ADVANCE CARE PLANNING: A NURSING EDUCATIONAL INTERVENTION

by

Shannon L. Pointer, MSN, RN, CHPN

A Doctoral Scholarly Project submitted to the faculty of
The University of North Carolina at Charlotte
in partial fulfillment of the requirements
for the degree of Doctor of
Nursing Practice

Charlotte

2021

Approved by:

____

Dr. Meredith Troutman-Jordan

____

Dr. Katie Shue-McGuffin

____

Dr. Joshua Borders

____

Dr. Teresa Scheid

ABSTRACT

SHANNON L. POINTER. ADVANCE CARE PLANNING: A NURSING EDUCATIONAL INTERVENTION.
(Under the direction of DR. MEREDITH TROUTMAN-JORDAN)

It is so rewarding to help someone to achieve their desires for their health care. The feeling of helping to empower others to know the choices that they have available to them while they can make those choices is profound. It is also gratifying to advocate for others to have a proactive role in the decisions related to their health care.

Registered nurses working in North Carolina each day have ample opportunities to engage with patients, caregivers, and community members on the topic of advance care planning and advance directives. The importance of ensuring that nurses receive education and awareness on these topics cannot be overstated. Improving a nurse’s education and awareness can impact a nurse’s ability and comfort level to discuss these topics with others. In addition to providing education and awareness, it is also important to allow for time of reflection on a nurse’s unique experiences and perceptions on barriers related to advance care planning and advance directive completion.

Through participants completing an initial survey, educational training including open-ended questions and post-survey, this DNP Scholarly Project sought to look at nurses’ knowledge, attitudes, experiences, perceptions, and self-efficacy related to advance care planning and advance directives while also gaining awareness to nurses’ thoughts on perceived barriers to advance care planning and advance directives and if nurses feel the educational training offered as part of this project would benefit other nurses.

ACKNOWLEDGEMENTS

To all the faculty and staff within the UNC-Charlotte Doctor of Nursing Practice program, your insight and knowledge in the development of my DNP Scholarly Project was invaluable. I would especially like to thank my Committee Chair, Dr. Meredith Troutman-Jordan and my Clinical Expert, Dr. Joshua Borders, for your consistent expertise, encouragement, and support.

I would like to acknowledge several people who helped me in the development of my educational content for the DNP Scholarly Project. Thank you to attorney Kenneth L. Burgess for your dedication to education and advocacy on the importance of advance care planning and advance directive completion. You have been so helpful and selflessly shared your time with me to help me improve my knowledgeability on these subjects over the years. I am forever grateful for your assistance when I had questions or sought clarifications regarding my project's educational content. I would also like to thank the North Carolina Secretary of State Elaine Marshall's office for your dedication and for being an advocate to ensure information is available for those within North Carolina on advance health care directives. Specifically, thank you to Ann McNellis Elmore, Agency Legal Consultant with the NC Department of the Secretary of State, for your expertise, encouragement, and support of my efforts with my project's educational content.

Thank you to my husband John, my daughter Bliss, and to my family for your love and support. Thank you to my co-workers and to my employer for your support and flexibility as I completed this project. I also want each person who has helped to mentor and educate me on advance care planning and advance directives to know that I have taken those experiences and continued to grow, learn, lead, and strive to do for others what you have done for me.

DEDICATION

I would like to dedicate this DNP Scholarly Project in memory of my brother, Terry Joe Boswell. Terry was a wonderful father, brother, as well as a talented welder. While you are no longer here with me, I will continue to encourage all to bravely enjoy life, never procrastinating or delaying on accomplishing those things that we dream about.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF ABBREVIATIONS

ACP	Advance Care Planning
AD	Advance Directives
ANA	American Nurses Association
CHPN®	Certified Hospice and Palliative Nurse
CDSR	Cochrane Database of Systematic Reviews
DNR	Do Not Resuscitate
HPCC	Hospice and Palliative Credentialing Center
HPNA	Hospice & Palliative Nurses Association
IRB	Institutional Review Board
KAESAD	Knowledge, Attitudinal, Experiential Survey on Advance Directives (KAESAD)
MOST	Medical Orders for Scope of Treatment
NCIOM	North Carolina Institute of Medicine
PSDA	Patient Self-Determination Act

CHAPTER I: INTRODUCTION

By nature, people desire the best health and sense of wellness possible. Wellness involves many dynamic components and is much more than mere physical health (World Health Organization, 2021). Regardless of status of health, all deserve to achieve their best possible social, mental, and physical self (World Health Organization, 2021). In this context, it is vital to consider what is important to every individual regarding their version of holistic health. Advance care planning (ACP) and advance directives (AD) can be important considerations in the context of holistic care. ACP involves constant analysis and frequent dialogue among all involved to ensure a patient's desires for their care are honored (Merlane & Armstrong, 2020).

The Conversation Project (2021) found that "while 92% of Americans say it's important to discuss their wishes for end-of-life care, only 32% have had such a conversation" (The Conversation Project National Survey, 2018, "By the Numbers" section). The Conversation Project (2021) also found that "95% of Americans say they would be willing to talk about their wishes, and 53% even say they'd be relieved to discuss it" (The Conversation Project National Survey, 2018, "By the Numbers" section). It is crucial to emphasize the development of knowledge, ability, and comfort level of nurses to be able to facilitate and advocate regarding advance directives (Miller, 2017).

Background

Yadav et al. (2017) "systematically reviewed studies published in the period 2011–16 to determine the proportion of US adults with a completed living will, health care power of attorney, or both" (p. 1244). Yadav et al. (2017) found that "among the 795,909 people in the 150 studies analyzed, 36.7 % had completed an advance directive, including 29.3 % with living wills" (p. 1244).

A systematic literature review by Fleuren et al. (2020) identified five aims inherent to ACP: “respecting individual patient autonomy, improving quality of care, strengthening relationships, preparing for end-of-life, and reducing overtreatment” (p. 13). Each day potentially affords an opportunity for nurses to educate and advocate for ACP and AD as a reflection of patient goals and desires for their care. Having dialogue with patients in a variety of care locations regarding ACP is a something that nurses should embrace (Izumi, 2017).

