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Nurses Addressing the Knowledge Gap in Advance Care Planning

Cover Page Footnote

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In 1990, the United States (U.S.) Congress passed the Patient Self-Determination Act (PSDA), supporting the right of patients to actively participate in their own health care, to accept or refuse medical treatment and to legally direct their care at the end of life (EOL) through documentation called advance health care directives. This law requires hospitals and healthcare facilities who participate in Medicare or Medicaid to provide patients a summary of their decision-making rights, to determine if the patient has existing advance directives, to provide education to staff and community about advance directives and prohibits discrimination against patients who do not have advance directives (Tucker, 2003). In 2016, Medicare established billing codes and coverage for medical professionals to discuss EOL planning with patients (Moore & Hays, 2016).

Advance care planning involves documentation of an individual's wishes about the care they will receive at the EOL, to include a living will and a durable healthcare power of attorney. Other documents may include Do Not Resuscitate orders, wishes about organ and tissue donation and, depending on the state of residence, Physician Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOST) (Mayo Clinic, 2020).

A living will describes a patient's wishes regarding the use of medical interventions and comfort measures in the event of terminal illness or fatal injury. Appointing a health care surrogate by creating a durable healthcare power of attorney allows the patient to designate another person to make health care decisions on their behalf. This proxy is only used in the event the patient becomes incapacitated and can no longer communicate their wishes (DeMartino et al., 2017).

As the population ages and advanced technology and treatment extends life expectancy, the need for advance directives and goals for care at the EOL have become increasingly important. As families scatter, older patients tend to move into care facilities without the support of family or significant others. If patients have no advance directives in place, patients and healthcare providers are forced to make crisis healthcare decisions that add stress to an already stressful situation (Lowey et al., 2013). The care provided in the absence of advance directives can result in treatments that are financially, emotionally, and physically distressing, increasing patient and family suffering. Advance care planning can bridge the gap between patient preferences for EOL care and the treatment typically provided at the EOL (Bekelmen et al., 2016).

Projections indicate that by 2030, over half of the 8.5 million Americans over 85 years of age will suffer from dementia and have no spouse or children to care for them. Healthcare professionals will be increasingly confronted with concerns regarding individual autonomy and EOL decisions (Gomez et al., 2020; Johnson et al., 2018). For advance directives about patient's goals for care at the EOL to be utilized effectively, communication with family and/or caregivers, as well as with healthcare providers, is essential (Waldrop & McGinley, 2022). Even patients who believe they have an existing plan for EOL care may find that documents created during a hospital admission or during estate planning does not comprehensively address the patient's wishes for EOL care.

Often patients who are admitted to acute care, even older patients, do not have documentation of advance directives (Knight et al., 2020). An extensive review of healthcare spending at EOL for several developed countries showed the U.S. devotes a larger amount of the gross domestic product (GDP) to EOL spending than other developed countries (French et al., 2017). This is often the result of dissonance between patient preference for EOL care and being admitted to and dying in an acute care setting (Bekelmen, et al., 2016). Obstacles to effective advance care planning includes the need for education about advance directives and more open communication among healthcare providers, patients, and families, help with interpretation of complex legal forms, and difficulty identifying a healthcare surrogate (Kossman, 2014).

Early preparation of advance care planning documents is an opportunity for individuals to express their wishes about future medical care, which relieves burdens for loved ones and provides a clear picture of patient preferences for EOL care. The use of living wills and health care surrogates was developed to allow patients to express their preferences for EOL care and to create a surrogate decision-maker in case the patient loses decision-making capacity (U.S. Department of Health and Human Services [HHS], n.d.; Centers for Disease Control [CDC], 2018).

While more recently there has been some controversy about the usefulness of advance care planning, there is ample research to show that patients with advance directives are less likely to have increased stress and painful procedures at EOL, such as placement of feeding tubes, repeated hospital admissions or dying in an acute care facility. Patients with advance directives receive EOL care that is more in accordance with their wishes, and they are less likely to die in a hospital (Kossman, 2014). Further studies have shown patients with advance directives reduce healthcare funds spent on unwanted aggressive care at the EOL (Silveria et al., 2014).

Often there is hesitancy on the part of family members, who may feel conflicted about discussing EOL issues or may be in denial about the need for advance care planning. Family members who are then faced with the serious illness of a loved one may experience anxiety and face care decisions about their loved ones that they are unprepared to make. Having specific and detailed documentation of EOL wishes can alleviate the stress and alleviate regret about the care of their loved ones (Waldrop & McGinley, 2022).

