the healthcare team to improved patient-centered care.

Limitations included being a small non-randomized study. Participants were recruited from one men's homeless shelter which may not allow the study to be generalizable to other homeless populations and settings. Outcomes came from chart reviews of the six area hospitals; however, participants could have been admitted to a hospital outside the one-mile radius of the shelter. In conclusion, this study does provide evidence that a shelter based advance directive intervention program for homeless individuals can increase the likelihood that healthcare professionals have access to specific information on patient preferences in future hospitalizations.

A study conducted by Leung, Nayyar, Sachdeva, Song, and Hwang (2015) on the chronically homeless population who have shown to have a high rate of hospitalizations and death would benefit from the completion of advance directives. Participants were recruited from programs that served chronically homeless people in Canada who were in managed alcohol harm reduction programs, or hospital programs that treat homeless individuals in acute or chronic illness programs. There were three requirements to be included in the study: (1) a resident in a shelter program, (2) able to communicate in English, and (3) had decisional capacity.

All participants were privately interviewed by a trained counselor, followed by a survey on their social-demographic characteristics and attitudes toward end-of-life care and death. A \$10 honorarium was given to each participant at the end of the survey and participants were informed that completion of an advance directive was optional. Afterward, each participant was invited to fill out an advance directive by one of the group surveyors (three medical students and two physicians). Of the 205 residents between the age of 24-78 at a homeless shelter, 103 participants (50.2%) completed an

advance directive, 89 (43.4%) declined, and 13 (6.3%) were found to lack the capacity or English comprehension to complete an advance directive. Of the participants who filled out an advance directive, 61.2% named a proxy decision maker to make healthcare decisions if they were no longer able to do so. In addition, 94.1% indicated that they would want to receive cardiopulmonary resuscitation in the event of a cardiorespiratory arrest if there was a chance that they could return to their present state of health. The findings of this study also indicated homeless individuals do not always have the opportunity to complete an advance directive.

Final data collected in the study (Leung et al., 2015) were analyzed using chi-square tests and t-tests to compare the characteristics of those who did and did not complete an advance directive. Mann-Whitney U tests were used to compare the attitudes of the participants toward end-of-life care. A Chi-square test was used to compare treatment preferences among Caucasians and non-Caucasians. The level of significance of all test was $p < 0.05$.

Limitations of this study (Leung et al., 2015) included participants from only one homeless shelter for men. The study was based on subjective self-report which may have led to recall bias. In addition, the study did not address if the completion of advance directives by homeless individuals is useful in guiding future health care decisions. However, the study emphasized that having access to end-of-life services and completing an advance directive may help improve the quality of care when hospitalized for this study population of homeless men.

Bravo et al., (2016) assessed the efficacy of healthcare advance planning interventions. The study focused on how interventions could improve the accuracy of

healthcare proxy's decision-making, and how it would affect the frequency of documented preferences for healthcare. In addition, this study investigated the financial impact on the healthcare system.

This was a single-blind, stratified, randomized, controlled trial study that consisted of 235 older adults, along with their previously selected proxy (Bravo et al., 2016). Eligibility criteria for participation in the study consisted of community-dwelling individuals age ≥ 70 , who spoke French, were free of cognitive deficits and lived in the Eastern Townships of the province of Quebec. Eligibility criteria for proxies were that they must be fluent in French and live in the same region. At the beginning of the research, a baseline was completed using hypothetical clinical situations and vignettes using four conceivable health conditions (i.e., participant's current health status to severe dementia). The healthcare cost was estimated under each situation. There were two visits in the home with each (participant and proxy) one week apart to review the results by a trained research facilitator in hopes that the participant would convey his or her wishes to the proxy. In addition, the participants were provided a "My Preferences" guide to help convey their wishes to the proxy. Follow up assessments were repeated at the end of the two intervention visits, once monthly over three months, and again at six months. During the final visit, the information was assessed for improvement in how accurate the proxy was able to determine the participant's wishes and if there would have been a financial cost savings for the healthcare system.

Findings of this study (Bravo et al., 2016) suggested an ongoing dialogue between patients and their proxies about end-of-life preferences improved the accuracy of the proxy's being able to relay the wishes of the participant. In addition, this study was

generalizable, and the results add to the current knowledge of advance healthcare planning for professionally-led discussions of preferences to improve proxy decision making.

Interventions

Campbell, Edwards, Ward, and Weatherby (2007) conducted a study to describe factors that influence the completion of advance directives. The study consisted of a convenience sample of 206 participants from six senior centers in Tennessee, USA. The center's newsletters and posted flyers were used to encourage participation in the study. Eligibility criteria included participants must be 60 years old or older, alert, and oriented to place and person and able to speak and read English.

Using a five-section questionnaire, (1) demographic, (2) the Advance Directive Attitudes Survey (ADAS) developed by Nolan (1997) to assess perceptions of advance directives, (3) the Short Test of Functional Health Literacy in Adults (STOFHLA) to measure health literacy, and (4) the Generalized Self Efficacy Scale (GSES), was used to indicate if personal beliefs and resulting actions are responsible for successful behavioral outcomes. Finally, (5) the Multidimensional Health Locus of Control (MHLC) was used to measure internal locus of control.