Problem Statement

Nurses receive an extensive amount of education on a variety of topics within their initial programs of study. Nurses’ training specifically on ACP and AD may vary drastically, dependent upon their academic program, clinical area of practice and subsequent continuing education received. The variability and gap of nursing knowledge on ACP and AD could impact opportunities for advocacy and education. Additional consideration must also be given to the experiences, values, beliefs and attitudes or perceptions of nurses, as these could have significant impact on ACP conversations and AD completion. Nurses empowered through education and awareness accompanied with collaborative interdisciplinary work can make substantial gains in the incorporation of ACP and AD into daily practice (Ryan & Jezewski, 2012).

It is important to note that state advance directive laws can vary. Within the state of North Carolina, there are North Carolina statutory requirements related to AD. Therefore, an educational training that specifically speaks to AD and state specific laws related to AD could be beneficial and improve knowledgeability for registered nurses in North Carolina. This knowledgeability could improve care delivery. Hospice and palliative care registered nurses working in North Carolina may feel more educated and empowered to advocate for patients related to ACP and AD with improved knowledge in both the Patient Self-Determination Act (PSDA) and North Carolina specific state laws related to AD.

The field of hospice and palliative care has many opportunities to discuss components of advance care planning and advance directives, both with patients but also within community educational outreach programs. Improving knowledge of registered nurses working within hospice and palliative care programs in North Carolina could benefit North Carolina communities. The North Carolina Institute of Medicine [NCIOM] (2020b) assembled a Task Force on Serious Illness Care in 2019. In 2020, NCIOM (2020a) issued a report with multiple recommendations that were derived from the efforts of this task force. Specifically, there were 9 identified recommendations (4.2-4.10), two of which were priority recommendations (4.2 and 4.9), that were addressing topics relevant to ACP, AD, and portable medical orders. The NCIOM (2020a) task force report recommendation 4.4 states “Promote training on advance care planning for health care professionals” (p. 46). The recommendations from the NCIOM (2020a) Serious Illness Task Force continue to be addressed through the establishment and continued advocacy and efforts of the North Carolina Serious Illness Coalition (2021).

Purpose of the Project

The purpose of this DNP Scholarly Project was to learn more about nurses’ knowledge, attitudes, experiences, perceptions, and self-efficacy related to ACP and AD. The hope is that through this project, nurses will become more knowledgeable regarding ACP and AD through an educational training and therefore, feel more able to discuss these topics with others. Additional rationale for this project was to gain insight into nurses’ perceived barriers to ACP and AD and if nurses felt the educational training offered was helpful.

Through an educational training approach that addresses both ACP and AD, nurses may improve knowledgeability, have changes in attitudes and potentially feel more able regarding ACP and AD. Having components of an educational training that include time for open-ended responses to perceived barriers and well as feedback on if this type of training was helpful may also lend to further knowledge on registered nurses' perceived barriers to ACP and AD and potential implications for further study and more specific in-depth educational offerings on these topics for registered nurses.

Clinical Question

Among registered nurses working within hospice and palliative care in North Carolina (P), does an educational training on advance care planning (ACP) and advance directives (AD) (I), improve nurses' knowledge, attitudes, and self-efficacy of ACP/AD (O) from initial survey to post-survey (C and T)?

Project Objectives

The overall objectives of this DNP Scholarly Project were to assess and evaluate nurses' knowledge, attitudes, experiences, perceptions, and self-efficacy related to ACP and AD. The specific questions this project hoped to address included: How knowledgeable are nurses on the topic of ACP and AD documents? What are nurses' attitudes and experiences in relationship to ACP and AD? What are nurses' perceptions of their self-efficacy in relation to ACP and AD? After an educational training, will nurses feel more knowledgeable and able regarding ACP and AD? Will nurses' attitude change from initial survey to post-survey? What are nurses' perceived barriers to ACP conversations or the completion of the AD documents?

A broader objective in relationship to nursing practice was to increase awareness and comfort level among nurses to improve ACP conversations and AD completion. The desired short-term outcomes were to improve nurses’ knowledge and self-efficacy on ACP and AD, as well as to gain insights on knowledge, attitudes, experiences, and perceived barriers to ACP and AD. Intermediate and long-term outcomes included improving the frequency of ACP conversations, AD document completion and utilization of ACP and AD. The additional insight provided by participants will help in determining if the educational training as part of the project was helpful. This knowledge may help to identify future study directions and further educational training objectives that could be beneficial for registered nurses.

CHAPTER II: LITERATURE REVIEW

The literature review involved searching for relevant content using The University of North Carolina at Charlotte Library Doctor of Nursing Practice Tool Kit resources: CINAHL Plus with Full Text, PubMed, and Cochrane Database of Systematic Reviews (CDSR). Search criteria utilized individual words and phrases such as advance care planning, advance care directives, end-of-life care conversations, and nurses. Boolean searches were also occasionally utilized. Specific article searches were also conducted by title of relevant literature or author. The literature evaluation table encompassed over 40 items with additional extensive items reviewed in the preparation and planning for the educational component of the project. Articles excluded included those that did not meet identified relevance needed for this specific project or were written in a language other than English.

Through literature review, it is apparent that health care professionals, including nurses, could benefit from additional education on ACP and AD (Chan et al., 2019; Christensen et al., 2019; Jezewski et al., 2005; Jezewski & Feng, 2007; Shepherd et al., 2018; Walerius et al., 2009). For nurses to actively engage in practice regarding ACP, it is crucial that they receive the appropriate education (Blackwood et al., 2019; Jezewski et al., 2005; Ludwick et al., 2018). Nurses are in a position to make significant impact in relationship to ACP and AD, but proper education and training is imperative (Blackwood et al., 2019; Christensen et al., 2019; Jezewski & Feng, 2007; Shepherd et al., 2018). Implementation of successful ACP communication involves multiple disciplines. Vanderhaeghen et al. (2019) state that “An important facilitator is multidisciplinary cooperation in a team where relevant information can be shared, and professionals can build upon previous communication with colleagues” (p. 441). Nurses may feel increased empowerment on ACP and AD through improved knowledge, which can improve interactions between patients, family, and those within the interdisciplinary teams in which they work. (Ryan & Jezewski, 2012).