In the U.S., only a quarter of adults have any form of advance directives (Ke et al., 2017; Koss, 2018). Research has demonstrated most individuals lack understanding of advance directives and avoid having discussions regarding EOL or rely on family members to make final decisions (Ke et al., 2017). A 2013 survey found 90% of Americans believed talking about EOL with their family was important. Conversely only 30% of individuals over the age of 18 have put their wishes into writing (Prince-Paul & DiFranco, 2017).

Documenting comprehensive EOL care planning and advance directives is not simply a matter of checking boxes but is rather an opportunity to communicate specifics thoughtfully and carefully about wishes for care at the EOL. Establishing open communication with family and caregivers about wishes for EOL care enhances relationships, relieves family and caregiver anxiety, and lays a strong foundation for a relationship of trust (Waldrop & McGinley, 2022).

Review of Literature

History of Advance Directives

In 1914, Justice Benjamin Cardozo stated in *Schloendorff v. Society of New York* that in his opinion “every human being of adult years and sound mind has a right to determine what shall be done with his own body.” These comments laid the foundation for the legal and medical belief that every patient has the right to determine their medical treatment and their EOL care (Chervenak et al., 2016). Building on the rising movement of patient autonomy, California was the first state to pass a statute in 1976 that recognized living wills as a legal document. California’s *Directive to Physicians* allowed patients “to limit the number of medical interventions that could be performed at EOL and also protected physicians from malpractice if they followed the patient's orders" (Lopez & Vars, 2019). Since establishment of the PSDA by the U.S. Congress in 1990, 47 states in the U.S. have enacted laws that recognize a patients' right to set parameters for medical interventions at the EOL (Rolnick et al., 2017; Tucker, 2003).

Barriers to Advance Care Planning

Impediments to advance care planning include a person's desire to defer to family members regarding EOL issues, concerns that advance directives will not be effective or respected, procrastination, denial about death in general, or lack of knowledge regarding advance directives. Another barrier is the ability to access the needed documents. Free copies are available online, but states typically require that advance directives be witnessed or notarized (Rolnick et al., 2017, *Five Wishes*, n.d.). This legal requirement can create significant barriers for people. Effective advance directives need to have specific details to guide providers and family members.

The general population typically lacks the medical knowledge to adequately complete living wills. Attorneys can advise individuals on legal requirements, but they typically lack knowledge regarding medical decisions at EOL. Rolnick et al. (2017) makes the case that existing laws vary widely from state-to-state and the documentation of advance care directives should be a clinical document, rather than a legal one. Barriers such as patients and families believing these legal documents are irrevocable, the burden of legal documentation such as notaries and specific templates, and the lack of understanding of medical terminology and processes on the part of the lawyers are all a part of the argument for moving advance directives to the clinical setting (Rolnick et al., 2017).

Advance care planning in primary care

Historically, health care providers are often reticent to discuss EOL issues with patients. Providers who were surveyed about their lack of conversations on this topic citied fear patients will become upset. Providers are unsure how to broach EOL topics or they believe that EOL guidance is outside the role of a healthcare provider. However, providers who initiate conversations with patients have found that the patients are waiting for the provider to speak first (Hemsley et al., 2019). Ideally, discussions regarding EOL issues should be conducted before patients become seriously ill or incapacitated. The natural starting point should be with an individual's primary care provider (Bowman & Katz, 2017).

Faith Based ACP Interventions

Health promotion programs that have been successful at increasing an individual's knowledge of advance directives share common themes such as having religious leaders serve as advocates. Church leaders promote congregation buy-in by presenting advance directives material in their services (McDonnell & Idler, 2020). Using national advance directive programs and utilizing church members who are health care workers increases a program's success rate. Church members who are health care workers add a two-fold benefit. The healthcare providers have existing medical knowledge that make explaining advance directives easier for them and being a fellow church member gives the providers needed credibility (McDonnell & Idler, 2020; Sun et al., 2017).

Sun et al. (2017) utilized churches in the Asian American community to promote discussion about advance care planning. In this study an advance directive educational curriculum was developed for Chinese and Vietnamese Catholic churches. The intervention consisted of two group sessions four weeks apart and was facilitated by healthcare professionals. Seventy-two percent of the participants completed an advance directive within three months of the second session. This was an increase from the previous study by Medven et al. (2003) that reported 69% completion. This study demonstrated that the use of culturally specific faith-based interventions can lead to a significant increase in the rate of completed advance directives.

