

ADVANCE CARE PLANNING AND ADVANCE DIRECTIVES: IMPLEMENTING ONLINE
EDUCATION FOR HEALTHCARE PROVIDERS

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ABSTRACT

Advance directives (ADs) summarize goals or preferences for future care regarding life-sustaining treatment and designates a surrogate decision-maker in the event a patient is unable to make healthcare decisions. These legal documents are especially important for providing patient autonomy and allowing people to communicate their medical care preferences to family, friends, and healthcare professionals. Two thirds of Americans have not completed an advance directive and 70% of Americans (more than 1.7 million) die of chronic diseases. Benefits of ADs include: autonomy during end-of-life, honored preferences, enhanced quality of medical decisions, less emotional distress, and even a decrease in healthcare costs. Approximately 60% of patients stated that they are open to talk about advance care planning (ACP); however, only 21% percent of providers reported talking frequently about matters related to ACP or end-of-life care.

Literature review findings revealed that providers lack training and education about ADs and ACP conversations, leading to discomfort in skills, confidence, and knowledge about having these essential discussions. The purpose of this practice improvement project (PIP) was to increase nurse practitioners' knowledge of facilitating ACP conversations, and completion of AD among patients living with a chronic disease, over the age of 65, seen within the primary care setting.

A total of 14 healthcare professionals participated in a one-hour educational webinar posted on the North Dakota Nurse Practitioner Association (NDNPA) website over a three-month time period between September 30, 2021 and December 30, 2021. Pre/post Likert scale surveys were administered to each participant electronically via Qualtrics. Confidence Likert scale surveys found the education increased participants' knowledge, confidence, and understanding of ACP and AD. PIP findings also demonstrated an increase in understanding of

the *Serious Illness Conversation Guide* and an increase in both confidence and likeliness of increasing and initiating ACP conversations with patients. Education on ACP and AD resources should continue to be provided for healthcare providers online. Future research should look into how providing ACP and AD education directly affects AD rates in patients living with a chronic disease, over the age of 65, seen within the primary care setting.

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DEDICATION

This dissertation is dedicated to my husband, William and my son, Liam.

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LIST OF ABBREVIATIONS

AANP	American Association of Nurse Practitioners
AMA	American Medical Association
AD	Advance Directive
ACP	Advance Care Planning
APRN	Advance Practice Registered Nurse
CDC	Centers for Disease Control and Prevention
CDSR	Cochrane Database of Systematic Reviews
CE	Continuing Education
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CME	Continuing Medical Education
COPD	Chronic Obstruction Pulmonary Disease
COVID-19	Coronavirus Disease 2019
DNP	Doctor of Nursing Practice
DNR	Do-Not-Resuscitate
EBP	Evidence-based Practice
EMR	Electronic Medical Record
EOL	End-of-Life
ESRD	End-Stage Renal Disease
HF	Heart Failure
ICU	Intensive Care Unit
IRB	Institutional Review Board
NCCDPHP	CDC's National Center for Chronic Disease Prevention and Health Promotion
NDBON	North Dakota Board of Nursing

NDNPA.....North Dakota Nurse Practitioner Association
NDSU.....North Dakota State University
NPNurse Practitioner
PAPhysician Associate
PIP.....Practice Improvement Project
PSDAPatient Self-Determination Act
SICGSerious Illness Conversation Guide

CHAPTER 1. INTRODUCTION

Background and Significance

Advance directives (ADs) summarize goals or preferences for future care regarding life-sustaining treatment and designates a surrogate decision-maker in the event a patient is unable to make healthcare decisions. These legal documents are especially important for providing patient autonomy and allowing people to communicate their medical care preferences to family, friends, and healthcare professionals (Silveira et al., 2014). The Patient Self-Determination Act (PSDA) was passed by Congress in 1991 to encourage institutions to promote the completion of advance directives and to facilitate more conversations of advance care planning (ACP). The PSDA requires all Medicare-certified institutions to inform hospitalized individuals of their right to complete an advance directive (AD). The PSDA introduced advance directives in hopes of alleviating unnecessary suffering, enhancing quality of care at end-of-life, and even having the potential of decreasing healthcare cost (Silveira et al., 2014).

Despite the potential benefits of advance directives, an abundance of supporting literature, and the enactment of PSDA, advance directive completion rates remain low (Morhaim & Pollack, 2013). Chronic disease in America is the leading cause of death, disability and a source of the nation's \$3.3 trillion debt in annual healthcare costs (NCCDPHP, n.d.). Two thirds of Americans have not completed an advance care directive and 70% of Americans (more than 1.7 million) die of chronic diseases (Kung, 2008; Penn Medicine News, 2017). By 2030, greater than 72.1 million people will be over the age of 65. Older adults consist of the greatest percentage of chronic disease, and comorbidities, requiring an increase in both medical attention and healthcare costs (Morhaim & Pollack, 2013).

When compared to the national average, patients living with chronic disease such as chronic obstructive pulmonary disease (COPD), heart failure (HF), stage IV cancer, and end-stage renal disease (ESRD) have only slightly higher completion rates of advance directives (Lendon et al. 2018; Yadav et al. 2017). Since January 2020 the existing threat of chronic diseases for people 65 years of age and older, has been magnified by the coronavirus disease (COVID-19) pandemic which has resulted in over 930,000 deaths and counting within the United States and a steep increase in hospitalizations for people 65 years of age and older (CDC, 2022). Current data indicates that patients living with chronic disease have a higher risk of morbidity, mortality and hospitalizations due to the COVID-19 pandemic (Javanmardi et al., 2020). Patients living with chronic disease also have a high risk of prolonged hospitalization, and possibly, aggressive care which could lead to care not aligning with patient's wishes and poor quality of care at end-of-life. Advance care planning and advance directives among patients during end-of-life can result in patient autonomy, honored preferences, enhanced quality of medical decisions, shared decision making, less emotional distress among patients' loved ones, and even a decrease in healthcare costs (Garrido et al., 2015; Hickman & Pinto, 2013).

Problem Statement and Purpose

Information must be collected regarding how healthcare providers can improve completion rates of advance directives in individuals over the age of 65 years old, who are living with chronic disease. Through more research, both the benefits and the barriers to advance care directive completion rates can reveal how to overcome the national issue of the lack of advance care planning among individuals living with chronic disease. A question that arises is how does early education about the benefits and facilitation of advance directives from healthcare providers overcome barriers perceived after receiving an online educational webinar over a 3-

month period? The purpose of the practice improvement project (PIP) was to increase healthcare providers' knowledge of facilitating advance care planning conversations, and to increase completion rates of advance directives among patients living with chronic disease(s), over the age of 65, seen within the primary care setting.

Objectives

1. Healthcare providers' perceived knowledge, confidence, and understanding of advance care planning and advance directives will increase after completing a one-hour online education webinar.
2. Healthcare providers perceived knowledge of how to use the *Serious Illness Conversation Guide* and its application to initiate advance care planning discussion will increase after a one-hour online education webinar.
3. Healthcare providers' knowledge of the role of advance care planning facilitators will increase after a one-hour online education webinar.