Within the context of hospice and palliative care with patients at end of life, the concepts of ACP and AD are ever present. The American Nurses Association [ANA] (2016) position statement on nurses' roles and responsibilities in providing care and support at the end of life emphasizes the importance of nurses working in partnership with patient, family, and other members of the health care team to help empower patients and families through advocacy and education (ANA, 2016). The Hospice & Palliative Nurses Association [HPNA] (2017) position statement on advance care planning also highlights how patient wishes may change over time and the importance of nurses having the necessary knowledgeability to support patients and families through training and advocacy (HPNA, 2017). The American Nurses Association [ANA] (2020) position statement on nursing care and do-not-resuscitate (DNR) decisions reflects continued support for the nurse's role in educating and being an advocate for patients and families (ANA, 2020).

Chan et al. (2018) conducted a randomised controlled trial. "This study showed that a nurse-led structured advance care planning programme could effectively improve didactic congruence regarding end-of-life care preferences, reduce patient's decisional conflict and increase the documentation of care preferences" (Chan et al., 2018, p. 26). Patients with significant illness can benefit from care provided by nurses who are able to clearly articulate and effectively communicate, both in collaboration on understanding the wishes of the patient, but also in regard to education that can be provided to patients and families who may be facing decisions. (Head et al., 2018). Without proactive planning and dialogue with patients and families about wishes for care at end of life, they may not be fully prepared to make informed decisions related to the care they would or would not want to receive (Aguilera, 2020).

Nurses need additional education on ACP and AD to improve their professional ability to help others, and to gain a better personal understanding and ability to apply ACP within their own lives (Shepherd et al., 2018). Improving nurses' understanding and ability regarding ACP and AD through implementation of an educational intervention may improve nurses' willingness to engage in this topic (Christensen et al., 2019 & Jezewski et al., 2005). Christensen et al. (2019) conducted a doctoral project to "assess rural nurses' knowledge, attitudes, and experiences with advance directives using the Knowledge, Attitudinal, and Experimental Surveys on Advance Directives" (p. 264). Christensen et al. (2019) stated that "one of the key findings from the KAESAD survey was that the overall knowledge of ADs was marginal, averaging 57%" (p. 268). Scherer et al. (2006) conducted a study to "describe critical care nurses' knowledge, attitudes, confidence and experiences regarding advance care directives and end-of-life decision making" (p. 31). Scherer et al. (2006) discussed within their findings that possible worksite training programs on AD might be a way to improve nurse's knowledgeability in AD. It is also important to note that several studies indicated nurses were not always knowledgeable in state laws applicable to ACP/AD or The Patient Self-Determination Act (PSDA) (Christensen et al., 2019; Jezewski et al., 2005; Jezewski & Feng, 2007; Sherer et al., 2006; Walerius et al., 2009).

Gazarian et al. (2019) conducted a systematic evaluation of advance care planning resources. "There are many ACP educational resources available to support the process of advance care planning, yet available resources are not universally accepted and under-utilized in clinical practice" (Gazarian et al., 2019, p. 174). It is important to tailor education to nurses to help demystify the process, and improve familiarity with appropriate applicable resources, federal legislation, and state laws, which as stated earlier, can vary related to AD.

Theoretical Framework/Significance

This project's theoretical framework was derived from the revised Health Promotion Model by Nola J. Pender (George, 2011). In the development, implementation and evaluation of this project, thoughts were continually processed on how ACP and AD can be a component of overall wellness and health promotion. Through many years of personal and professional experiences, numerous examples have occurred where ACP and AD completion have created a sense of peace and well-being. Within that same context, there have also been many examples of where ACP and AD were not comforting to discuss and may generate a negative response.

It is important to for nurses to have awareness that there may be factors related to an individual's life, background, knowledge, personal experiences, culture, and belief systems that can impact ACP discussions (Carabez & Scott, 2016; de Vries et al., 2019; Freytag & Rauscher, 2017). Many misconceptions abound regarding ACP and AD and nurses can play a valuable role in clarifying these misconceptions (Dobbins, 2019). Those who have reflected on their care and expressed their feelings through ACP and AD may be more likely to be at peace and have a greater sense of well-being, Good ACP communication and collaboration may improve the well-being of not only the individual, but their loved ones, as well as their health care professionals. Improved nursing education on ACP and AD could impact a nurse's ability to have ACP conversations and advocate for completion of AD documents.

Pender's revised Health Promotion Model (George, 2011) has components that would be relevant to consider as nurses advocate and educate on ACP and AD. Pender's revised Health

Promotion Model (George, 2011) includes many variables that could influence an individual's likelihood to engage in actions that reflect health promotion. These variables are:

> "Individual characteristics and experiences of prior related behavior and personal factors; behavior-specific cognitions and affect, including perceived benefits of action, perceived barriers to action, perceived self-efficacy, activity-related affect, interpersonal influences, and situational influences; commitment to a plan of action, immediate competing demands, and preferences" (George, 2011, p. 548).

This model and the variables within this model were continually reflected on throughout the project. In consideration of the focus of one of the project components being self-efficacy of nurses in relationship to ACP and AD, and the intent being that hopefully this project would lead to an increase in ACP and AD completion, this model was contemplated and considered in reflection during both the quantitative and qualitative components of this project.

CHAPTER III: METHODOLOGY

Project Design

The DNP Scholarly Project was approved by the University of North Carolina at Charlotte Institutional Review Board (IRB). This project was a one-day pilot study that was delivered virtually, consisting of completing an initial survey, educational training about ACP and AD, and a post-survey. The total time estimated to complete the study was approximately 2.5-3 hours. The educational training portion of the project's design included two open-ended questions at the conclusion of the educational training that were designed to gain insight from the participants on if the educational training was helpful and to gain insight into their perspectives on perceived barriers to ACP completion.

This design allowed for review of nurses' knowledge, attitudes, experiences, perceptions, and self-efficacy related to ACP and AD but also helped to determine if nurses became more knowledgeable and able to have conversations regarding ACP and AD through an educational training. This design also allowed for gaining further insight into nurses' perceived barriers to ACP and AD and if nurses felt the educational training offered was helpful.

Subjects

The sample for the project was a convenience sampling of registered nurses who work within hospice and palliative care organizations in North Carolina through utilizing an email database.

Recruitment of Subjects

The recruitment process began with a recruitment script being sent via email through the email database. The recruitment email included a description of the project, the criteria for enrolling in the study and how participants could indicate to the project coordinator their interest in participating in the study.