McDonnell and Idler (2020) published a literature review of church-based programs that promoted advance care planning in African American communities. Barriers this group encountered in building a successful advance care planning program were a reluctance to discuss death and dying, lack of information regarding advance directives, lack of trust in the healthcare system, and a value system that conflicted with advance care planning.

Programs that were successful shared common themes including having religious leaders serve as a key advocate. Church leaders could promote congregation acceptance by presenting advanced care planning material in their services. Using national advance care planning programs added to the sustainability of these interventions. In addition, utilizing church members who were healthcare providers was a positive trait.

Nurse-led interventions

A randomized controlled study was conducted that featured a nurse-led advance directive program. Volunteer nurses received training on how to discuss advance directives with patients. The nurses visited patients three times at their homes and provided information and assistance composing the patient’s goals and preferences for EOL care. At the beginning of the study only 3% of the subjects had heard of advance directives and only 14% had discussed EOL care with their family. At the end of the study, 16.5% of the group that participated in the nurse-led intervention completed advance directives vs 1.7% in the control group. This study demonstrated that a nurse-led intervention can be an effective tool to increase patient’s awareness of advance directives (Chan et al., 2018).

Izumi et al. (2019) examined the effectiveness of having bedside nurses provide advance directive education to inpatients. This quality improvement project was designed to educate nurses on how to have conversations with patients regarding advance care planning. The researchers found that providing nurses with the education and tools to discuss advance directives did result in an increase of conversations with patients. However, the project was unsuccessful because the bedside nurses lacked sufficient time to adequately educate patients (Izumi et al., 2019).

Use of Technology in Health Promotion

ZOOM® is web-based audio and videoconferencing service that facilitates virtual group meetings and allows a secure recording of meetings. Archibald et al. (2019) utilized ZOOM® to interview nurses who were involved in a research project in Australia. To recruit enough nurses, ZOOM® technology was used to reach nurses in geographically diverse areas. Researchers determined that ZOOM® was an effective research tool. Most of the participants stated they preferred ZOOM® to in-person interviews. Sixty-nine percent found ZOOM® was effective for forming a rapport with the researchers. While in-person interviews were still rated positively, ZOOM® was the next best alternative (Archibald et al., 2019).

In 2020 the Survivorship Wellness Group Program, at the University of California, San Francisco moved their in-person group sessions for cancer patients to ZOOM® because of

California's stay-at-home order. Researchers found attendance at the meetings tripled when it moved to ZOOM®. Participants of the meetings cited the barriers of distance and dependent care scheduling being eliminated with the use of ZOOM®. While lack of technology remained ~~as~~ an issue for many patients, the researchers found that an online and remote approach to education increased accessibility and expanded the reach of the program (Jhaveri et al., 2020).

Daly et al. (2021) researched the impact of social isolation during the COVID pandemic on older adults. Subjects were asked to participate in four ZOOM® focus groups. Most subjects reported having a smartphone and reported that ZOOM® and Skype™ were effective at connecting with family and friends. Subjects reported they regularly used ZOOM® to have virtual book club meetings and support groups. While subjects preferred face to face meetings, they found the ZOOM® meetings to be very convenient and they felt comfortable using this modality to communicate with their health care providers (Daly et al., 2021).

Theoretical Framework

The theoretical framework for this project is the Transtheoretical Model of Behavioral Change.

The Transtheoretical Model of Behavior Change (TTM) was developed by Prochaska and DiClemente in the late 1970's. The TTM is a model of intentional change which occurs through a cyclical process (Hemsley et al., 2019; Pekmezi et al., 2010). Individuals move through five stages of change: precontemplation, contemplation, preparation, action, and maintenance. Strategies and techniques used by people to advance through these stages are called processes of change (Pekmezi et al., 2010). Subjects begin the process of behavior change in the precontemplation stage. In this stage the patient has no intention of changing or stopping their behavior. As the patient becomes aware that a problem exists, they begin to think about making a change. This is the contemplation stage. The third stage is the preparation stage and occurs when the patient makes plans to act within the next month. At the fourth stage, the patient takes action to change their behavior. The final stage is maintenance stage. The patient is maintaining their behavior change for at least six months and seeks to avoid a relapse (Glanz et al., 2018).

The process of completing advance care directives is not a simple signing of a document, but is a complex cognitive process that involves motivation, barriers, and self-efficacy. Effective interventions to increase advance care directives must be tailored based on a patient's readiness for change. Fried et al. (2010) determined that a subject's readiness to discuss advance care directives varied widely. Most patients (65%-75%) over the age of 65 were in a precontemplation stage. This was consistent with previous studies that show low rates of communication between patients and providers regarding EOL issues (Fried et al., 2010).