CHAPTER 2. THEORETICAL FRAMEWORK AND LITERATURE REVIEW

In order to provide sufficient evidence for confident clinical decision-making, an extensive systematic search of the literature was conducted between October 2020 and June 2021. The four electronic databases utilized for the systematic search included: Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, Cochrane Database of Systematic Reviews (CDSR), and Elsevier (Appendix A). Keywords and controlled vocabulary searches included the following terms: advance directive, advance care planning, end-of-life, primary care, barriers, and geriatrics. Databases were further narrowed to include age 65 and older, chronic obstructive pulmonary disease (COPD), heart failure (HF), stage IV cancer, end-stage renal disease (ESRD), COVID-19, academic journals, years 2010 to 2020, and English language.

The Cochrane database search consisted of terms “advance directives”, “end-of-life”, and “advance care planning” which resulted in seven trials relevant to the topic. Only one Cochrane trial was within the past 10 years. While searching CINAHL, the search yielded a total of 163 search results. From there, further search terms were introduced such as “chronic disease” and “geriatrics” to narrow the search. PubMed and Elsevier were searched using the exact search terms and limiters, yielding 93 results and 298 results respectively. After screening the titles and abstracts, five articles were left from CINAHL, 13 articles from PubMed, and seven articles from Elsevier were read in full by the co-investigator (author). Articles with insufficient data or results were excluded. Available studies were chosen based on measurable outcomes and levels of evidence. At the end of the search process, 23 articles were included in the literature review. Further reading of these articles led to hand-searching and grey literature. In the end of the screening process, an additional 16 research articles from other sources were included in the

review of literature. After reviewing multiple articles, several similarities were discovered, which will be described in the literature review.

Advance Directives

Advance care planning is an ongoing process of conversation between patients, family members, caregivers, and healthcare professionals. ACP process discusses a patient's future goals of care and facilitates decision-making in situations when patients are unable to communicate their own preferences (Sinclair et al., 2017). Advance directives are legal documents used in the ACP process to help provide guidance for medical and healthcare decisions (such as the termination of life support) in an event the patient becomes incapable to make such decisions (Ache et al., 2014). According to Butler et al. (2015), two major components of ADs are the living will and the power of attorney. When a patient completes a living will, they indicate what type of life sustaining care they would or would not like to receive. The medical power of attorney is a person who the patient names to make decisions about the patient's medical care if the patient is temporarily or permanently unable to communicate or make medical decisions. Both ACP and the use of ADs are essential in the days before death or a period in which a patient is actively dying (end-of-life).

Based on the review of literature, a large amount of literature supports the benefits of advance directives for patients, caregivers, providers, and healthcare costs. In a systematic review of randomized control trials, the use of advance directives decreased healthcare resources, hospitalization rates, and healthcare costs (Weathers et al., 2016). Silveira et al. (2014) also supported how the use of advance directives is associated with a decrease in hospitalization rates and economic burden during end-of-life (EOL) care. Although researchers from both studies claimed a reduction of healthcare costs associated with the use of advance directives, neither

study specified the exact dollar amount. In an additional study, advance directive use was associated with less invasive interventions within the hospital setting (Garrido et al., 2015). Ache et al. (2014) further supported the importance of completion of advance directives by saying patients with advance directives were more likely to receive less aggressive treatment within the hospital setting. Furthermore, patients with advance directives had a longer stay in hospice and were less likely to die in an inpatient setting. Hospice care earlier in end-of-life was associated with patients living longer, giving more time for families to prepare, and making death at home more feasible (Ache et al., 2014).

Advance directive completion has also been associated with reduced levels of stress, anxiety, and depression in family members (Garrido et al., 2015). Both patient and family satisfaction with care increased and distress associated with decisional conflict decreased when advance directives were utilized. Advance directives also served as an effective formal guidance resulting in less decisional burden, and improving bereavement adjustment among caregivers (Garrido et al., 2015; Hickman & Pinto, 2013; Weathers et al., 2016). A systematic realist review stated once the patient, family, and healthcare provider had a common understanding of the patient's preferences, both the family and the provider had an increased likelihood to act together to enact those preferences even when the patients were to lose decisional capacity (O'Halloran et al., 2018). O'Halloran et al. (2018) further found that advance directive rates increased with advance care planning discussions between patients, family, and clinical staff. ACP conversations led to increased patients' perceived quality of communication and increased congruence between patients and surrogates. Enhanced proxy-decision making, improved patient experience, and enhanced healthcare outcomes were also associated with the use of advance directives (Weathers et al., 2016). Weathers et al. (2016) findings further align with the

National Guideline Clearinghouse’s endorsement that all adults have the right to decide what will be done with their bodies, are presumed to have decision-making capacity until proven otherwise, and should be approached to discuss their treatment preferences and wishes.

Chronic Disease

According to the World Health Organization (WHO) (2016), chronic disease is defined as “being long in duration and is a result of a combination of genetic, physiological, environmental, and behavioral factors.” Conceptually, the WHO (2016) goes on further to explain that these diseases include cardiovascular disease, cancers, chronic respiratory diseases (such as asthma) and diabetes. For the PIP, patients with chronic disease were defined as patients who have chronic obstructive pulmonary disease (COPD), heart failure (HF), stage IV cancer, and end-stage renal disease (ESRD). Findings suggested these chronic diseases to be most common among literature.

Despite several benefits of advance directives, there remains a large deficit in AD completion rates, even in patients with chronic disease. According to the Centers for Disease Control and Prevention (CDC) (2012), 70% of the leading causes of death within the United States are due to chronic disease. In the United States, approximately 32% of all adults have an advance directive in place, and patients living with chronic disease such as COPD, HF, stage IV cancer, and ESRD, have only slightly higher completion rates (Lendon et al. 2018; Yadav et al. 2017).

The following are findings of advance directive completion rates for patients with COPD, heart failure, stage IV cancer, and ESRD:

- Only 21% of 24,291 individuals admitted with heart failure had an AD. The majority of advance directives in heart failure patients failed to have end-of-life medical

decisions addressed, and more than 80% of patients did not have ADs documented in their medical record (Butler et al., 2015; Dunlay et al., 2012).

- In a retrospective study of 2904 proxy reporters, those with stage IV cancer or lung disease were more likely to complete an AD within the last three months before death. Completion of ADs within the last three months of life was associated with a higher prevalence for aggressive care (Enguidanos & Ailshire, 2017).
- In a cohort study consisting of 794 patients living with stage IV lung or colorectal cancer, the majority (63%) of conversations regarding advance care planning during end-of-life took place in the inpatient hospital setting rather than the primary care setting (Mack et al., 2012).
- Among patients living with ESRD, the prevalence of advance directives ranged from 12-49%, however, very few actually addressed management of life sustaining treatments such as dialysis (Courtright et al., 2017; Feely et al., 2016).
- Patients with treatment-limiting advance directives and/or a surrogate decision maker appointed, had fewer hospitalizations, intensive care unit admissions, invasive procedures, inpatient deaths, and were more likely to use palliative care or hospice before death (Feely et al., 2016; Kurella Tamura et al., 2017).
- Predictors of increased documented ADs included: Caucasian race, older age, female, higher socioeconomic status, unmarried, higher clinical risk scores, length of stay greater than five days, hospice discharge, palliative care consult, and a do-not-resuscitate (DNR) order (Butler et al., 2015).