Inclusion and Exclusion Criteria

The recruitment for sample size population was desired to be no more than 30 participants due to this being a pilot project. Inclusion criteria included being Registered Nurses, 18 years of age or older, and working in hospice and palliative care in North Carolina. Inclusion criteria also included only those with the ability to read, speak and write/type in English, and those who had access to technology to complete the online study. Exclusion criteria were those who were not Registered Nurses working in hospice and palliative care in North Carolina and were not able to read, speak and write/type in English. Exclusion criteria also included those who did not have access to technology to complete the online study.

Procedures

A signed letter of approval was obtained to use an email database of hospice and palliative organizations across the state of North Carolina to recruit subjects. The recruitment email was sent three times. Two of these times it was in the early morning hours before 8:00am. The third time was sent just after 5:00pm. Each recruitment email was sent within a three-month time frame; once in June, once in July and once in August, 2021.

Interest Survey

If after reading the recruitment email and if the participant was interested, they were able to visit the recruitment survey link embedded in the recruitment email to indicate their interest. The interest survey contained three items. The first two items were yes/no responses. The first item was to indicate that they wanted more information. The second item was to indicate whether they met the project criteria. If they answered “yes” to the first and second question, the third question is where they would proceed to provide their first name, last name, and email address. Those who expressed interest would then be sent a consent form through an electronic signature program to review and sign if they wanted to be included in the project.

Consent Process

The consents were sent to the potential participants who expressed interest using an electronic signature program. Participants received their completed copy of the consent after the project coordinator also signed through the electronic signature program. Once the project coordinator received a completed consent, the project coordinator was able to allow some of the initial respondents to be offered several time choices to determine what would work best. Once the time was set, there were no additional offers of time choices. When the date of the intervention was set, a registration invitation was sent to those who had completed consent for the project. Participants who consented but did not register were reminded to register again with a reminder email.

Setting

The setting was within a web-based platform. The project coordinator sent an email to the participant with the date and time of the study and the study log-in instructions. Only those who returned a signed consent form to participate were sent the log-in instructions for the study. Participants also received one reminder email prior to the study date of the study date and time. Participants used the log-in instructions provided by the project coordinator to log in on the day and time of the study to begin the study. Once they logged in for the study, they were asked to assign themselves a one letter and one number combination. Participants were then asked to complete an initial online survey through a provided online link that took approximately 30-45 minutes to complete. Once finished, the participant waited until the project coordinator announced the start of the educational training. The project coordinator began the online educational training through the web-based platform. The online educational training lasted approximately 60 minutes. After completion of the educational training, participants were asked to complete an online post-survey through an online link that took approximately 30-45 minutes to complete.

Data Collection

Instrument

The quantitative measurement tool utilized in the DNP Scholarly Project was an adapted version of the Knowledge, Attitudinal, Experiential Survey on Advance Directives (KAESAD) Instrument© (Jezewski et al., 2005). The project coordinator obtained permission on 4/1/2020 from the author, Mary Ann Jezewski, RN, PhD, FAAN, to use this instrument for this study, and obtained additional permission on 9/2/2020 from the author, Mary Ann Jezewski, RN, PhD, FAAN, to use this instrument online for this study as the DNP Scholarly Project would be completed virtually.

The adapted (KAESAD) Instrument© for this DNP Scholarly Project consisted of sections that would ask questions of participants based on knowledge, attitudes, experience, and confidence. The project coordinator placed the instrument components within an electronic survey platform so that the survey could be delivered virtually to participants both before and after the educational intervention. The first section of questions focused on knowledgeability. This included 10 questions on general knowledge of AD, 7 questions on knowledge related to the Patient Self-Determination Act (PSDA), and 11 questions on knowledge of North Carolina State laws regarding AD.

There were 20 questions related to professional attitudes regarding AD and end of life decision-making. The questions then transitioned to focus on 7 questions related to experiences with AD and 11 questions related to participant level of confidence. Participants completed 20 additional questions related to professional experiences with end of life decision-making. The types of questions within the initial survey and post-survey consisted of "yes/no/don't know" and "yes/no" style responses as well as Likert scale responses. There was a final demographic component which included 26 questions in the personal, professional, and institutional realm.

The adaptations occurring to the original (KAESAD) Instrument© for this project included administering the instrument through a virtual platform, adapting the demographic section to fit the project's sample population and project design, including a change (Demographic Question 1) to ask for participant age, rather than birthdate, and changes to adapt to the DNP Scholarly Project sample population and study design (Demographic Question 16, 17, and post-survey final open ended-question as well as changing state specific information to reflect North Carolina state laws). There were also two questions eliminated from the North Carolina State law section of the original (KAESAD) Instrument© for this project's initial survey and post-survey. The demographic section of the initial survey and one question in the post-survey required potentially a "other" response or an open-ended response, as well as a "check all that apply" type response and these responses were enabled through the online platform process. Any open-ended responses within the initial survey or post-survey were analyzed for context and themes.

The adapted (KAESAD) Instrument© for this project also consisted of a post-survey. The post survey included the original 28 knowledge, 20 attitude, and 11 confidence questions. The final question on the post-survey was an open-ended response question from the original demographic section of the (KAESAD) Instrument©. It is important to note that while the (KAESAD) Instrument© had shown reliability through pilot test-retest and content validity through expert panel review (Jezewski et al., 2005), the changes made within this project's adapted version, along with the limited sample size, means that this previously established reliability and validity cannot be attributed to the adapted version used within this project.

Educational Training

The topics that were covered during the educational training were delivered similarly to other common types of professional development educational offering practices, using presentation slides and a handout. The intent of the educational training was to improve knowledge and to also determine if this type of educational training was helpful for participants and if they feel other registered nurses would benefit from this type of educational training. The objectives within the educational training are provided in Table 1.

There were two open ended- questions that were discussed at the conclusion of the training. These questions were: *"What do you perceive as barriers to advance care planning and advance directive completion?"* and *"Do you feel this educational training was helpful? If yes, would other nurses benefit from attending this type of educational training?"*

During the educational training, participants could ask questions and communicate with the project coordinator verbally or in writing and provide written or verbal feedback to the project coordinator when asked open-ended questions. The study was audio and video recorded to ensure the project coordinator was able to have accurate record of participant questions and responses. Any questions or responses by participants were analyzed for themes, including perceived barriers to ACP and AD as well as responses on the helpfulness of the educational training.