The participant's age range was between 64-95 (M=73.4). The sample population consisted of 81% female, 86% white non-Hispanic, 11%, Black, and 1% Asian, Hispanic, or American Indian. Participants reported their education level as follows: 21.2% completed at least some college, 42% high school, and 1% reported having a sixth-grade education. Almost 64% (63.9%) reported having an advance directive; 36.1% reported not having an advance directive. Of the 206 participants, 47.8% reported they had not

received any information on advance directives, while 46.6% reported they have never received any information from hospitals or other agencies.

Results from the ADAS questionnaire mean score was 3.24 indicating that on average participants scores were more positive than negative. The STOFHLA mean score of 29.10 out of 36 indicated more adequate than inadequate health literacy. The GSES mean of 3.13 of a possible 4 indicated a strong sense of self-efficacy or control, and the mean for internal locus of control was 4.44. Data obtained from the surveys were used to construct 15 independent variables for logistic regression analysis to develop a predictor model for completion of advance directives. Bandura's triad of determinants was represented in the analysis to develop the Main Effects Model and the Parsimonious Model, which showed that 25% of older adults had completed an advance directive. The results also indicated both cognitive and affective factors influenced desired behavior.

There are several limitations to this study (Campbell et al., 2007). The self-selection recruitment method of using the senior center's newsletters and flyers may have biased the findings, and the overall length of the questionnaire might have influenced the number of completed surveys. The findings in this study are limited; however, the information obtained could benefit health care professionals about possible factors that might influence the completion of advance directives in older adults.

This study results indicated the completion of an advance directive was influenced by information, attitudes, and health literacy (Campbell et al., 2007). The authors recommended future studies be done using Bandura's Social Cognitive Theory to explain the relationship of possible determinants on end-of-life decisions. This study can add to the literature; however, the sample size is too small for drawing generalizations,

Salmond and Estrella (2005) performed a descriptive correlational survey study to identify significant attitudes and barriers that influence patients admitted to a medical/surgical unit in completing an advance directive. Although with the passing of the Patient Self-Determination Act (PSDA) in 1990 requiring all healthcare institutions receiving funds from Medicare and Medicaid to inform patients of their right to participate in health care decisions, including the right to complete or decline an advance directive, the rate of completing an advance directive continues to be low. The lack of knowledge on advance directives has been thought to be a significant factor as to why many people fail to complete an advance directive.

A convenience sample of patients was provided a face to face interview and the option to complete an Advance Directive Attitude Survey. There were three criteria to participate in the study, each participant (1) must be at least 18 years old, (2) must be alert and oriented to person and place, and (3) be able to speak and understand English. Although hospital policy requires all patients admitted to a hospital be provided information on PSDA, only 82% of the sample reported receiving information on advance directives and only 18% had completed an advance directive, 8% completed an advance directive after the interview.

Salmond and Estrella (2005) found that the basic attitude towards advance directives was somewhat positive; also, there was little difference in attitude between patients with or without an advance directive. In addition, the findings of this study indicated that the low completion of advance directives among patient's admitted to the medical-surgical unit suggest that there are other factors beyond having access to the information that influences an individual's decision to not complete an advance directive.

The time it takes to educate a patient appropriately and to clarify terms and meanings of an advance directive may be more than can be completed in the confines of an acute care hospital.

The findings from this study (Salmond & Estrella, 2005) also supported that education and understanding of advance directives do not directly translate into completion, but it may have some influence. Indication for future research using random sampling utilizing multiple hospitals would enhance the generalization of the findings. In addition, using a qualitative research design would allow the study to explore different factors related to individuals who decline to complete an advance directive. All areas should be considered using an ethnically diverse patient population. Both would need to be compared to find out if hospitals' policies on advance directive information need to be revised.

Douglas and Brown (2002), completed a study on hospitalized patients' attitudes toward advance directives and to see if demographic difference played a part on whether patients completed or did not complete one. A convenience sample of 30 participants were surveyed over a three-week period from an oncology and a medical telemetry unit at a teaching hospital in North Carolina. Eligible criteria included that participants must be over the age of 18, oriented to person and place, and already been approached by a registered nurse (RN) regarding advance directives.

An adapted version of Nolan and Bruder's (1997) advance directive attitude survey (ADAS – 16 item, 4-point Likert scale) and demographic form was used to collect data. Validity and reliability were established on the adapted tool. Participants were provided a copy of the ADAS tool to read along as the researcher read each question.

Participant's age ranged between 24 and 85 years, with a mean age of 57 years. Nineteen reported their race as Caucasian, 10 were African American, and one was Hispanic. Reported education level ranged from grade school or junior high (10), high school (13), or had completed college (7). Participants with the highest mean score were female (19), African Americans, between the ages of 35-39, with a high school education. Further, participants reported their health status as poor (7), fair (9), good (12) or very good (2). Hospitalization in the past two years was reported as the first time (6), two to five times (18), more than five times (6). Of the 30 participants, 23 (77%) reported receiving information on advance directives prior to this study and seven (23%) had not. The mean (66.9) and median (66) scores (total range 22 to 88) on the ADAS were examined and indicated a moderately positive attitude toward advance directives. The data indicated that female, Caucasian, over the age of 65, with less than a high school education and perceived their health status to be poor were more likely to initiate advance directives.