Advance directive completion rates for patients with chronic diseases remains low; while mortality rates remain high for patients with chronic disease. Due to the low AD completion

rates, there is an increased chance for undesirable, aggressive care within the population of patients with chronic disease (Dunlay et al., 2012).

COVID-19

Mortality rates of chronic disease and quality of care during end-of-life have been further affected by the coronavirus (COVID-19) pandemic. Although everyone was susceptible to the COVID-19 virus, older adults and those with certain chronic diseases were at greater risk for worse outcomes. Studies have shown that those living with cardiovascular disease, COPD, malignancy, and chronic kidney disease had a higher risk of being hospitalized when infected with COVID-19 (Javanmardi et al., 2020). According to Javanmardi et al. (2020), approximately 12% of 76,993 patients hospitalized due to COVID-19 had cardiovascular disease. Individuals with cardiovascular diseases, especially heart failure, had the highest prevalence among the chronic diseases to acquire COVID-19. Some studies suggest that COPD was a strong predictive comorbidity for intensive care unit (ICU) admission related to COVID-19 (Alqahtani et al., 2020; Jain & Yuan, 2020; Javanmardi et al., 2020). The presence of COPD was associated with a 60% higher mortality and patients had almost a seven times greater chance of progressing to serious, life-threatening events (Alqahtani et al., 2020). Although COPD was a prominent risk factor throughout the literature, all patients with medical comorbidities are still at a higher risk of ICU admissions, mechanical intubation, and death in relation to COVID-19 infections (Alqahtani et al., 2020; Nandy et al., 2020).

Available literature does indicate poor quality of end-of-life conversations following an acute event or clinical deterioration (Pearse et al., 2019). Having end-of-life conversations in an acute event leads to lack of time to discuss important topics with doctor and family, thus leading to rushed decision-making. Early discussions of goals of care can help to ensure an alignment of

patients' priorities and preferences. In a pandemic where resources are limited, advance care planning may have the potential to reduce the need for inappropriate intervention and may allow the redistribution of resources to patients whose deterioration is reversible. Since deaths from COVID-19 cases have risen significantly, and uncertainty remains of acquiring the illness, research further supports the use of advance directives to prevent undesirable, aggressive care in patients with chronic diseases.

Barriers

Although attempts for improvement of advance directive completion have been made, several barriers remain. Since advance directive completion rates remain low, understanding barriers to advance care planning by healthcare professionals is critical. Barriers are faced at several levels including: individual, interpersonal, provider, and system (Risk et al., 2019). Identifying both the barriers and enablers at these various levels may be the key to helping patients, families, providers, and systems increase the uptake of advance directives completion.

A lack of knowledge and uncertainty from both the provider and patient regarding how to discuss ADs and ACP are significant. Approximately 60% of patients stated that they are open to talk about ACP; however, only 21% percent of providers reported talking frequently about matters related to ACP or end-of-life care (Fulmer et al., 2018; Risk et al., 2019). Another study found that 68%of physicians reported having no training related to talking with patients and families about end-of-life care (Fulmer et al., 2018). Insufficient training and education can lead to admitted discomfort or difficulty on how to talk with patients about end-of-life issues.

Findings also attribute to potential lack of communication in areas such as initiating essential end-of-life conversations, having the right words to say, and knowing the right time for the conversation (Blackwood et al., 2019; Wickersham et al., 2019). Initiating discussions about

ADs is a multi-faceted challenge in which both emotional and personal components are addressed. Risk et al. (2019) identified enablers at the provider level to be those who possess strong communication skills, confidence, and knowledge about ACP. Achieving ACP confidence was described through provider education and training, skills development, deliberative discussion, and through the clarification of provider attitudes and roles. Research by Dube et al. (2015) further supports the importance of education by finding providers who had taken education courses were more than twice as likely to have had ACP discussions with patients compared to providers who had not taken classes.

The most common barrier identified by healthcare professionals was a lack of time to have ACP discussions (Blackwood et al., 2019; Risk et al., 2019). Dube et al. (2015) found that providers reported not knowing about the federal mandate for healthcare institutions that accept Medicare to provide AD information to patients. According to the American Medical Association (2018), ACP should take, at minimum, half an hour and may often last longer. In a busy clinical setting, there may not be adequate time needed to discuss ACP with one patient. Although there is an emerging consensus that ACP discussion should occur in the primary care setting, the largest system barrier is time pressures to keep up with busy primary care schedules. Busy schedules can ultimately, limit providers willingness to initiate time consuming ACP discussions.

Healthcare systems should provide resources for sufficient provider time and the education needed for both ACP and completion of ADs with patients. ACP programs have significantly increased knowledge, attitudes towards shared decision-making, perceived communication skills, confidence, comfort, and experiences in discussing end-of-life issues (Chan et al., 2019). Healthcare systems are making efforts to train nurses, healthcare providers,

social workers, and chaplains to become advance care planning (ACP) facilitators. ACP facilitators are trained professionals certified to have sufficient knowledge and skills to assist others in making end-of-life treatment decisions (Respecting Choices, n.d.). Kirchoff et al. (2012) found that the use of an ACP facilitators resulted in a significant increase in adhering to a desired care plan at the end-of-life. Schellinger et al. (2011) also found that when referred to an ACP facilitator, approximately 94% of 1,894 heart failure patients completed an AD. The ACP facilitators in the Schellinger et al. (2011) study used individualized planning tailored to the patients' disease process and also found that patients engaged with ACP facilitators were more likely to use hospice towards the end-of-life. Other findings suggest a primary benefit to non-physician facilitators is less time constraints as well as involvement of the patient's surrogate or family members in the ACP process (Freeland & Wu, 2019; Kirchoff et al., 2012). Although ACP facilitator referrals are in place among many healthcare systems, the lack of referral may be a barrier that needs to be addressed to meet ACP demands and to increase AD completion rates.

Other initiatives healthcare systems have used to increase completion of AD rates include the use of electronic medical records (EMR) to help with ACP facilitator referrals, documentation of ADs, and for offering more resources for patients (Courtright et al. 2017; Dube et al., 2015). However, Courtright et al. (2017) found that offering more options for AD completion in seriously ill patients still provided no improvement in completion rates. In fact, the longer the AD document, the less motivated patients were to actually complete the document. Documentation of ACP and ADs on the EMR is a system method of implementation that helps to offer more congruent care for patients among frontline healthcare workers and providers (Dube et al., 2015).

Advance Care Planning Facilitators

An essential part to advance care planning and advance directives are facilitators. Facilitators can come from various roles and backgrounds such as physicians, nurses, and social workers. New advances in technology have also had a role of ACP facilitation. The use of facilitators helps patients to understand translation of values, life goals, and preferences into corresponding medical care in different stages of life and illness (Fahner et al., 2019).