In this quality improvement project, the participants were members of churches in rural western North Carolina. The participants were predominantly Caucasian with a majority being between the ages of 50 to 80 years old. Recruitment consisted of an information table attended by the principal investigator before and after church services in the two weeks prior to the intervention. In addition, the church advertised the ZOOM® meetings on their weekly emails to parishioners, in the church bulletin and during the sermons. The participants were primarily in the contemplation or preparation stage of the Transtheoretical Model of Behavior Change. People in the precontemplation stage did approach the table to get information, but stated they were not interested in attending the meeting. Typical responses of this group of individuals were that they felt the documents did not apply to them. Participants in the contemplation stage stated they were aware of the need for advanced directive documents but were unsure how to obtain them or they had been avoiding making decisions. Participants in the preparation stage were already familiar with the need for advanced directives and were excited about attending the ZOOM® meeting to learn how to complete the documents or to update their existing document.

Purpose

The purpose of this quality improvement (QI) project was to increase participant's knowledge of advance directives and increase comfort when discussing EOL care.

Methods

Context

This project was designed to increase participants' knowledge of advance directives and their comfort discussing their EOL wishes. The project recruited two groups of subjects; nurses who are members of churches in western North Carolina and church members who are interested in learning more about advance directives.

The nurses recruited for this quality improvement project were both members of the church and known to the participants. The first nurse leader was well known in the church community for her work on educating parishioners about COVID-19. She had developed several programs for the church to increase vaccine awareness and increase the number of church members who received the vaccine. The second nurse leader was a registered nurse with over ten years of experience and was also a familiar person to the church members. The principal investigator and the nurse leaders met in advance via ZOOM® to prepare for the intervention. The principal investigator went through the schedule of the intervention and provided each nurse leader with a script detailing how to run the meeting and a suggested use of questions and answers for the conclusion of the meeting. At the conclusion of the training session both nurse leaders felt comfortable with the format of the intervention, the materials that would be used and possible questions that may be posed to them at the conclusion. During the ZOOM® training session, both nurse leaders requested the presence of the principal investigator during the intervention in the event any technical issues occurred.

The nurses led the ZOOM® meetings utilizing the national program, *Five Wishes*. Church members who attended the ZOOM® meeting learned about advance directives, how to complete a living will and healthcare proxy and had their questions answered by the nurse leader. The results of the survey demonstrated that this QI project can be adopted by other churches to educate their parishioners about advance directives.

Intervention

This QI project provided comprehensive education and counseling about advance directives and documentation regarding EOL care. The project recruited registered nurses who presented the *Five Wishes* curriculum to the participants in their own faith community. Church members recruited were interested in learning more about advance directives. The nurses led the ZOOM® meetings utilizing the national program, *Five Wishes*. Church members attended the ZOOM® meeting and learned about advance directives, how to complete a living will and healthcare proxy and had their questions answered by the nurse leader. The expected outcome was to increase participant's knowledge of advance directives and increase comfort when discussing EOL care. A secondary outcome was the creation of a sustainable program that can be adopted by other churches to educate their parishioners about advance directives. By utilizing existing church members who are nurses, the training to conduct these seminars does not need to be extensive. In addition, having existing church members act as leaders creates a non-threatening environment and increases the rapport.

Measures

Five Wishes is an evidence-based curriculum focused on advanced care planning. The *Five Wishes* curriculum ". . . was the first advance directive to address personal, emotional, and spiritual issues in addition to meeting medical and legal criteria." *Five Wishes* is an established advance directive curriculum that allows individuals to learn about advance directives, have questions answered and complete the required forms that are recognized by 42 states (*Five Wishes*, n.d.).

The project intervention was a one-time ZOOM® meeting between the nurse leader and the church members who voluntarily agreed to participate in the project. Prior to the ZOOM® meeting, participants were given a packet that includes the *Five Wishes* booklet, instructions on how to join the ZOOM® meeting and instructions on how to complete the two surveys. Participants who volunteered completed a pre-intervention survey (see Appendix A) to collect demographic data and information about current advance directives.

The nurse leader initially asked the participants to complete the pre-intervention survey. This included four questions on a Likert scale of one to five, one being strongly disagree to five being a strongly agree. Participants were asked if they knew the process for creating a living well, the purpose of a living will, did they feel comfortable talking with their family or close friends about care they desired at EOL, and if they felt comfortable talking with their healthcare provider about EOL.