A limitation of this study was its small sample size. The authors recommended that long-term studies be done to determine the extent to which advance directives could affect end-of-life care, and to identify factors that might prohibit advance directives from positively affecting patient care (Douglas & Brown, 2002).

Sinclair et al. (2016) performed a multicenter randomized controlled study with a preference arm allowed individuals with a strong preference to either receive or avoid the intervention to be assigned to their preferred group) to evaluate whether nurses who learned advance care planning interventions would increase a patient's willingness to complete an advance directive. The study setting was in a metropolitan area and a rural setting in Australia. After screening, 149 participants met the criteria for the study.

Study criteria included participants must be >18 years old, and either been diagnosed with a respiratory malignancy, chronic obstructive pulmonary disease, or interstitial lung disease with a prognosis of less than one-year mortality rate. The intervention provided discussions on advance care planning by nurse facilitators which prompted further discussions with doctors and family, which lead to the individual completing an advance directive or appointing a proxy medical decision maker. The outcomes measures were self-reported and by medical note audits at baseline and again at six months.

Sinclair et al. (2016) found that participants were receptive to nurse-led facilitated advance care planning sessions which increased discussion and completion of documents. At six months advance care planning was significantly higher ($p < 0.005$) in the intervention arm (54 out of 106 or 51%), compared to the conventional care (6 out of 43, or 14%). Individuals having had discussions with doctors also were significantly higher ($p < 0.005$) in the interventional arm (76 out of 106, or 72%) compared to the conventional care (20 out of 43, or 47%).

This study (Sinclair et al., 2016) has several limitations such as the study arm was unblinded; the preference design was bias because participants were able to select their intervention group. Due to the attrition of participants (patients dying) interpretation of follow up was not always possible, leading to a decrease in sample size. Additionally, utilizing the same two nurses to collect data from both study sites could have led to bias. However, the study did indicate that 78% of the surveyed patients and 98% of chart audits indicated completion of advance care planning among a specific group with advanced respiratory disease. The authors suggested that this outcome was because of

the ongoing relationship between the nurse and the participants, leading to a higher success rate of completion of advance directive planning.

This study (Sinclair et al., 2016) provided a systematic screening process to identify patients with end-stage lung disease at high risk of death, leading to programs that aim to promote advance directive planning with prepared nurses. Relationship building between the nurse and participants may have been a strong motivator for the participant to complete his or her advance care plans.

Tan and Jatoi (2011) performed a retrospective exploratory study that focused on whether the prior existence of an advance directive or the route (e.g., clinic, hospice, emergency department, or transferred from an outside hospital) of hospital admission with a face-to-face discussion concerning advance directive impacted or lowered end-of-life hospitalization cost among cancer patients with incurable solid tumors. A single facility study focused on 120 oncology patients with incurable solid tumors over two years. The study consisted of 62 men and 58 women with a median age at death of 61 years old.

Medical records were examined to obtain the information on whether the patient had an advance directive before hospitalization or had a face-to-face discussion about advance healthcare planning when admitted. Data were collected on patients' age at death, gender, cancer diagnosis, admission diagnoses, whether the cancer was curable or not at the time of admission, and whether an advanced directive had been completed before hospital admission. In addition, data on how the patient was admitted to the hospital (clinic, hospice, emergency department, or transfer from outside hospital) was also collected. The hospital accounting services provided the total cost of medical

services on patients in the study. Comparative statistics were performed using a Wilcoxon Rank Sum test and t-test. Median time in the hospital per patient prior to death was four days.

The finding showed there was not a significance ($p=0.24$) in the difference with the costs of hospitalizations in oncology patients who were admitted with an advanced directive or received a face-to-face discussion about end-of-life decisions when admitted to the hospital. However, this study (Tan & Jatoi, 2011) underscores the need for further research on how best to decrease the utilization of expensive, at the end-of-life, on heroic measures among cancer patients with incurable solid tumors. In addition, the authors suggest that there needs to be an improvement in educating and helping patients understand end-of-life and heroic interventions, such as cardiopulmonary resuscitation, intensive care units, and intubation. By educating patients on futile outcomes, it will allow them to convey more precisely their feelings on what their wishes may be at the end-of-life and their feelings on heroic measures. A limitation of this study was that it was a retrospective study design with only one institution.

A recommendation to pursue further studies on whether face-to-face discussions about advance directives prior to a significant decline in health would change the cost of end-of-life hospitalizations. In addition, research should focus on the negative impact on patients that range beyond a financial cost such as decreased quality of life for patients, and poorer coping with bereavement among family members.

A study by Rao et al. (2014) characterized who did, and who did not have an advance directive in the United States and examined factors associated with completion rates. Of the 7,946 adults who participated in the 2009 and 2010 postal mail survey

(Porter Novelli HealthStyles Survey), 2,093 (26.3%) reported they had an advance directive. The advance directive completion rates were significantly linked to older age, higher education, and a higher income. Participants who reported having a chronic illness and access to regular health care were more likely to have an advance directive. Whites were more likely to have an advance directive than other racial and ethnic groups. Lack of awareness (24%) was the most reported reason for not having an advance directive, and another reason for not having an advance directive was the belief that their family was aware (16.4%) of their wishes. Findings indicated 67.8% reported concerns about their end of life care, costs of care, the pain they might experience, and concerns about their comfort and dignity.