There is a growing need for healthcare providers to use encounters with patients, especially those with complex disease or illness, to review and discuss patients' ACP and to document ADs (Feely et al., 2016). Butler et al. (2015) and Risk et al. (2019) further found that patients' goals and values of care need to be understood early in the disease course when opportunity exists. Risk et al. (2019) also found that 60% percent of patients were willing to discuss ACP only if the topic was initiated by the provider. Since a course of chronic disease is different for every individual, responsibility falls on individuals, families, and their provider to have ACP conversations about appointing a surrogate decision maker and engaging in conversation about the individuals' wishes for care under various scenarios that might occur. Patients with chronic disease may frequently interact with providers, offering more opportunity for advocacy of ACP and documentation of updated ADs.

Despite the benefits of having end-of-life conversations early in the disease course, patients have reported not discussing ACP or completing ADs with their physicians (McDonald et al., 2016; Young et al., 2017). O'Halloran et al. (2018) and O'Sullivan et al. (2015) found that patients preferred to initiate advance care planning discussions at a clinic visit with their trusted provider; however, patients found difficulty in raising advance care planning topics with providers. Greater access to information about the patient's comprehensive health history and

disease trajectory are in the primary care setting; therefore, these trusted providers are in the best role to guide such conversations (Pearse et al., 2019). There is an emerging consensus that ACP discussion should occur in the primary care setting, prior to hospitalization and before critical situations. Barriers such as lack of time and knowledge still exist for providers but to help meet this demand, evidence also suggests that additional involvement of both nurses and social workers have the potential to be great facilitators in advance care planning discussion.

Evidence suggests that the professional features of nurses would be beneficial for facilitating implementation of ACP and ADs. Some of these features include an understanding of clinical symptoms of illness and death, respect for different cultures and opinions, and having expertise to tell patients and their families about possible outcomes. Nurses also serve as important mediators between patients, families, and the rest of the healthcare team. Nurses are the most trusted profession year after year and are seen as advocates for patients by helping both the family and the healthcare team to be more aware of patients' views with a realistic outlook (Ke et al., 2015). Despite having several beneficial attributes for facilitating implementation of ACP and ADs, over 50% of nurses surveyed from an acute care setting did not fully understand advance directives (Conelius, 2010). Similar to providers, nurses identified lack of knowledge, available resources, time, culture, and team support as barriers that hindered ACP implementation (Ke et al., 2015).

Compared to providers and nurses, social workers have other attributes to promote ADs and ACP. Wang et al. (2017) found that social workers play an important role in promoting ACP through initiating discussions, advocating patients' rights, facilitating communication and conflict resolution, and documenting ADs. Social workers are well-trained and educated in areas of psychosocial and behavioral interventions, therefore, providing valuable expertise in

educating both patients and family members on ACP (Stein & Fineberg, 2013). Wang et al. (2017) further found that social workers have positive attitudes towards ACP, more knowledge about ADs, and greater degree of familiarity with patients' wishes and needs than other healthcare professionals. Social workers were also initiating topics about ADs more frequently than providers or nurses. Although social workers are well-suited as ACP facilitators, most reported time spent in AD communication was inadequate and interactions for end-of-life planning were limited through lack of referrals by either the provider or nurses.

Since both a lack of time and education are common barriers among the healthcare team, advances in technology have been initiated to facilitate ACP and documentation of ADs. In a randomized control trial among 414 veterans with chronic disease, the PREPARE website increased ACP documentation by 35% (Sudore et al., 2017). Participants were given an easy-to-read advance directive as well as access to the PREPARE website without clinician and/or system-level interventions. On the PREPARE website, patients had free access to education videos, patient testimonials, free education handouts for advance care planning, and easy directions on completing an advance directive. The study suggested that use of PREPARE website as a facilitator may increase planning documentation with minimal healthcare system resources. Although technology facilitation at home seems promising, Risk et al. (2019) found patients who preferred to discuss end-of-life matters privately with family resulted in lack of formal documentation in patients' medical record. Technology facilitation may be a partial solution to barriers mentioned previously, however, both ACP and AD discussions need to be closely followed up in the primary care setting to ensure adequate documentation and for continuity of patients' preferences.

Patient Preferences and Clinical Expertise

Sinclair et al. (2017) stated that advance care planning and advance directive completion rates are directly correlated with a patient's family and social support systems. Among 149 participants with respiratory malignancy, COPD or interstitial lung disease, patients reported a higher preference for advance care planning follow up when a family or a social support system was present. Patients with greater support systems have more informal discussions about end-of-life care outside of clinical relationships. On the other hand, patients with lower support systems may need a health professional to proactively initiate advance care planning conversations.

Advance directives and advance care planning need to be a collaborative effort with both the patient and the family to ensure patient preferences are carried out. Patients with no family or support system are especially vulnerable when they are incapacitated. Healthcare providers need to proactively initiate advance care planning discussions among patients whose illness has led to losses in social support networks.

Serious Illness Conversation Guide

The *Serious Illness Conversation Guide* is a tool created by palliative care experts, which offers providers patient-centered questions designed to gain more understanding about their patients' goals, values, and preferences in future care decisions (Ariadne Labs, n.d.). The *Serious Illness Conversation Guide* consists of eight elements for discussion: understanding, information preferences, prognosis, goals, fears/worries, function, trade-offs, and family (Appendix B). The *Serious Illness Care Program* addresses the challenges providers, patients, families, and caregivers may face during a time of serious life-threatening illness. The *Serious Illness Conversation Guide* was developed to allow healthcare providers to lead timely conversations

involving what is important to both patients and loved ones during times of a patient's serious illness.

During a four-year randomized control trial using the *Serious Illness Care Program*, patients and healthcare providers had serious illness conversations 2.4 months earlier with 90 percent of patients discussing goals and values (Bernacki et al., 2019). Study findings indicated more frequent, earlier, and better conversations between patients and their oncology clinicians, which led to significant reductions in emotional suffering for patients with advanced cancer. Among participants in the *Serious Illness Care Program*, moderate to severe anxiety and depression symptoms were reduced by half, and the anxiety improvements were still evident 24 weeks later. In the primary care setting, the *Serious Illness Care Program* led to more frequent and timely conversations. On average, conversations with a patient regarding serious illness was 22 minutes (Ariadne Labs, n.d.). Evidence suggests that using the *Serious Illness Conversation Guide* can address the most common barriers to end-of-life communication in a clinical setting. The *Serious Illness Conversation Guide* can improve the quality, timing, and occurrence of patient-centered conversations. Such conversations help enable providers to engage in shared-decision making and to promote patient-centered care; ultimately, leading to an alignment in medical treatments and interventions with patients' values, preferences, and treatment goals.

Malcolm Knowles' Adult Learning Theory

Malcolm Knowles' Adult Learning Theory was selected as the theoretical framework to guide the development and implementation of the PIP. In 1980, Malcolm Knowles popularized the concept known as andragogy or "the art and science of helping adults learn," and was contrasted with pedagogy, the art and science of helping children learn (Knowles, 1980, p. 43). Andragogy attempts to identify how adult learners are mature learners, self-directed, and are

motivated by internal factors. Andragogy became a reference to help define the field of adult education as separate from other areas of education (Merriam, 2001). Knowles recognized that in order for learning to occur, learning activities needed to be conducive to the needs of adult learners (Smith, 2002). Furthermore, the Adult Learning Theory was an appropriate theoretic framework that best guided the practice improvement project.