Once the participants accessed and completed the pre-intervention survey, the nurse leader presented the *Five Wishes* curriculum. The nurse leader led the meeting with the supplied script, played the DVD supplied by *Five Wishes,* and led a question-and-answer session at the end of the ZOOM® meeting.

Upon completion of the *Five Wishes* program, participants were asked to complete a post-intervention survey to measure understanding of the process for creating a living well, the purpose of advanced directives, likelihood they would complete documentation of advance directives, and if they would feel more comfortable discussing advance directives with their family or close friends and their healthcare provider about care at the EOL.

The surveys were completed with paper and pencil and returned via U.S. mail to the principal investigator in a stamped, self-addressed envelope that was provided in the packet. Participants could also complete the surveys using a secure online program called SurveyMonkey®. Participants were asked to list the last four digits of their phone number to match the pre-intervention surveys to the post-intervention surveys.

Analysis

Quantitative Data

Descriptive statistics was used to summarize demographic characteristics of the participants. Paired T-test for continuous variables and chi square analysis for categorical variables examine comparability of pre- and post-interventions. Statistical analysis was performed using the Intellectus™ statistical program.

Ethical Considerations

This QI project was reviewed and approved by the Lenoir-Rhyne University Institutional Review Board (IRB) and classified as exempt. Participation in the project was voluntary and participants had the right to withdraw at any time without consequence or prejudice. Project participants were given contact information for faculty advisors in the event they had concerns about the principal investigator or the project. The contact information for the principal investigator was also available, along with the contact information for the Chair of the Lenoir Rhyne University IRB, so any questions or concerns that may have arisen from the project participant could be addressed at any time.

The data was collected and stored using the Intellectus™ Statistics program. A duplicate data set was stored on a password-protected external drive to ensure safety in the event of damage to the original information. Data will be stored for five years after project completion and then destroyed.

There was no funding for this project. The use of the *Five Wishes* program is free and readily available online and for purchase. Since most of the project was conducted using video conferencing platforms, there was a risk of intrusion by outside agents. The surveys had SSL encryption, so all the volunteers' responses were protected. This encryption helped ensure that any data intercepted during transmission could not be decoded and individual responses could not be traced back to an individual respondent. Participants were asked to avoid using personal identification on the survey responses to minimize the chance that information could be targeted by outside agents.

Project participants were given contact information for confidential counseling services at their church in case their participation in the research caused any personal concerns or feelings of discomfort. All data was confidential, and the project adhered to the Health Insurance Portability and Accountability Act (HIPAA) guidelines for all data collection and storage. The data collected avoided any patient identifiers such as name, date of birth, social security numbers or address. Subjects were informed that participation in the project was voluntary and refusal to participate or answer any question would not result in any penalty.

Results

This project had 38 participants (*n* = 38) and two nurse leaders. Sixty percent of the participants were female, predominantly white, between the ages 60 to 69, and college educated. This is consistent with past studies that examined advanced directives (Koss, 2018). The statistical analysis included descriptive statistics, chi square analysis and two-tailed paired T-test. An analysis of the demographic information showed that gender had no significant impact on the completion of advanced directives (see Table 1 for comprehensive demographic profile).

The intervention did increase participant's knowledge of how to create a living will and the purpose of a living will (see Tables 2 & 3). The result of the two-tailed paired samples *t*-test was significant based on an alpha value of .05, $t(37) = -5.77$, $p < .001$. This finding suggests that the intervention did increase participants' knowledge of the purpose of and how to create a living will.

The post intervention quiz demonstrated that participants gained knowledge regarding advanced directives. The four-question quiz asked participants questions regarding when living wills are used, how they can be modified, and where to store documents. Eighty percent (*n* = 30) of the participants were able to correctly answer all four questions on the post-intervention survey, with 20% (*n* = 8) responding incorrectly to one question.

Discussion

The findings of this project demonstrate the feasibility and efficacy of a church-based educational program promoting advanced directive awareness and completion. Sixty-six percent of the project participants already had completed advanced directives prior to participating in this project. However, the participants generally had a poor level of understanding of their documents and how they were to be used. At the conclusion of the ZOOM® meeting, statistical analysis demonstrated that participants had a better understanding of the purpose of their advanced directives and how to make changes to their advanced directive documents if needed.

Limitations

Several limitations of this study should be acknowledged. The researcher was only able to recruit 38 participants and two nurse leaders. Subject recruitment was limited to the churches in western North Carolina and participants were primarily older, Caucasian, and members of one specific religious denomination. This limits generalization of the findings beyond this demographic.