This study (Rao et al., 2014), indicated a disparity in race and education in advance directive completion rates. Another indication was the necessity for education about the need to facilitate an individual's end of life decisions. The researchers recommend communication interventions would help improve physicians' skills in discussing end of life with patients. Although this study is generalizable for further research, it does not allow for the education and support to the individuals who completed the surveys.

Project Results

Through community education and assistance concerning advance health care planning, the aim of this Advance Healthcare Planning Project was to assist individuals in better understanding and comprehending how to make their healthcare wishes known by completing an advance directive during an arranged session or later to be determined by the participant. The Advance Healthcare Planning Project was developed with the goal to

continue the project once this capstone assignment was completed. The program could be utilized in the community throughout the year to assist individuals to better understand and complete an advance directive before they are diagnosed with a major illness, chronic illness, or a traumatic event occurs.

Theoretical Framework

Nursing is a profession that continues to be shaped by diverse theories and ethical principles. Nurse's fundamental responsibilities are to teach and promote health and wellness, the restoration of health, and the alleviation of suffering (Epstein, & Turner, 2015). In addition to the fundamental responsibilities, nurses are responsible for respecting all human rights, including the right to life, the right to choose, and the right to be treated with respect. The process and principles of this Advanced Healthcare Planning Project address and emphasize several of these basic patient rights. These basic patient rights include informed decision making, autonomy, patient advocacy, human dignity, and compassion (Epstein, & Turner, 2015; Patients' Rights Council, 2013). The Advance Healthcare Planning Project was designed by the project leader and guided and conducted using the theories and principles of Joyce Travelbee's Human-to-Human Relationship model (Travelbee, 1971) and by adhering to the principles, guidelines, and responsibilities of the progression of nursing as stated in the International Code of Ethics for Nurses (Epstein, & Turner, 2015).

Travelbee (1971) was a psychiatric nurse, educator, and author who based her Human-to-Human Relationship model on the concepts of existentialism by Rollo May, and logotherapy by Viktor Frankl. Existentialism is defined as a philosophical theory, which emphasizes the belief that the individual person is a free, and responsible agent

who determines his/her own development through acts of the individuals own will. Logotherapy is defined as a meaning-centered psychotherapy. The assumption of logotherapy is to assist patients in finding meaning in life to protect against emotional instability (Travelbee, 1971, p. 61). Travelbee also based her model on the interpersonal relationship theories of Hildegard Peplau and Ida Jean Orlando. The role of the nurse needs to be able to relate to the patient as one human being to another human being instead of the nurse to the patient (Butts & Rich, 2015 p. 283 -285; Travelbee, 1971, p. 61, p. 157).

As a nurse theorist, Travelbee developed the Human-to-Human Relationship Model, which includes compassion, empathy, and a personal relationship to aid in developing the relationship between the nurse and the patient (individual). The challenge for nurses is to look within himself or herself as being individually human, while also seeing the patient as an individual human being. With this transcending role, a relationship between the nurse and patient can be established. The relationship opens the bond for the nurse to not only care for the patient's physical health but also their emotional health (Butts & Rich, 2015, p. 259-266; Shelton, 2016; Travelbee, 1971, p. 33).

Although Travelbee's model was developed for the nurse practicing at the bedside, the concept can also be useful in various areas such as in education (individual, patient, or in the community). The theory and ethical principles of Travelbee are embedded throughout the philosophies that support and reinforces the need for an advance healthcare planning program in the community. By being able to connect with others and form a relationship that goes beyond nursing tasks, a more productive and

meaningful experience with individuals within the community can be established
(Travelbee, 1971).

SECTION III

Methodology

Method

The Advanced Healthcare Planning Project utilized a convenience sample from three senior groups who meet monthly for a meal and educational presentations. To be eligible to participate in this Advance Healthcare Planning Project, members had to meet certain criteria. Selection criteria included the following: participants were required to be at least 18 years of age or older, and able to speak, read, and write English. The participants were invited to complete a 16-item questionnaire before and after the presentation with the same set of questions concerning attitude on the opportunity for treatment choices, the impact of advance directives on the family, the effect of an advance directive on treatment, and their own illness perceptions. The survey included three additional questions on whether the participant already completed an advance directive and if so, were they interested in updating it, and if they did not have an advance directive, were they interested in completing one. In addition, information was collected regarding participants age by category (i.e. 55-64, 65-74, etc.) marital status, educational level, and perceived health status. However, this information was not linked to the pre- or post-survey.

Sample

Recruitment for this study came from three community senior citizen groups located in a rural county in the southeastern United States. The three community senior groups are labeled site #1, site #2, and site #3. Membership consisted of men and women between the ages of 55 and 95 years old. Prior membership in the senior programs was

recruited through newspapers, churches, local healthcare systems, and by word of mouth. The site #1 senior group had 110 members, the site #2 senior group had 95 members, and the site #3 senior group had 45 members. The average attendance for each group per month consists of site #1 location 74, site #2 location 60, and site #3 location 25 members per month.