There are five assumptions underlying andragogy to describe the adult learner. An adult learner is assumed to be someone who is: 1) independent of self-concept and who can direct his or her own learning, 2) has accumulated a reservoir of life experiences, which is a rich resource for learning, 3) has learning needs that are influenced by social roles, 4) is problem-centered and interested in immediate application of knowledge, and 5) is motivated to learn by internal rather than external factors (Merriam, 2001). Based on these assumptions, Knowles's Adult Learning Theory was a promising resource for the project in designing, implementing, and evaluating educational experiences with adults regarding their knowledge and use of ADs. The following andragogy principles were applied to the development and execution of the project.

According to the Knowles Theory; first assumption, adults are self-directed and independent learners (Merriam, 2001). Since adults have multiple roles outside of the student role, adults need to be both actively and independently involved as their schedule permits (Smith, 2002; Ross-Gordon, 2011). The online AD educational webinar was available for participants to complete at his or her own personal leisure. To engage all types of adult learners, numerous learning preferences including auditory, visual, and applications will be utilized through the webinar provided. Content included education on the benefits of advance directives and advance care planning, a video example of having a serious illness conversation, case studies for participants to work through for application, and other resources to meet the needs of healthcare

providers in the primary care setting. Online courses and distance learning are becoming increasingly popular and an effective method for adult learners to enhance their knowledge and obtain degrees. An online webinar met the demands of the adult learner by providing a flexible schedule to accommodate the multiple roles of the learner (Ross-Gordon, 2011). The ability of healthcare providers to obtain continuing education credits through online learning is also an effective method to meet credentialing requirements of healthcare providers. The educational webinar was available on the North Dakota Nurse Practitioner Association (NDNPA) website for participation by any healthcare provider who had access to provide incentive and independent, flexible learning.

The second assumption of Knowles's Adult Learning Theory is that adult learners have accumulated a reservoir of life experiences, which is a rich resource for learning (Merriam, 2001). Healthcare providers can enter learning situations with prior life experiences that affect how they process and retain information. An adult learner feels responsible for their learning when the teacher acknowledges their prior experiences and knowledge (Spies et al., 2015). The education webinar challenged participants to reflect on past experiences and to apply those experiences to better retain learning. The use of case studies during the education webinar allowed healthcare providers to draw on past experiences and knowledge to help determine their actions and responses.

The third assumption of andragogy is that adult learners are goal oriented and wish to enhance knowledge associated with their social role (Merriam, 2001). The learning webinar was available through the NDNPA website and accredited through North Dakota Board of Nursing (NDBON) for one hour of continuing education (CE) credit. Participants were able to freely participate to learn about advanced directives and advance care planning. Objectives were clearly

stated at the beginning of the learning webinar to meet the needs of adults as goal-oriented learners.

The fourth assumption is that adult learning is problem centered and adults want to apply new information immediately (Merriam, 2001). Adult learners prefer a problem-solving approach in contrast to a subject-centered approach (Park et al., 2016). Primary care providers are in a position to increase advance directive completion rates in patients living with a chronic disease. In addition, through primary care providers' regular interactions with patients, emphasis on advance care planning conversations is possible. The online learning webinar provided the most current information and resources necessary for completion of advance directives. Teaching about evidence-based tools, such as the *Serious Illness Conversation Guide*, supplied providers with knowledge that can be applied to clinical practice and healthcare providers' current patient population. Participants were able to practice application of knowledge to the patient population through multiple case studies, a recorded video example, and tools supplied within the learning webinar and toolkit.

Intrinsic motivation is the final assumption which helps adults learn best when they know the importance of an issue (Merriam, 2001). Adult learners place a higher priority on internal factors and need to be aware of the reason for education (Spies et al., 2015). Participants in the project were informed by the educational objectives about the benefits of completing serious illness conversations early and for completion of advance directives. By participating in the online learning webinar, providers had the potential for a personal increase in comfort regarding advance care planning conversations. Knowledge of advance care planning conversations can impact a healthcare provider's practice by contributing to both personal satisfaction and enhanced self-esteem when discussing goals of care during a serious illness.

CHAPTER 3. METHODS

Project Design and Implementation Plan

IOWA Model

The IOWA Model Revised: Evidence-Based Practice to Promote Excellence in Healthcare (Appendix C) is known for aiding providers through the evidence-based practice (EBP) process by following a problem-solving approach, simplifying the process, and being highly application oriented (Melnik & Fineout-Overholt, 2018). Permission to utilize the IOWA evidence-based practice model was obtained from the University of Iowa Hospitals and Clinics (Appendix D). The IOWA model helped to facilitate the development and implementation of an education webinar for healthcare providers regarding advance directives and advance care planning. According to Melnyk and Fineout-Overholt (2018), the IOWA model is known for both its applicability and ease of use by interprofessional healthcare teams. By addressing feedback loops through a multiphase change process, the IOWA model is further strengthened to offer guidance in making decisions about clinical and administrative practices, thus, impacting healthcare outcomes.

Step 1: Problem and Knowledge Focused Triggers

- Patients living with chronic disease have a high risk of hospitalization, prolonged, and possibly aggressive care which may lead to care not aligning with a patient's wishes and poor quality of care at end-of-life. Advance care planning and advance directives among these patients can result in patient autonomy during end-of-life, honored preferences, enhanced quality of medical decisions, shared decision making, less emotional distress among patients' loved ones, and even a decrease in healthcare costs (Garrido et al., 2015; Hickman & Pinto, 2013).

- Despite documented benefits of advance directives, there remains a large deficit in completion rates, especially in patients with chronic disease such as COPD, HF, stage IV cancer, and ESRD (Lendon et al. 2018; Yadav et al. 2017).
- Research revealed that providers lack training and education about advance directives and advance care planning conversations, leading to discomfort in skills, confidence, and knowledge about having these essential discussions (Blackwood et al., 2019; Fulmer et al., 2018; Wickersham et al., 2019)

Step 2: Topic priority for organization

- According to a prior dissertation project by Heisler (2019), there was an evident institutional need and priority for the increase of advance directive rates, especially among patients older than 65 years of age with either HF, stage IV cancer, ESRD, and/or COPD. Future recommendations for continuing education of advance care planning among healthcare providers, as well as providing online education, was the ultimate guide to the development and implementation of this PIP.
- Research suggests there is a need to close the knowledge gap among providers regarding how to perform advance care planning conversations and advance directives. The knowledge gap among providers can be best addressed through education to increase providers' confidence, comfort, and experiences in discussing end-of-life issues (Bernacki et al., 2019; Chan et al., 2019; Dube et al., 2015).
- The North Dakota Nurse Practitioner Association website was chosen to distribute education about ADs and ACP since their mission includes support, advocacy, leadership, and continued education for nurse practitioners.