The COVID pandemic likely contributed to the low level of respondents since church services and activities were closed during the project timeframe. Several churches were initially recruited to participate in the project; however, two churches withdrew secondary to a spike in COVID case numbers and a nationwide restriction on public gatherings. The project being conducted at one church resulted in less diversity in the participants.

Several participants were unable to complete the project due to lack of knowledge in accessing the video conferencing platform. While many older adults have become more comfortable with the use of ZOOM® during the COVID pandemic, issues with internet access and navigation of virtual applications remained. There were possible participation bias as recruited subjects who are more receptive to the concept of advanced care planning were more likely to volunteer for the project. Since the study involved the use of a ZOOM®, meeting participants who were not comfortable with ZOOM® possibly self-selected out of the study. One unanticipated action was that participants who were comfortable with the ZOOM® technology invited other members to their home for the meeting, allowing participation by more members. This option should be included in future projects as it allowed participants who were unfamiliar with ZOOM® to participate and should be included in future projects.

Conclusions

Advance care planning and legal documentation of advance directives can improve the quality of care and compliance with an individual’s wishes for EOL care in the presence of a life-altering health crisis. Interventions to provide direct counseling for increasing knowledge about advance directives and comfort with discussion of EOL care have been shown to be effective. The principal investigator theorized that church-based interventions led by nurses who are known to the participants increases the level of comfort in discussing these personal issues, but additional research is needed to confirm this theory. The nurse leaders expressed that their background in healthcare increased their level of comfort in discussing EOL issues with their fellow church members.

The use of a video conferencing platform may have been an impediment for some church members, but the project was unable to measure this aspect, since the recruitment materials were clear in stating the project would be conducted using online applications.

The pre-intervention survey revealed many participants already had living wills in place but also showed lack of understanding of advance directives and many of the details provided by the *Five Wishes* program. Several participants indicated their living wills were created many years prior and they were created by an attorney, without any clear indication of the actual care they would like to receive at the EOL.

Lack of the legal documentation of advance directives at the time of a life-altering health crisis can result in higher likelihood of death in an acute care facility, lower utilization of hospice care, decreased quality of life, higher patient and Medicare costs, and increased emotional trauma to loved ones (Splendore & Grant, 2017). Increasing the public's perception of the necessity of advanced directives should be a primary concern for all health care providers. However, numerous studies have shown that most American adults do not have any form of advanced directives. This church-based project using the *Five Wishes* program demonstrated the effectiveness of community-based advance care planning programs.

Implications for Future Research and Nursing

In research projects involving advance directives, recruitment is one of the largest obstacles. Recruitment can be difficult even with the support of church leaders. In casual discussion with church members, the principal investigator discerned one obstacle to participation was that many church members had living wills in place and that this program would not be of any further assistance for them. For future recruitment it would be more effective to have the church leaders specifically address the benefits of the *Five Wishes* document and to describe how *Five Wishes* allows individuals to record their preferences for comfort care at EOL and the type of medical treatment they wish to have at the EOL.

The second issue that will need to be addressed in future projects is how COVID has affected EOL decisions. Prior to COVID, the use of a ventilator was seen by many people as an undesirable EOL medical treatment. However, during the COVID pandemic the ventilator was used as a temporary measure for people too weak to breathe and many patients were able to be weaned off the ventilator and recover. Participants in this project commented in the meeting that they appreciated the ability to indicate they would want medical treatments, including a ventilator, if there is a chance they could be weaned from the ventilator and recover.

The presence of legal and explicit guides for preferences of care at the EOL eases patient and family concerns at a time of a health care crisis. This project demonstrates the practicality and value of nurses and advanced practice nurses leading educational programs that facilitate advance care planning. Trust, caring and reciprocity in nurse-patient relationships is carried into the community and promotes improved communication and trust in the process of advance care planning. Both participants and nurse leaders derive gratification and fulfillment through completion of advance care planning.

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Appendix A

Nurses Addressing the Knowledge Gap in Advance Care Planning

Program Survey One

Stephanie Winkel

DNP Student and Student Investigator

Last 4 digits of your phone number:

Gender: Male Female Prefer not to answer

Age: 18 to 29 30 to 39 40 to 49 50 to 59 60 to 69 70 to 79 80 to 89 90 and over

Marital status: Married Single Divorced Widow Widower

Race/ethnicity: Please circle one:

American Indian or Alaska Native

Hispanic or Latino

Asian

Black or African American

Native Hawaiian or Other Pacific Islander

White

Two or more races

Highest level of education: High School College degree Masters or Doctoral degree

This survey will be used by the student investigator for her project to measure knowledge about advanced care planning prior to participation in the program. The *Five Wishes* program you will participate in is focused on advanced care planning. Following completion of the *Five Wishes* program, there will be another survey to determine knowledge gained from the program.