Human Subjects Protection

The Advance Healthcare Planning Project was approved by the facility and university's Institutional Review Board (IRB). Participants in the project were instructed prior to each educational presentation that they may leave at any point prior to or during the session, or they may stay, and chose not to complete the demographic form, the pre-survey, and the post-survey questionnaire. Additionally, individuals were informed that those who choose to stay for the presentation but chose not to participate in the demographic form, the pre-survey and the post surveys could simply place their uncompleted surveys into the collection envelopes. All questions concerning the purpose of the project were answered prior to the beginning of each presentation. A hardcopy of the informed consent form was provided to participants. However, attendance inferred the participants' informed consent. No gifts or money was given to participate in the study.

There was no identifying information such as name, date of birth, or medical records numbers on either the demographic form or the pre-survey and post-survey. However, to be able to match pre-survey and post-survey changes, the tools were numbered and randomly distributed. Each participant received the same number on their pre-survey and post surveys, however, their name or identifying information, nor their

demographic information was connected to the number on the surveys. Surveys were completed using pen and paper. All data collected was secured by the project leader.

Instrument

A written pre-survey and a post-survey questionnaire was used to collect the data. The scale was designed to measure attitudes concerning the individuals' opportunity for treatment choices, the impact of advanced directives on the family, the effect of an advance directive on treatment, and the individual's illness perception. The average time to complete the demographics, the pre-questionnaire survey, and the post-questionnaire survey was about 15-20 minutes. The instrument used in this project to collect data was developed by Nolan (1997). The Advance Directive Attitude Survey (ADAS) was originally used in 1996 in two inpatient medical units in a tertiary care teaching hospital to assess the patients' attitudes towards advance directives.

The instrument consisted of a 16-item questionnaire, with a four-point Likert scale to determine the extent to which an individual views advance directive as positive or negative. Participants selected answers from a range of 1 (strongly disagree), 2 (disagree), 3 (agree), or 4 (strongly agree). Higher scores on the survey (except for three questions 7, 9, & 16, which the scores were reversed) are associated with a more favorable attitude towards advance directives (Nolan & Bruder, 1997). The tool included questions about the opportunity for treatment choices, the impact of advanced directives on the family, the effect of an advance directive on treatment, and the individual's health (illness) perception.

The ADAS tool used was modified (with authors permission) by adding three additional questions to determine if individuals currently had an advance directive and if

so, were they interested in updating the advance directive, and if they did not currently have an advance directive are they interested in completing one. The participants had the option to select a yes or no answer. Demographic data was also obtained. Participants were asked five general questions that would group individuals without identifying the individual. Demographic categories consisted of age, gender, marital status, and level of education.

There was no identifying information such as name, date of birth, or medical records numbers on the pre-survey or post-survey. Nolan and Bruder (1997) evaluated the ADAS tool for validity and reliability prior to their study by using a pilot study with 20 medical inpatients. Survey questions were revised for clarity based on the participant's feedback. The ADAS survey had a coefficient Cronbach's alpha of 0.74.

SECTION IV

Implementation

Evidence-based Project Implementation

The evidence-based project was performed at three community sites located in one southeastern United States rural community. Members of the three senior groups were routinely mailed monthly calendars of upcoming events. In addition, a monthly newsletter reminded members of the upcoming monthly topic. Posters were visible at the doorway, and at the podium stating what the educational session was about and the opportunity to leave prior to or anytime during the presentation.

Demographic information was collected prior to each educational presentation. Demographic data collected during the project was used to address diversity and inclusion presented in the community. The PowerPoint titled “Empowering Individuals in the Community: Let Your Healthcare Wishes Be Known through Advance Healthcare Planning” was presented. Following the senior group’s agenda, a meal was served prior to each presentation. If members decided not to stay for a monthly presentation, they were given an opportunity to leave after the meal, but prior to the presentation. Each pre-survey and post-survey were numbered the same to allow the surveys to be matched after all surveys had been turned in and the presentations were completed. The demographic form and pre-survey were provided (paper clipped) on the outside of a manila envelope, and a post-survey was provided inside the manila envelope. Participants were asked not to view the post-survey until after the presentation. Surveys were randomly distributed to the participants by working volunteers from the senior group. Because the pre-survey and post-surveys were the same, to decrease confusion as to whether participants had

already completed the survey, the pre-survey was color-coded by printing on light yellow paper, and the post-survey was printed on light green paper. Three envelopes were provided at the appropriate time to collect the demographic forms, the pre-surveys, and the post-surveys, thus providing participants who did not want to complete a survey the opportunity to submit his or her uncompleted survey along with other participants who did complete the surveys. This process assisted in protecting the anonymity of those who chose to complete or decline participation. Time was provided for participants to fill out the demographic form, and the pre-survey prior to the presentation, as well as time provided afterward to complete the post-survey.

To protect and support all participants in case the information elicited unexpected emotions, a counselor/chaplain was present during each presentation to counsel and support the participants in the event of emotional distress. The chaplain had a master's degree in divinity and in counseling and worked three years as a spiritual counselor and chaplain at a local Hospice, four years as a volunteer chaplain and facilitator of grief support services at two local hospitals and was presently a chaplain at a local medical center.