Participants were provided the handouts for the education training during the education session through the web-based platform. There was time allowed to ensure everyone received and was able to open all items shared within the educational training. Only one participant expressed difficulty accessing the handouts and requested they be sent via email. The project coordinator did follow through and provide these as requested to the participant via email.

CHAPTER IV: RESULTS

Interest Survey

The interest survey received 10 responses in June, 10 responses in July, and 8 responses in August. Table 2 highlights some of the data from the interest survey. Of the total 28 responses, 100% of all respondents completed question one, which was utilized to indicate whether the respondent wanted to learn more about participating in the project and wanted to receive a consent form to review. 100% of all respondents also completed question two, which asked the respondent to state whether they met project's inclusion criteria or not. 92.86% of the respondents answered "yes" to questions one and two and 7.14% answered "no" to questions one and two. Of those 28 responses, two had answered no to the interest survey questions and one of those two did not provide their first name, last name, or email address.

The project coordinator emailed the person who answered no to the two questions but provided their contact information, to ensure they completed the survey correctly and that they were not interested in participating. The project coordinator did not receive a response, so the project coordinator excluded this response. This made the interest survey a total of 26 responses. There were to 2 duplicate entries by the same respondent. Excluding the two duplicate entries took the number to 24 responses. What was interesting to note is that after the first two recruitment emails, the most responses happened on the same day the email was sent. As time passed, less responses occurred until the next recruitment email. The recruitment email was set to expire August 20, 2021.

Consent, Project Registration and Final Sample Size

A total of 24 consent documents were sent to potential participants and of those 24, 16 were returned completed. Ten participants registered for the project and 8 virtually attended the project. One person had to leave early due to a meeting and no additional participants left during the educational training. The total number of participants in the initial survey was 8 (N=8) participants. The total number of full educational training and post-survey participants was 7 (N=7). The project was completed in one day and within the estimated timeframe of 2.5 to 3 hours.

Quantitative Data Analysis

The initial survey and post-survey data were collected online through a web-based program that would prohibit editing of the instrument by participants. The data from the initial survey and post-survey were analyzed using descriptive statistics. The project coordinator conducted descriptive statistical analyses (frequencies and means) with continuous demographic variables, and frequencies with categorical demographic variables, to characterize the sample. Descriptive statistics (frequencies and means) were conducted with all major study variables as subscale score analysis from the initial survey: Knowledge, attitudes, experiences, and confidence.

Descriptive statistics (frequencies and means) were conducted as subscale score analysis with all major study variables from the post-survey: Knowledge, attitudes, and confidence. The attitude scores were reverse coded as appropriate in the initial and post-survey and data cleaning was completed as needed. Any “don’t know” answers were coded as incorrect for both the initial and post-survey in all knowledge section subscale analysis. The project coordinator evaluated responses to the educational training and looked for any differences between the initial survey and post-survey variables. The responses to the demographic information were analyzed based on the variables within the questions: Personal, professional, and institutional information.

Initial Survey

The demographic component of the initial survey included 26 questions in the personal, professional, and institutional realm. The sample was predominantly female (87.5%), Caucasian (100%), and were married or living as married (62.5%). There was one participant who was divorced (12.5%) and one who was widowed (12.5%). The sample included 62.5% of participants who identified their religion as Protestant, one participant who was Catholic (12.5%) and one who identified as “Christian” (12.5%), and one person (12.5%) chose “other” for religion but did not provide a written response. Of the sample, 62.5% identified themselves as not having an advance directive. Interestingly, 62.5% did identify as knowing someone in their immediate family who had an advance directive. All participants had a baccalaureate degree as their basic RN preparation. The highest degree earned was reported to be DNP (37.5%), Master’s Degree (37.5%), and Baccalaureate (25%).

Table 3 highlights some of the additional demographic data collected in this project, such as the year participants received their last degree, how many years they had practiced as an RN, and how many years they had practiced in hospice and palliative care. The highest percentage identified as the participant’s current practice site was in a hospice setting (62.5%). Other settings mentioned by participants included “home health and hospice; post-acute setting that includes rehab hospital, HH, hospice, and outpatient rehab; Palliative Care.” The current positions held by participants included staff nurse (12.5%), nurse educator (25%), and nurse manager (12.5%). Other current positions identified included “Clinical Practice Director; Chief Nursing Officer; VP; Nurse Navigator.” The majority of participants (87.5%) worked full time and did not provide direct patient care. There were 25% of participants who indicated they were certified through The Hospice and Palliative Care Credentialing Center (HPCC). Of these two participants, both were Certified Hospice and Palliative Nurse (CHPN®) certified.

There were just over 60% of participants who indicated they had some type of formal instruction about AD at their present institution, while 60% of participants indicated that they had received this instruction through an in-service program/workshop and 40% received this instruction through video/tapes. The locations of participants' workplace were identified as 50% urban, 37.5% suburban and 12.5% rural. The majority of participants (87.5%) identified having an ethics committee at their workplace, but 87.5% of participants also indicated they were not on their workplace ethics committee. The ethics committee's frequency of meetings varied within the sample responses. The most frequent choices indicated by participants on how patient's wishes regarding AD are formally communicated to the health care team were through being on the care plan (37.5%) and in a specifically indexed section of the chart (37.5%).

Table 4 shows the participant scores on the knowledgeability subscale scores from the initial survey. This section included 10 questions on general knowledge of AD, 7 questions on knowledge related to the PSDA, and 11 questions on knowledge of North Carolina State laws regarding AD. The 20 questions related to professional attitudes regarding AD and end of life decision making were reviewed. The 7 questions related to experiences with AD and 11 questions related to participant confidence in assisting with AD were also reviewed; 100% of participants had cared for a patient with and advance directive, while 75% had initiated discussions about AD with a patient. Participants completed 20 additional questions related to professional experiences with end of life decision-making.