"Many individuals create living wills to direct end of life decisions but may not understand all of the legal jargon. *Five Wishes* is a very simple legal document written in plain language to ensure individuals receive the end of life care they desire."

A living will and a durable power of attorney for healthcare are two forms of advance directives. *Five Wishes* is an advance directive program that covers living wills and durable powers of attorney, but the *Five Wishes* program also addresses the individual's desires for spiritual, emotional, and personal care.

The information you provide on these surveys will be anonymous and the data collected will only be used in total to show the effectiveness of the *Five Wishes* program in improving knowledge about advanced care planning. No names or other identifying information and no individual responses will ever be used, and the data collected from this survey will only be available to the student investigator.

Please respond to the following questions:

1. Do you currently have any form of advance directive, living will or healthcare proxy/surrogate?

   Yes No

2. Have you considered making a living will?

   Yes No

For the following questions, please respond with your level of agreement on a scale of 1 to 5, with 1 being ***STRONGLY DISAGREE*** and 5 being ***STRONGLY AGREE***.

3. I know the process for creating a living will.

   1 2 3 4 5

4. I have a good understanding of the purpose of a living will.

   1 2 3 4 5

5. I feel comfortable talking with my family or close friends about the care I desire at the end of life.

   1 2 3 4 5

6. I feel comfortable talking with my healthcare provider about how I wish to be cared for if I have a terminal illness.

   1 2 3 4 5

Appendix B

Nurses Addressing the Knowledge Gap in Advance Care Planning

Program Survey Two

Please enter the last four digits of your phone number or the same four digits you used when completing the first survey.

For the following questions, please respond with your level of agreement on a scale of 1 to 5, with 1 being ***STRONGLY DISAGREE*** and 5 being ***STRONGLY AGREE***.

1. After participating in this program, I will complete the *Five Wishes* document.

   1 2 3 4 5

2. I understand the purpose of a living will.

   1 2 3 4 5

3. I understand the process for preparing a living will.

   1 2 3 4 5

4. I feel more comfortable talking with family and close friends about my final wishes.

   1 2 3 4 5

5. I feel more comfortable talking with my healthcare provider about how I wish to be cared for if I have a terminal illness.
   1 2 3 4 5

The following questions are designed to measure your understanding of the *Five Wishes* program. Please respond either TRUE or FALSE.

1. A living will is only used if the patient is unable to speak for themselves.

   True False

2. Once created and notarized, a living will is not changeable.

   True False

3. It is very important for family or healthcare surrogate and healthcare providers to have a copy of your living will.

   True False

4. A living will gives my family reassurance about the type of care I desire if I am unable to speak for myself.

   True False

Table 1

Frequency Table for Nominal and Ordinal Variables

Variable	*n*	%
Gender		
Male	15	39.47
Female	23	60.53
Missing	0	0.00
Race		
Hispanic or Latino	3	7.89
Asian	1	2.63
Black or African American	1	2.63
White	31	81.58
Two or more races	2	5.26
Missing	0	0.00
Age		
30 to 39	2	5.26
40 to 49	7	18.42
50 to 59	7	18.42
60 to 69	11	28.95
70 to 79	7	18.42
80 to 89	4	10.53
Missing	0	0.00
Education		
High school	5	13.16
College degree	10	26.32
Masters or higher	23	60.53
Missing	0	0.00
Martial Status		
Married	28	73.68
Single	2	5.26
Divorced	5	13.16
Widow	1	2.63
Widower	2	5.26
Missing	0	0.00

Note. Due to rounding errors, percentages may not equal 100%.

Table 2

Purpose of a Living Will

The result of the two-tailed paired samples *t*-test was significant based on an alpha value of .05, *t*(37) = -5.77, *p* < .001. This finding suggests the difference in the mean of Survey 1 Question 3 and the mean of Survey 2 Question 3 was significantly different from zero. The mean of Survey 1 Question 3 was significantly lower than the mean of Survey 2 Question 3. The results are presented in Table 3. A bar plot of the means is presented in Figure 1.