Following each educational presentation, participants were informed that someone (project leader and or chaplain) would be available to answer questions or assist with initiating advance healthcare planning. Individuals most often make determinations about advance directives during a time that they are emotionally vulnerable such as during hospitalization for a major illness. This Advance Healthcare Planning Project provided education on advance directives to individuals in the community that he or she

can utilize to make decisions and inform his or her family and friends prior to a major illness, or traumatic event occurring.

SECTION V

Interpretation of the Data

Data Collection

Data was collected from 153 men and women over the age of 55 years. The data collection method used was a self-report survey given before and after an intervention to examine if it would change attitudes about advance directives. There were three different senior groups; two were held in church fellowship halls, and one was held in a community classroom located within a hospital. The senior groups' monthly meetings always consisted of presentations which promote healthcare and lifestyle education programs, and they are informed of these topics via membership letters and monthly calendars. The Advance Healthcare Planning project was presented using a PowerPoint presentation. Participants were provided an opportunity to ask questions before, during, and after the presentation.

The convenience sample of 153 people from the three senior groups at three different locations are referred to as site #1, site #2, and site #3. Table 1 shows a total of 166 attendees, of which 153 participated fully or partially in filling out the demographic form, the pre-survey questionnaire, or the post-survey questionnaire. There were 153 participants who filled out the demographic form, 153 participated in the pre-survey, and 148 participated in the post-survey.

Table 1

Demographic Data

	date	location	attendees	participants	demographic	pre-surveys	post-surveys
1	1/8/2019	Site #1	23	23	23	23	22
2	1/22/2019	Site #2	60	52	52	52	48
3	2/5/2019	Site #3	83	78	78	78	78
	Total		166	153	153	153	148

Anonymity

Protecting participants' anonymity was important during this project. No identifiable data was collected to connect the surveys to the participants. To assure that the pre-survey questionnaires and post-survey questionnaires could be matched together after they were turned in at the end of the presentation, a number was placed on the upper right hand corner of each pre- and post-survey and participants were informed of this procedure. Further to assure anonymity, the pre-survey and post-surveys were placed randomly on tables prior to participants entering the room. The demographic tool did not have a number associated with the form and therefore could not be matched to the pre- and or post-survey. Participants were provided time to ask questions.

Survey Instruments

Demographic data was obtained using five general questions that would categorize individuals without identifying the individuals based on their age, gender, marital status, level of education, and perceived health status. The Advance Directives Attitudes Survey (ADAS) tool was modified (with authors permission) for the pre-survey by adding three preliminary questions to the demographic sheet to determine if

individuals currently had an advance directive (yes or no) and if so, were they interested in updating the advance directive (yes or no), and if they did not currently have an advance directive, were they interested in completing one (yes or no).

The ADAS instrument consisted of a 16-item questionnaire with four-point Likert scales (1 = strongly disagree, 2 = disagree, 3 = agree, or 4 = strongly agree) to determine how positive or negative participants viewed advance directives. Higher scores on the survey were associated with a more favorable attitude towards advance directives after three items were reverse coded (questions 7, 9, & 16) (Nolan & Bruder, 1997). The instrument included questions about the opportunity for treatment choices, the impact of advanced directives on the family, the effect of an advance directive on treatment, and the person's health (illness) perception.

Analysis and Interpretation of Data

Statistical calculations were conducted by entering the data into a Statistical Package for the Social Sciences (SPSS) version 25 and then analyzed by the project leader using frequencies, descriptive statistics, and paired t-tests (for questions answered in both pre-survey and post-survey). The differences in attitudes before and after the presentation for each question and for an average across all questions were tested for statistical significance at the alpha .05 level using paired t-tests.

SECTION VI

Results

Demographics of Sample

Of the 153 individuals who met the study criteria and who fully or partially participated in the survey, 46 (30%) identified themselves as males, and 107 (70%) identified themselves as females. Eighty-two (54%) reported they were either married or had a partner. Nineteen (12%) reported they were single/divorced, 51 (33%) reported they were widowed, and one person did not respond to the question concerning marital status. Age groups are shown in Table 2, and revealed about half (49%) of participants reported their age to be between 55-74 years old and of the 51% who were older, 40.5% were in the largest single group of ages 75-84.

Table 2

Age

Groups	Frequency	Percent
55-64	21	13.7
65-74	54	35.3
75-84	62	40.5
85-94	15	9.8
95>	1	0.7
Total	153	100.0

Table 3 reveals the level of education for the 152 participants who responded to this question. As seen below, the vast majority (67%) stated they had at least a high school education.

Table 3

Level of Education

	Frequency	Percent
No formal schooling	2	1.3
Middle school	2	1.3
High school	103	67.3
Associate degree	24	15.7
Bachelor's degree	15	9.8
Master's degree	6	3.9
Total	152	99.3
Missing	1	0.7
	153	100.0

Table 4 reveals participants perceived health status. Nearly three-quarters of participants (114 or 74.5%) considered themselves to be in good or excellent health, while only two (1.3%) felt their health was poor. One person did not respond to their perceived health status.