Post-Survey

The post-survey included the same 10 questions on general knowledge of AD, 7 questions on knowledge related to the PSDA, 11 questions on knowledge of North Carolina State laws regarding AD, and 11 question related to confidence. Table 5 highlights the results from the post-survey subscale score analysis. The mean score in the initial survey for general knowledge on AD was 12.38 (range 11-14), *sd* 0.92. The mean score in the post-survey for general knowledge on AD was 12.14 (range 10-14), *sd* 1.35. The participants appeared to increase their scores on confidence in the post-survey compared to the initial survey. The mean level of confidence score in the initial survey was 39.50 (range 32-51) *sd* 8.05. The mean level of confidence score in the post-survey was 48.29 (range 42-55) *sd* 4.89.

Qualitative Data Analysis

Open-Ended Post-Survey Question

The post-survey contained one open ended question that asked participants what do hospice and palliative care nurses need most to increase their ability to assist patients with advance directives? 62.5% of participants responded. Below are the responses received:

"*Knowledge to advocate for this very important step in their life and resources to turn to if they don't have the knowledge.*"

"Education, education and education. The approach to initiate discussion and then the words that help reflect the wishes of the patient. Laws that protect the patient and providers."

"Great presentation! Would like to see education start in nursing schools and in med schools."

"Known resources and training on how to have those conversations"

"education"

Qualitative Themes: Review of Open-Ended Questions and Responses After Educational Training

Participants were given the opportunity to discuss two open ended questions at the end of the educational training. The first question asked was "*What do you perceive as barriers to advance care planning and advance directive completion*?"

The responses were analyzed for themes of generalized context due to the small sample size. One initial theme that emerged was related to the lack of "normalization" of these conversations with people who are not health care providers. An additional theme arose in continuation of the discussion on potential reasons why the conversations are not being normalized, and themes emerged for the need for education and specialized training to help better prepare nurses to have conversations on ACP and AD.

Additional context emerged in realizing that the COVID-19 pandemic has provided additional momentum to have dialogue on ACP and AD and that it is important to continue to find ways to use the momentum to increase ACP and AD completion. One participant reflected and discussed a time that this participant had seen where discussions with others during the pandemic allowed for a potential space for introducing communication regarding ACP and AD.

Contextual analysis continued to reflect how the nurse could be the catalyst to start the conversation with others, and one participant reflected on that an individual might find ACP "*uncomfortable*" and wait "*until it's too late*" to have those conversations. Additional context was noted around a participant sharing regarding how a nurse starting the conversation could lead to the individual being willing to talk more.

As discussions continued, one powerful theme emerged around "*opening the door*." One participant said: "*We need to open the door, and then later on open the door a little bit more, and* *peek in and see if somebody is ready, and it's not a once and done conversation, even in hospice*." Another theme was also identified as considering these conversations as one participant expressed as: "*small conversations and sometimes going there by inches rather than by feet*." "*I think is an important way to view the way we do outreach about advance directives.*"

Additional discussion occurred on perceived barriers. The barrier of time and competing requirements was an additional thought expressed by one of the participants as to a perceived barriers to ACP and AD completion. Another point within the context made during the discussion was the difficulty of trying to balance what the patient wants with the desires and opinions of the family. This generated additional conversation from one participant on the context of the importance of not being focused on what the nurse wants for patients and families, but rather on the importance of understanding and respecting the individuality of each situation.

The participants were asked a second question: "*Do you feel this education training was helpful, and if yes, would other nurses benefit from attending this type of educational training?*" The responses noted were overwhelmingly in favor with multiple "yes" statements and one "Absolutely" and one "I agree" statement.

CHAPTER V: SIGNIFICANCE/IMPLICATIONS

Limitations

Limitations to the project include one-day virtual implementation and time constraints. Some people were not able to make the time constraints for this project work or the specific day of the study would not work with their schedules, and this caused them to decide not to participate in the study. Additional limitations involve the electronic survey process and electronic consent process. There were some survey questions that some of the participants identified not being able to effectively select more than one option on a “check all that apply” question in the initial survey. Further increasing comfort level with the survey design would need to occur, including allowing for testing of this specific type of question to ensure functionality prior to implementation.

The consent process through electronic signature may not have been a process that all participants were used to in reviewing online or signing electronically. This needs to be taken into consideration as a possible limitation to obtain participant consent. The results of this project are not generalizable to larger populations and must be taken in context as this was a pilot study with a minimal sample size. This was a one-day project and therefore, there could be areas for improving and providing more in-depth trainings with future project development. This was a DNP Scholarly Project and a more specific research focused project in the future could help to expand on knowledge gathered through this type of study.

Discussion

This DNP Scholarly Project was overall a successful project where the project coordinator learned and grew from the experience. Nurses who participated in this project clearly identified the need for education on this topic, as over half offered narrative comments to this effect, and one participant also indicated the need for training and access to resources. This project helped to strengthen the project coordinator’s ability to excel in areas such as the American Association of Colleges of Nursing (2006) DNP Essentials III, IV, V, VI, and VII. Due to the COVID-19 pandemic, this project was able to adapt and be implemented in a completely virtual format. This required the project coordinator to learn new ways to collect, disseminate, analyze, and evaluate information.

This project did show that an educational training on ACP and AD can improve confidence on ACP/AD among registered nurses working within hospice and palliative care in North Carolina. Through successful implementation, this project’s success could encourage further opportunities to provide education on ACP and AD in a virtual format for nurses. The virtual format may make the training easier to attend and allow for more nurses to participate. It was very rewarding to hear each participant share their experiences and perceptions and it was also rewarding to see the participants confidence improve after a short educational training.

ACP and AD are more than mere paperwork and processes. They involve helping all people to accomplish holistic health though empowerment in expression of what is most important to them. Ultimately, the DNP Scholarly Project successfully gained perceptions from nurses on barriers to ACP and AD completion. The results from this DNP Scholarly Project can add to the body of knowledge related to nursing and ACP and AD, and potentially support further study on the topic.