Step 3: Form a Team

- The team consists of the co-investigator and four committee members from North Dakota State University (NDSU): a committee chair, two members, and a graduate appointee. The co-investigator role facilitated the recruitment process, implemented the education webinar, and evaluated the results following the implementation period. The committee chair is a nurse practitioner currently practicing in an emergency department in a rural setting and has chaired prior AD practice improvement projects. The two committee members are both practicing nurse practitioners, one in a rural setting. All committee nurse practitioners are faculty at NDSU with extensive knowledge in the family nurse practitioner (FNP) curriculum. The graduate appointee has a background in adult development and aging with extensive knowledge in human development and family science.
- Partnership with a key stakeholder, the President of Honoring Choices® North Dakota was involved with both designing and delivery of the education webinar and is a certified medical discussions expert, a medical decisions advocate, and she holds a certification as an Advanced Practice Hospice and Palliative Care Nurse. Her support was critical in the practice improvement project implementation. A letter of support was obtained prior initiating the project (see Appendix E).

Step 4: Assemble and Analyze Relevant Research

- A literature review and synthesis were completed with the research indicating that there is an adequate base of information to continue with the next step of piloting the change in practice. As explained in the literature review, several benefits exist of advance directives and the use of the *Serious of Illness Conversation Guide*. The

literature review supported implementation of an online education webinar to educate providers about advance directives and advance care planning conversations. The practice improvement project consisted of objectives, evidenced-based provider education, evaluation of the process and outcomes, and recommended practice modifications for advance directive discussions.

Step 5: Pilot the Change in Practice

- Project outcomes were determined, and baseline data was collected. The practice improvement project's goal was to increase advance directive completion rates and advance care planning conversations among providers who complete a one-hour education webinar on the NDNPA website. The webinar provided ACP and AD education and copies of *Serious Illness Conversation Guide* to participants. After supervisory committee and IRB approval, implementation of the intervention began September 30, 2021 and ended December 30, 2021.

Step 6: Integrate and Sustain the Practice Change and Disseminate Results

- Data used to evaluate the project intervention was based on the pre- and post-surveys when participants completed the online education webinar. Evaluation of the online webinar effectiveness was assessed through the survey results over a 3-month time period. Recommendation for further implementation and research was provided after the project.
- After healthcare providers completed the education webinar, results collected from the project were disseminated at North Dakota State University through poster board presentations and PowerPoint presentations at other institutions.

- Training materials were provided to all healthcare providers who completed the education webinar, at no cost, to integrate and sustain the practice change.

Education Content Development

During the development of the project, members of the faith community, nursing, health ministry, and the President of Honoring Choices® North Dakota were consulted for education development. The co-investigator first had to become a certified advance care planning facilitator by completing two 8-hour classes, *First Steps Advance Care Planning (ACP)* and *Last Steps Advance Care Planning (ACP) Facilitator Certification Courses* offered through Respecting Choices® at Sanford Health Hospital. Both classes were led by an experienced certified ACP facilitator. The classes consisted of PowerPoint content on advance directives and physician's orders for life-sustaining treatment (POLST), workbook materials, and advance care planning discussion role-play. Lastly, the class required completion of a certification test.

The key stakeholder for this PIP was the President of Honoring Choices® North Dakota, Nancy Joyner, MS, CNS-BC, APRN, ACHPN®. The development of the educational webinar was accomplished through 10 meetings, which occurred speaking via Skype or telephone with the key stakeholder. The meetings were needed to practice ACP discussions and to formulate the presentation of education materials for the online webinar. The co-investigator integrated evidence from the literature review, Ariadne Labs, and other free EBP resources to complete the education content.

Methods

Prior to and after the completion of the online education webinar, participants completed an electronic pre- and post-survey via Qualtrics. The surveys assessed participant demographics including age, gender, profession, and years of practice. Survey questions evaluated the

participants' pre and post education knowledge, benefits, confidence, and initiation of advance directives and advance care planning conversations (see Appendix F). The pre- and post-surveys were developed using content from Dr. Mary Jezewski's Knowledge, Attitudinal, and Experiential Survey on Advance Directives (KAESAD) instrument, prior advance care planning implementations, and evidence from the literature review. Approval for use of the KAESAD instrument was obtained from Dr. Mary Jezewski (see Appendix G). The KAESAD instrument was used in prior studies and was reviewed by an expert panel consisting of disciplines from nursing, law, and medicine. Due to the instrument consisting of eight principal components and 115 items, only select content was used based on conclusions from a prior dissertation project by Heisler (2019). Content selected for this PIP was based on evaluation of the project's objectives. Topics not disclosed in the education webinar were omitted. Project objectives and the quality of the educational webinar were analyzed via descriptive statistics. Participants' questions regarding demographics, experience, and area of practice were analyzed via content analysis for possible themes and feedback.

Setting

The PIP project was implemented via the NDNPA website and could be accessed by healthcare providers from North Dakota. According to the North Dakota Board of Nursing, there are currently 2,122 advance practice registered nurse (APRN) licensed within North Dakota (NDBON website December 2021). The North Dakota Nurse Practitioner Association website was chosen to distribute education about ADs and ACP since their mission includes support, advocacy, leadership, and continued education for nurse practitioners. However, other healthcare providers including physician associates, nurses, and students of these professions from other

states also had access to the webinar since advertisement of the webinar was made at the NDNPA Annual 2021 Pharmacology conference.

Sample

Participation in the webinar and survey could be accessed by any healthcare provider including nurse practitioners, physicians, physician associates, and students of these professions. All practitioners, physicians, physician associates, and students of these professions were chosen as the target population after gaps in research suggested the importance for healthcare providers to have a better understanding of ACP and completion of ADs. The educational webinar was focused on serious illness conversations with patients over the age of 65 years old who are living with chronic diseases such as heart disease, chronic obstruction pulmonary disease, stage IV cancer, and end-stage renal disease seen within the primary care setting.

Protection of Human Subjects

Recruitment for the PIP occurred through voluntary access of the NDNPA website by healthcare providers after advertisement was initiated at the NDNPA Annual 2021 Pharmacology conference. Other opportunities for recruitment occurred through advertising by the co-investigator (e.g., emails, flyer, webpage posts, social media). Recruitment efforts were conducted from September 23, 2021 through December 30, 2021. All healthcare providers, members and non-members, were able to access the online webinar. Implied consent of the participants was assumed by the participant's voluntary completion of the one-hour education webinar, pre- and post-surveys, and posttest. Printable presentation slides and the *Serious Illness Conversation Guide* were available as part of the webinar. Participants were informed about the benefits of the project including improvement in advance directive completion rates,

improvement in advance care planning, and improvement of personal knowledge regarding advance directives.

Participation in the practice improvement project did not involve direct patient contact and therefore provided minimal risk to the participant. All data obtained from the pre- and post-surveys were reported as cohort data and kept confidential via Qualtrics. Qualtrics is a web-based survey platform that groups data and reports automatically to include a wide range of statistics, charts, and graphs to be customized. Surveys were protected with a password made by the co-investigator. Demographic information was reported and all participant data gathered was accessed in a password protected computer with only the investigator's accessibility. The webinar was created in accordance with the NDBON continuing education (CE) policies and standards. A consent form was available on the NDNPA website for participants to read prior to participation. Refer to Appendix H for a copy of the advertising flyer and Appendix I for the informed consent form.