Table 4

Perceived Health Status

	Frequency	Percent
Excellent	15	9.8
Good	99	64.7
Fair	36	23.5
Poor	2	1.3
Total	152	99.3
Missing	1	0.7
	153	100.0

Of the 153 participants in the project, 145 answered the question about whether or not they had an advance directive prior to the presentation. One hundred and five (69%) reported that they did have an advance directive, while 40 (26%) reported that they did not have an advance directive. Follow up questions about whether they were interested in updating their advance directive and whether they were interested in obtaining an advanced directive were intended for those who did and did not have one, respectively, although many participants answered questions not applicable or intended for them. Of the 105 who reported that they had an advanced directive, there were 92 who answered the question about whether or not they were interested in updating it, and 20 (21.7% of applicable responses) indicated they were interested in updating it. Of the 40 who reported that they did not have an advanced directive, there were 36 who answered the question about whether or not they were interested in obtaining one, and 18 (50% of applicable responses) indicated they were interested in obtaining one.

Pre- and Post-Intervention Attitudes

The ADAS scores range from 1 to 4 with higher scores indicating a more favorable attitude towards advance directives (three items were reverse coded) (Nolan & Bruder, 1997). As seen in Table 5, attitudes were positive overall, and even before the intervention people agreed or had positive attitudes about the majority of the items. Only item nine had average attitudes in the negative direction, and only the additional items of 7 and 16 were below a score of 3 indicating agreement.

The 16 items were combined to represent four different subscales of (1) opportunity for treatment choices, (2) impact of advance directives on the family, (3)

effect of an advance directive on treatment, and (4) illness perception. In addition, there was a total average across all the items.

Table 5

Descriptive of Pre- and Post-Intervention Attitudes

	Pre-Intervention			Post Intervention		
	<i>N</i>	Mean	<i>SD</i>	<i>N</i>	Mean	<i>SD</i>
Opportunity for treatment choices (4 items)	155	3.59	0.47	139	3.63	0.45
Impact of advanced directives on the family (8 items)	155	3.21	0.52	138	3.29	0.43
Effect of an advanced directive on treatment (3 items)	155	3.47	0.54	139	3.56	0.46
Illness perception (1 item)	154	2.67	1.08	135	2.82	1.15
Total advanced directive survey (16 items)	155	3.32	0.44	139	3.40	0.37

The aim of this project was to find out if participants' attitudes improved with education, so paired sample t-tests were used to determine if there were any significant differences from the pre-survey attitude questions to the post-survey attitudes on the subscales among those who did answer both. As seen in Table 6 most pre- and post-items improved as indicated by the positive p values. But only their illness perception showed significance improvement. The remainder of the items did not show significances difference.

Table 6

Paired Sample t-tests Pre- to Post-Intervention

	Post - Pre-Difference			<i>df</i>	<i>p</i>
	Mean	<i>SD</i>	<i>t</i>		
Opportunity for treatment choices (4 items)	-0.004	0.423	-0.10	136	.92
Impact of advanced directives on the family (8 items)	0.031	0.399	0.89	135	.374
Effect of an advanced directive on treatment (3 items)	0.043	0.497	1.00	136	.317
Illness perception (1 item)	0.180	1.072	1.94	132	.054
Total advanced directive survey (16 items)	0.038	0.326	1.36	136	.176

Most questions improved as indicated by a positive *t* values, however only question 12 showed significant improvement, while questions 13 and 16 showed marginally significant improvement. Attitudes on the overall average of the 16 items also improved but were also not a significant change.

The purpose of the Advance Healthcare Planning Project was to educate the community about advance healthcare planning so that completion rates for advance directives would increase. It is noted that only four individuals from the three groups completed an advance directive onsite. However, multiple participants requested copies of the advance directive form stating they wanted to read the information at home, discuss the information with their family, or obtain a copy to give to family members and or friends.

SECTION VII

Discussion

Implications

The Advance Healthcare Planning Project has provided a baseline on community attitudes concerning advance directive completion rates. Reviewing the pre-survey data indicated that 72% (105) of the participants surveyed already had an advance directive. Data collected during this project indicated the participants were an extremely informed sample group. Findings indicated that most participants believe that an advance directive would provide families and friends a greater comfort in guiding the individual's treatment plan. The survey responses show strong attitudes already exists toward honoring patient's treatment choices. While this project consisted of three senior groups in a rural community in the southeastern U.S., the responses revealed a similar attitude toward advance directives in inpatient research concerning advance directives in previous studies (Douglas & Brown, 2002; Duke, Thompson & Hastie, 2007; Rao et al., 2014; Salmond & Estrella, 2005;).

Several participants in the project verbalized that they would like to have a copy of the advance directive form, which was provided at the end of the education session, to talk to their family members regarding their healthcare wishes. Individuals requesting written information to share with family members would suggest that educational programs about advance healthcare planning may be more effective if family members were included in the sessions. Further, community education concerning advance healthcare planning can help empower individuals in the community to take an active role in their end-of-life treatment decisions. Additionally, research has indicated that the

use of advance directives could help contain healthcare cost at the end-of-life (Advance Care Planning, 2017; Bastable, 2019, p120; Chastek et al., 2012; Gardner, 2012).