REFERENCES

American Association of Colleges of Nursing. (2006, October). *The essentials of doctoral education for advanced nursing practice*. https://www.aacnnursing.org/DNP/DNP-Essentials

American Nurses Association. (2020). *Nursing care and do-not-resuscitate (DNR) decisions*. https://www.nursingworld.org/~494a87/globalassets/practiceandpolicy/nursing-excellence/ana-position-statements/social-causes-and-health-care/nursing-care-and-do-not-resuscitate-dnr-decisions-final-nursingworld.pdf

American Nurses Association. (2016). *Nurses' roles and responsibilities in providing care and support at the end of life*. https://www.nursingworld.org/practice-policy/nursing-excellence/official-position-statements/id/nurses-roles-and-responsibilities-in-providing-care-and-support-at-the-end-of-life/

Aguilera, V. (2020). Conversations that go unspoken: The necessity of advance care planning. *Nursing*, *50*(1), 67–68. https://doi.org/10.1097/01.NURSE.0000615136.46705.66

Blackwood, D. H., Walker, D., Mythen, M. G., Taylor, R. M., & Vindrola-Padros, C. (2019). Barriers to advance care planning with patients as perceived by nurses and other healthcare professionals: A systematic review. *Journal of Clinical Nursing*, *28*(23-24), 4276–4297. https://doi.org/10.1111/jocn.15049

Carabez, R., & Scott, M. (2016). 'Nurses don't deal with these issues': Nurses' role in advance care planning for lesbian, gay, bisexual and transgender patients. *Journal of Clinical Nursing*, *25*(23-24), 3707–3715. https://doi.org/10.1111/jocn.13336

Chan, C. W. H., Ng, N. H. Y., Chan, H. Y. L., Wong, M. M. H., & Chow, K. M. (2019). A systematic review of the effects of advance care planning facilitators training programs. *BMC Health Services Research*, *19*(362), 1-14. https://doi.org/10.1186/s12913-019-4192-0

Chan, H. Y.-L., Ng, J. S.-C., Chan, K.-S., Ko, P.-S., Leung, D. Y.-P., Chan, C. W.-H., Chan, L.-N., Lee, I. F.-K., & Lee, D. T.-F. (2018). Effects of a nurse-led post-discharge advance care planning programme for community-dwelling patients nearing the end of life and their family members: A randomised controlled trial. *International Journal of Nursing Studies, 87,* 26-33. https://doi.org/10.1016/j.ijnurstu.2018.07.008

Christensen, K. L., Winters, C. A., Colclough, Y., Oley, E., & Luparell, S. (2019). Advance care planning in rural Montana: Exploring the nurse's role. *Journal of Hospice & Palliative Nursing, 21*(4), 264–271. https://doi.org/10.1097/NJH.0000000000000556

de Vries, K., Banister, E., Dening, K. H., & Ochieng, B. (2019). Advance care planning for older people: The influence of ethnicity, religiosity, spirituality and health literacy. *Nursing Ethics, 26*(7-8), 1946–1954. https://doi.org/10.1177/0969733019833130

Dobbins, E. (2019). Advance directives: Replacing myths with facts. *Nursing, 49*(10), 11-13. https://doi.org/10.1097/01.NURSE.0000558102.43538.8f

Fleuren, N., Depla, M. F. I. A., Janssen, D. J. A., Huisman, M., & Hertogh, C. M. P. M. (2020). Underlying goals of advance care planning (ACP): A qualitative analysis of the literature. *BMC Palliative Care, 19*(27), 1–15. https://doi.org/10.1186/s12904-020-0535-1

Freytag, J., & Rauscher, E. A. (2017). The importance of intergenerational communication in advance care planning: Generational relationships among perceptions and beliefs. *Journal of Health Communication*, *22*(6), 488–496. https://doi.org/10.1080/10810730.2017.1311971

Gazarian, P. K., Cronin, J., Dalto, J. L., Baker, K. M., Friel, B. J., Bruce-Baiden, W., & Rodriguez, L. Y. (2019). A systematic evaluation of advance care planning patient educational resources. *Geriatric Nursing, 40*(2), 174–180. https://doi.org/10.1016/j.gerinurse.2018.09.011

George, J. B. (2011). Health promotion model: Nola J. Pender. In J. B. George. (Ed.), *Nursing theories: The basis for professional practice* (6th ed., pp. 544-576). Pearson Education.

Head, B. A., Song, M.-K., Wiencek, C., Nevidjon, B., Fraser, D., & Mazanec, P. (2018). Palliative nursing summit: Nurses leading change and transforming care: The nurse's role in communication and advance care planning. *Journal of Hospice & Palliative Nursing, 20*(1), 23-29. https://doi.org/10.1097/NJH.0000000000000406

Hospice & Palliative Nurses Association. (2017). *HPNA position statement: Advance care planning*. https://advancingexpertcare.org/position-statements

Izumi, S. (2017, June). Advance care planning: The nurse's role. *American Journal of Nursing, 117*(6), 56–61. https://doi.org/10.1097/01.NAJ.0000520255.65083.35

Jezewski, M. A., & Feng, J.-Y. (2007). Emergency nurses' knowledge, attitudes, and experiential survey on advance directives. *Applied Nursing Research, 20*(3), 132-139. https://doi.org/10.1016/j.apnr.2006.05.003

Jezewski, M. A. Knowledge, Attitudinal, Experiential Survey on Advance Directives (KAESAD) instrument. Used with Permission.

Jezewski, M. A., Brown, J. K., Wu, Y.-W., B., Meeker, M.A., Feng, J.-Y., & Bu, X. (2005). Oncology nurses' knowledge, attitudes, and experiences regarding advance directives. *Oncology Nursing Forum, 32*(2), 319–327. https://doi.org/10.1188/05.ONF.319-327

Ludwick, R., Baughman, K. R., Jarjoura, D., & Kropp, D. J. (2018). CE: Original research:

Advance care planning: An exploration of the beliefs, self-efficacy, education, and practices of RNs and LPNs. *American Journal of Nursing, 118*(12), 26–32. https://doi.org/10.1097/01.NAJ.0000549664.43827.ce

Merlane, H., & Armstrong, L. (2020). Advance care planning. *British Journal of Nursing, 29*(2), 96–97. https://doi.org/10.12968/bjon.2020.29.2.96

Miller, B. (2017). Nurses in the know: The history and future of advance directives. *Online Journal of Issues in Nursing, 22*(3), 1. https://ojin.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol-22-2017/No3-Sep-2017/Articles-Previous-Topics/History-and-Future-of-Advance-Directives.html

North Carolina Institute of Medicine. (2020a). *Improving serious illness care in North Carolina*. Morrisville, NC: North Carolina Institute of Medicine. https://nciom.org/wp-content/uploads/2020/06/NCIOM_Improving-Serious-Illness-Care-in-North-Carolina_Full-Report_April-2020.pdf