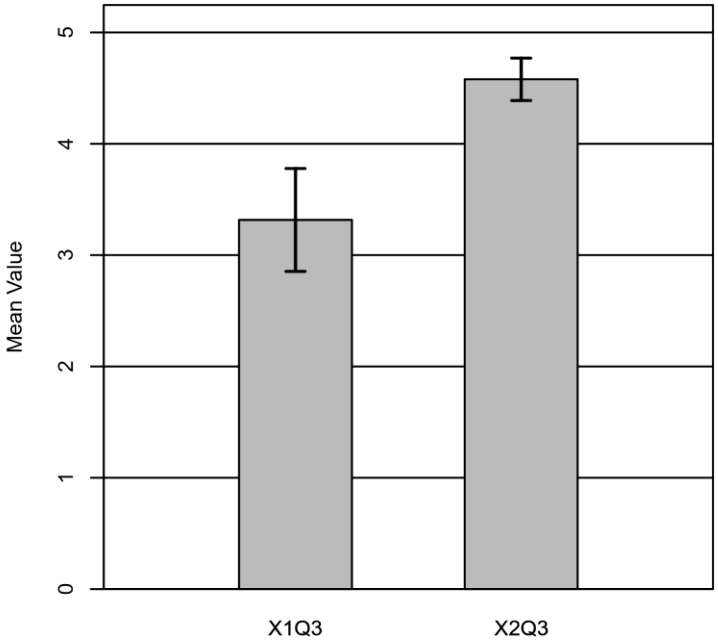
Two-Tailed Paired Samples t-Test for the Difference Between X1Q3 and X2Q3

Survey 1 Question 3		Survey 2 Question 3				
M	*SD*	*M*	*SD*	*t*	*p*	*d*
3.32	1.45	4.58	0.60	-5.77	< .001	0.94

Note. N = 38. Degrees of Freedom for the *t*-statistic = 37. *d* represents Cohen's *d.*

Figure 1

The means of Survey 1 Question 3 (X1Q3) and Survey 2 Question 3 (X2Q3) with 95.00% CI Error Bars



The result of the two-tailed paired samples *t*-test was significant based on an alpha value of .05, *t*(37) = -4.95, *p* < .001. This finding suggests the difference in the mean of Survey 1 Question 4 and the mean of Survey 2 Question 4 was significantly different from zero. The mean of Survey 1 Question 4 was significantly lower than the mean of Survey 2 Question 4. The results are presented in Table 4. A bar plot of the means is presented in Figure 3.

Table 3

Two-Tailed Paired Samples t-Test for the Difference Between Survey 1 Question 4 (*X1Q4) and* Survey 2 Question 4 (*X2Q2)*

X1Q4		X2Q2				
M	*SD*	*M*	*SD*	*t*	*p*	*d*
3.66	1.48	4.82	0.39	-4.95	< .001	0.80

Note. N = 38. Degrees of Freedom for the *t*-statistic = 37. *d* represents Cohen's *d*.

Figure 2

The means of Survey 1 Question 4 (X1Q4) and Survey 2 Question 4 (X2Q2)

with 95.00% CI Error Bars

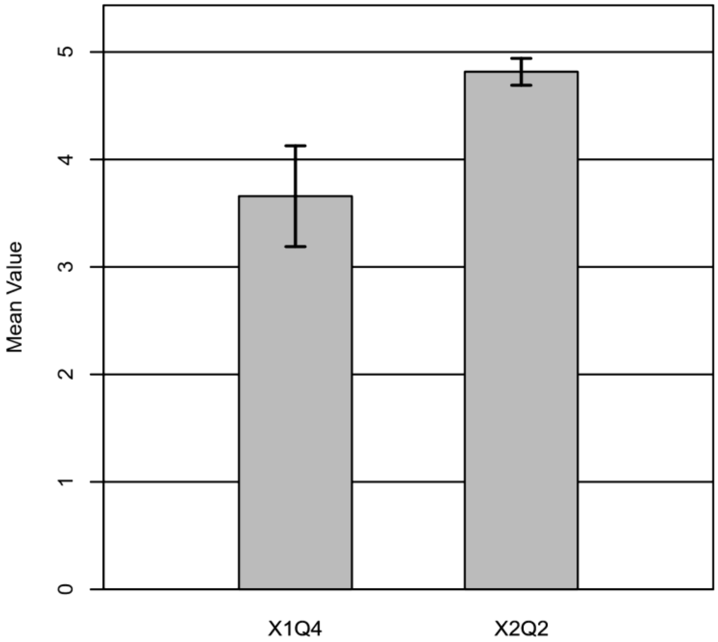


Table 4

Frequency Table for Post-Intervention Quiz

Variable	*n*	%
Correct Quiz Answers		
Question 1	38	85.3
Question 2	38	95
Question 3	38	100
Question 4	38	100