Institutional Review Board Approval

An Institutional Review Board (IRB) approval by North Dakota State University was obtained. Approval for protocol #IRB0003818 was received from North Dakota State University's IRB board (see Appendix J). The project was determined exempt (category 1) in accordance with federal regulations (*Code of Federal Regulations, Title 45, Part 46, Protection of Human Subjects*).

Intervention

Evidence based practice begins with the vital step of piloting an intervention (Melnik & Fineout-Overholt, 2018). Implementation for the project began September 30, 2021 and ended December 30, 2021. The one-hour AD education webinar, *Advance Care Planning and Advance*

Directives, was posted on the NDNPA website and accredited through the NDBON for a 1.0 continuing education (CE) credit. To obtain the 1.0 CE credit, participants had to complete the pre-survey, watch the one-hour education webinar, pass the posttest with an 80% and complete the post-survey to obtain certificate of participation. Evidence-based tools, such as the *Serious Illness Conversation Guide*, supplied providers with knowledge that could be applied to their clinical practice and current patient population. Participants were able to practice application of their AD knowledge through case studies and a video example supplied within the learning webinar. As part of the educational webinar, copies of the PowerPoint educational content, the *Serious Illness Conversation Guide*, videos, books, and several other resources were provided free of cost in a toolkit link on the education webinar (Appendix O). Approval for use of the *Serious Illness Conversation Guide* for the project was received from Ariadne Labs (Appendix K). The co-investigator, who is a certified advance care planning facilitator (Appendix L), conducted the prerecorded education on the online webinar.

Resources Required

Personnel. Board members of the NDNPA were consulted for approval of the education content and advertising among healthcare providers of the organization. Members of the faith community nursing and health ministry and the President of Honoring Choices of North Dakota were consulted for education development and certification for the co-investigator to be able to teach the education webinar.

Technology. Development of the online webinar required advanced technology aided by NDNPA's webpage master. The webpage was posted online with a description of the PIP as well as links to resources, Qualtrics, and a zoom link to the one-hour education webinar. Participants used an electronic device (laptop, tablet, computer, phone) with Wi-Fi connection and Firefox or

Google Chrome for ease of use. A computer was also essential for advertising via emails, flyers, and webpage posts.

Budget. The budget for implementing the education webinar included cost of NDBON CE accreditation of \$100 and the co-investigator’s ACP facilitator certification course of \$275 (Appendix M). Additional learning resources such as links to PowerPoint slides and *the Serious Illness Conversation Guide* were free of expenses. Posting the education webinar on the NDNPA website was also free.

Evaluation/Data Analysis

Evaluation of Objective One

Objective one was “healthcare providers’ perceived knowledge, confidence, and understanding of advance care planning and advance directives will increase after completing a one-hour online education webinar posted on the NDNPA website.” Objective one was measured using a Likert scale consisting of strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree in regard to the educational content. The Likert scale items used a five-point numerical value assigned to each category for all non-demographic questions. Strongly agree was given a five, somewhat agree was given a four, neither agree nor disagree was given a three, somewhat disagree was given a two, and strongly disagree was given a one. Mean values were calculated for each non-demographic question allowing for value analysis of question responses using descriptive statistics. Survey questions that evaluated objective one included:

- Question one pre-survey, “I have sufficient knowledge on advance care planning and advance directives.”

- Question one post-survey, “after the education webinar, I have sufficient knowledge on advance care planning and advance directives.”
- Question two pre-survey, “I know the benefits of advance care planning and advance directives.”
- Question two post-survey, “after the education webinar, I know the benefits of advance care planning and advance directives.”
- Question three pre-survey, “I feel confident in initiating advance care planning and advance directive discussions with patients.”
- Question three post-survey, “after the education webinar, I feel confident initiating advance care planning and advance directive discussions with patients.”

Evaluation of Objective Two

Objective two was “healthcare providers’ perceived knowledge of how to use the *Serious Illness Conversation Guide* and its application to initiate advance care planning discussion will increase after a one-hour online education webinar.” Mean values were calculated for each non-demographic question allowing for value analysis of question responses using descriptive statistics. Survey questions that evaluated objective two included:

- Question four pre-survey, “I understand how to use the *Serious Illness Conversation Guide* with patients.”
- Question four post-survey, “after the education webinar, I understand how to use the *Serious Illness Conversation Guide* with patients.”
- Question six post-survey, “after the education webinar, I will increase advance care planning discussions with patients.”

Evaluation of Objective Three

Objective three was “healthcare providers’ knowledge of the role of advance care planning facilitators will increase after a one-hour online education webinar.” Mean values were calculated for each non-demographic question allowing for value analysis of question responses using descriptive statistics. Survey questions that evaluated objective three included:

- Question five pre-survey, “I understand the role of advance care planning facilitators.”
- Question five post-survey, “after to the education webinar, I understand the role of advance care planning facilitators.”

Participant Experience

Evaluation of the practice improvement project included collecting participants’ past experiences with ACP and AD. Survey questions that evaluated participants’ experiences included:

- Question seven post-survey, “have you had conversations about advance care planning or advance directives in your practice setting?”
- Question eight post-survey, “have you been a witness (i.e., involved in documentation) for an advance directive for a patient?”
- Question nine post-survey, “have you initiated a discussion about advance directives with a patient?”
- Question ten post-survey, “have you provided treatment to patients whose advance directive indicated otherwise (i.e., family’s goals of care didn’t align with patient’s)?”
- Question eleven post-survey, “have you observed others providing treatment to patients whose advance directive indicated otherwise?”

Participant Demographics

Evaluation of the practice improvement project included collecting participants' demographics. Survey questions that evaluated participants' demographics included:

- “What is your profession?”
- “What is your age?”
- “What is your gender?”
- “Please specify your area of specialty.”
- “How many years have you been practicing?”

Education Webinar

Evaluation of the practice improvement project also included an evaluation of the developed webinar education content. Survey questions that evaluate the effectiveness of the education webinar included:

- Question twelve post-survey, “information presented was current and could be applied to own practice area.”
- Question thirteen post-survey “the teaching/learning resources and instructed materials were effective and suited for the topic.”
- Question fourteen post-survey, “administration and technology of the online webinar was smooth and customer-friendly.”
- Question fifteen post-survey, “instructions for participation and receiving continuing education credits were adequate.”
- Question sixteen post-survey, “is there anything else related to advance directives and advance care planning you wished we discussed in the education webinar?”

CHAPTER 4. RESULTS

The one-hour education webinar, *Advance Care Planning and Advance Directives*, was posted online via the NDNPA website from September 30, 2021 through December 30, 2021. Education content developed included: definitions of advance directives, advance care planning, POLST, phrases used when discussing prognosis, benefits of ACP and AD, barriers to ACP and AD completion, how and when to use the *Serious Illness Conversation Guide* in ACP, role of ACP facilitators, and ACP resources available via a toolkit. The webinar entailed a pre-recorded one-hour voice over PowerPoint developed by the co-investigator and the key stakeholder, as well as videos and case studies (See Appendix N). To obtain the 1.0 CE, participants were required to complete a pre-survey, post-survey, and score an 80% on the posttest via Qualtrics.