Discussion

Research has indicated the lack of knowledge concerning advance directives has been thought to be a significant factor as to why many people fail to complete an advance directive (Boucher et al., 2014; Detering et al., 2010; Miller et al., 2016; Spoelhof & Elliott, 2012; O'Sullivan et al., 2015; Volandes et al., 2012). Although hospital policy requires all patients admitted to a hospital to be provided information on PSDA, a study by Salmond and Estrella (2005) indicated only 82% of the sample reported receiving information on advance directives and only 18% had completed an advance directive. The purpose of this Advance Healthcare Planning Project was to explore the attitudes of the community population about advance healthcare planning. A series of 16 questions concerning attitudes about advance directives were given to three senior groups. The questions focused on four specific areas, the opportunity for treatment choices, the impact of advance directives on the family, the effect of an advance directive on treatment, and an individual's perception of his or her own health status (illness perception) (Nolan, 1997).

Benefits

The results of this project partially substantiate the finding of previous investigators (Douglas & Brown, 2002; Nolan & Bruder, 1997; Salmond & Estrella, 2005) which supported the hypothesis that education increases advance directive completion rates within the inpatient arena. In 1990, the Patient Self-Determination Act (PSDA) was passed to ensure that a patient's right to self-determination in health care

decisions is adequately communicated, as well as protected (Duke et al., 2009; H. R. 4449- Patient Self Determination Act, 1990). The PSDA is a federal law that makes it easier for individuals who have an advance directive or Living Will to be able to control decisions affecting his or her healthcare even after he or she is no longer able. The PSDA was also passed to encourage people to prepare an advance directive before one is needed (Douglas & Brown, 2002; H. R. 4449- Patient Self Determination Act, 1990; Kelley, 1995; Rao et al., 2014). The goals of the PSDA may be more reachable if advance healthcare planning education is conducted in the community prior to a health care crisis occurring (Nolan & Bruder, 1997).

Limitations

Limitations of this project included a convenience sampling methodology, thus limiting the ability to generalize the findings to all community-dwelling seniors. As part of the study criteria, participants were required to be able to speak English. The areas of cultural diversity were not addressed. All the participants in this project were older adults attending one of three senior groups in a rural community in the southeastern United States. They are not representative of all community-dwelling seniors, as different demographics could theoretically yield different results.

The small sample size (153) of the project was determined solely based on three senior groups. Limited sample size can result in inaccurate results, and thus affect the power of the data collected. The sample population utilized in this project was individuals already engaged in increasing their knowledge in general by attending monthly meetings with the agenda focused on educational presentations. Another factor that may have led to non-significant results in many areas between the pre- and post-

questionnaires' surveys was the time limit of the monthly meetings. The regular meeting time was for one hour (30 minutes for presentation). Although time was provided after the presentation for questions and answers, there was not adequate time provided for one on one discussions due to the locations and time limit of the meetings.

Recommendations

Recommendations following the conclusion of this project included having advance health care planning education and discussions take place in the community setting, such as but not limited to community centers, churches, shelters, community colleges, and Young Men's Christian Associations (YMCAs). Community education concerning healthcare planning should take place throughout the year, not just during certain times, i.e., Healthcare Decision month (April). Another recommendation would be to assess for changes in healthcare organization culture regarding advance health care planning. Assessing a patient's advance healthcare planning needs should occur at each annual healthcare visit, not just one time (Spoelhof & Elliot, 2012). Although participants were required to be able to read, write, and speak English, the surveys did not account for the level of education, or the cognitive state of each individual. A recommendation would be for the questions to be read to the audience rather than leaving it to the individual to read. Another recommendation would be to include multi-generations, as well as to include a more culturally diverse population.

Conclusion

The lack of advance healthcare planning often leads to an increase in family emotional turmoil, and needless patient suffering at the end of life. Community education should focus on increasing community awareness concerning advance

healthcare planning, including the completion of advance directives. Education could increase the number of individuals with advance directives prior to entering the hospital with an acute or chronic terminal illness, or before a traumatic event occurs.

Furthermore, the completion of healthcare planning would help families and providers identify the most appropriate end-of-life care based upon the patient's wishes, which would ease end-of-life decision-making for family members and friends.

The findings of this project provided a baseline to help guide future education in the community. The Advance Healthcare Planning project should be repeated which could include different variables, such as age, gender, income, education, culture diversity, cognitive levels, prior knowledge of healthcare planning, and family support to provide education to empower individuals with the knowledge to let their healthcare wishes be known.

The focus of this project was to empower individuals in the community toward advance healthcare planning. The instrument used in this study was originally developed for a hospital inpatient setting; it should be evaluated for use in the community arena. The findings of this project within the community regarding their attitudes towards advance directives indicate a slight positive response. There has been a plethora of research focusing on advance healthcare planning with the aim to increase completion rates of advance directives. However, improvement of advance directive completion rates does not automatically improve medical care or end of life care (Detering et al., 2010).

Healthcare planning must be through education and individual autonomy. Research has shown that community education allowing open, honest discussion

concerning advance health care preferences and end-of-life decisions could assist in reducing stress, anxiety, and depression in surviving family members and friends.

Education information used in the Advance Healthcare Planning Project may be used in future educational sessions conducted in community settings.

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