North Carolina Institute of Medicine. (2020b). *Task force on serious illness care*. https://nciom.org/task-force-on-serious-illness-care/

North Carolina Serious Illness Coalition. (2021). https://www.ncsicoalition.org/

Ryan, D., & Jezewski, M. A. (2012). Knowledge, attitudes, experiences, and confidence of nurses in completing advance directives: A systematic synthesis of three studies. *The Journal of Nursing Research, 20*(2), 131-141. https://doi.org/10.1097/jnr.0b013e318256095f

Scherer, Y., Jezewski, M.A., Graves, B., Wu, Y.-W., B., & Bu, X. (2006). Advance directives and end-of-life decision making: Survey of critical care nurses' knowledge, attitude, and experience. *Critical Care Nurse, 26*(4), 30-40. https://doi.org/10.4037/ccn2006.26.4.30

Shepherd, J., Waller, A., Sanson-Fisher, R., Clark, K., & Ball, J. (2018). Knowledge of, and participation in, advance care planning: A cross-sectional study of acute and critical care nurses' perceptions. *International Journal of Nursing Studies, 86*, 74-81. https://doi.org/10.1016/j.ijnurstu.2018.06.005

The Conversation Project (2021). *About us*. Retrieved from https://theconversationproject.org/about/

Vanderhaeghen, B., Bossuyt, I., Menten, J., & Rober, P., (2019). Helping hospital professionals to implement advance care planning in daily practice: A European delphi study from field experts. *Journal of Research in Nursing, 24*(6), 433–443. https://doi.org/10.1177/1744987118772604

World Health Organization (2021). *Constitution.* https://www.who.int/about/governance/constitution

Walerius, T., Hill, P. D., & Anderson, M. A. (2009). Nurses' knowledge of advance directives, patient self-determination act, and Illinois advance directive law. *Clinical Nurse Specialist: The Journal for Advanced Nursing Practice, 23*(6), 316–320, https://doi.org/10.1097/NUR.0b013e3181be3273

Yadav, K. N., Gabler, N. B., Cooney, E., Kent, S., Kim, J., Herbst, N., Mante, A., Halpern, S. D., & Courtright, K. R. (2017). Approximately one in three US adults completes any type of advance directive for end-of-life care. *Health Affairs, 36*(7), 1244–1251. https://doi.org/10.1377/hlthaff.2017.0175

TABLE 1: Educational Training Objectives

Objective 1: Define Advance Care Planning and Advance Directives

Objective 2: Review the Patient Self-Determination Act (PSDA)

Objective 3: Review North Carolina General Statutes related to Advance Care Planning and Advance Directives

Objective 4: Describe North Carolina specific Advance Directives including:

- Health Care Power of Attorney (HCPOA)
- Advance Directive for a Natural Death (Living Will)
- Advance Instruction for Mental Health Treatment

Objective 5: Discuss completion requirements of Advance Directives in North Carolina.

Objective 6: Review additional types of Advance Directives: The Five Wishes® webpage and the VA Geriatrics and Extended Care Advance Directives webpage.

Objective 7: Review portable medical orders in North Carolina

- Do Not Resuscitate (DNR)
- Medical Orders for Scope of Treatment (MOST)

Objective 8: Discuss the NC Advance Health Care Directive Registry

Objective 9: Review helpful resources, references, and discuss two open-ended questions

Table 2: DNP Scholarly Project Interest Survey Data

Interest Survey Questions	N	Yes Responses (%)	No Responses (%)
1. “I am interested in learning more about participating in the study called Advance Care Planning: A Nursing Educational Intervention and would like to receive a consent form for this study to review.”	N=28	26 (92.86%)	2(7.14%)
2. “I meet the criteria to be included in the study: Registered Nurse working in hospice and palliative care in North Carolina who is 18 years of age and older, able to read, speak and write/type in English, and have access to technology to complete this online study.”	N=28	26 (92.86%)	2 (7.14%)
Contact Information Provided	N=27		

TABLE 3: Personal, Professional and Institutional Demographic Data

Personal, Professional and Institutional Demographic Data							
	N	Range	Minimum	Maximum	Mean	Std. Deviation	Variance
Age (years)	8	36	31	67	50.13	12.44	154.98
Year of Last Degree	8	7	2014	2021	2018	2.93	8.57
Years Practicing as RN	8	39	6	45	27.00	13.76	189.43
Years practicing in Hospice & Palliative Care	8	32.58	.416	33.00	6.43	10.88	118.39
Hours of instruction in AD during your education	8	8	0	8	1.75	2.77	7.64

TABLE 4: Initial Survey: Knowledge, Attitude, Confidence and Experience Scores

Initial Survey: Knowledge, Attitude, Confidence and Experience Scores							
	N	Range	Minimum	Maximum	Mean	Std. Deviation	Variance
General Knowledge (10 items)	8	3.00	11.00	14.00	12.38	.92	.84
PSDA Knowledge (7 items)	8	3.00	7.00	10.00	8.75	1.04	1.07
NC State Law Knowledge (11 items)	8	3.00	12.00	15.00	13.50	1.07	1.14
Professional Attitudes (20 items)	7	12.00	48.00	60.00	54.86	3.80	14.48
Confidence (11 items)	8	19.00	32.00	51.00	39.50	8.05	64.86
Professional Experience (AD) (7 items)	8	5.00	7.00	12.00	9.75	1.75	3.07
Professional Experience (EOL) (20 items)	8	13.00	47.00	60.00	51.13	4.36	18.98

TABLE 5: Post-Survey: Knowledge, Attitude, and Confidence Scores

Post-Survey: Knowledge, Attitude, and Confidence Scores							
	N	Range	Minimum	Maximum	Mean	Std. Deviation	Variance
General Knowledge (10 items)	7	4.00	10.00	14.00	12.14	1.35	1.81
PSDA Knowledge (7 items)	7	2.00	7.00	9.00	8.00	.58	.33
NC State Law Knowledge (11 items)	7	6.00	12.00	18.00	15.00	2.00	4.00
Professional Attitudes (20 items)	7	13.00	45.00	58.00	53.71	4.82	23.24
Confidence (11 items)	7	13.00	42.00	55.00	48.29	4.89	23.90