Demographic of Participants

A total of 14 participants participated in the project's confidence Likert scale survey which was administered online via Qualtrics. Participants included Nurse Practitioners ($n=11$) and Nurse Practitioner students ($n=3$). Of the fourteen participants, 100% completed the pre- and post-surveys and posttest. Approximately 57.1% ($n=8$) of participants listed their area of specialty as Family Medicine and 14.3% ($n=2$) of participants listed their specialty as Palliative. The majority of participants were 85.7% ($n=12$) females with approximately 64.3% ($n=9$) between the ages of 20-39. Participants had a variety of experience with 28.6% ($n=4$) having greater than 12 years of experience, 21.4% ($n=3$) having 7-9 years, 14.3% ($n=2$) having 4-6 years of experience, 21.4% ($n=3$) having 1-3 years of experience, and 14.3% ($n=2$) having less than 1 year experience. Additional data regarding participant demographics is noted in Table 1.

Table 1*Demographic Results*

Demographics		N=14	N%
What is your profession?	Physician	0	0.0%
	Nurse Practitioner	11	78.6%
	Physician Associate	0	0.0%
	Nurse Practitioner Student	3	21.4%
What is your age?	20-29	4	28.6%
	30-39	5	35.7%
	40-49	2	14.3%
	50-59	1	7.1%
	60-69	2	14.3%
	70+	0	0.0%
What is your gender?	Male	1	7.1%
	Female	12	85.7%
	Prefer Not to Say	1	7.1%
Please specify your area of specialty:	Family Medicine	8	57.1%
	Cardiology	1	7.1%
	Palliative	2	14.3%
	OBGYN	1	7.1%
	Internal Medicine	1	7.1%
	Other/Unspecified	1	7.1%
How many years have you been practicing?	<1 year	2	14.3%
	1-3 years	3	21.4%
	4-6 years	2	14.3%
	7-9 years	3	21.4%
	10-12 years	0	0.0%
	>12 years	4	28.6%

Objective Results**Objective One**

Objective one assessed healthcare providers' perceived knowledge, confidence, and understanding of advance care planning and advance directives after completing the one-hour online education webinar. A series of pre- and post-survey questions were asked regarding participants' knowledge of ACP and AD, knowledge of benefits of ACP and AD, and confidence in initiating ACP and AD discussions with patients.

Figure 1

Pre/Post Knowledge on ACP/AD

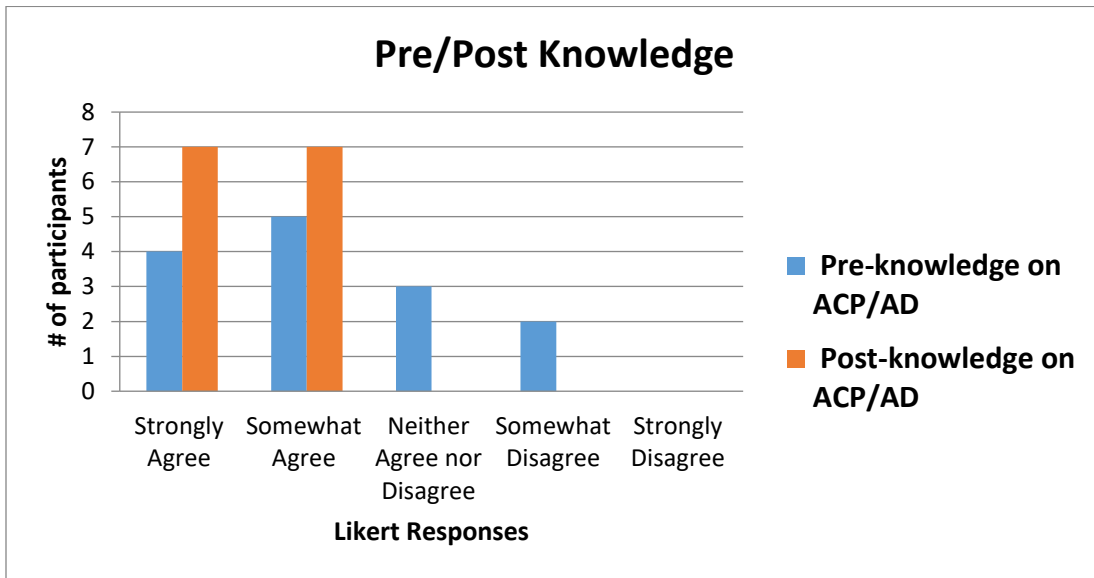


Figure 1 represents the responses from participants when asked in the pre-survey, “I have sufficient knowledge on advance care planning and advance directives,” four participants responded with “strongly agree,” five participants responded with “somewhat agree,” and three participants responded with “neither agree nor disagree,” and two participants responded with “somewhat agree.” When participants were asked in the post-survey, “after the education webinar, I have sufficient knowledge on advance care planning and advance directives,” seven participants responded with “strongly agree” and seven participants responded with “somewhat agree.”

Figure 2

Pre/Post Knowledge of Benefits of ACP/AD

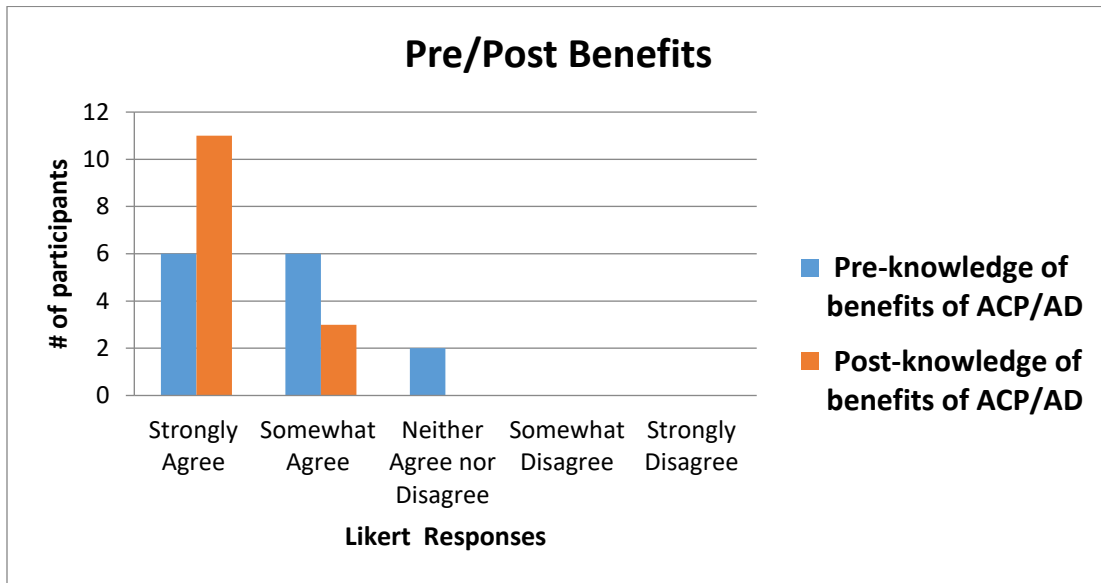


Figure 2 represents the responses from participants when asked in the pre-survey, “I know the benefits of advance care planning and advance directives,” six participants answered “strongly agree,” six participants answered “somewhat agree,” and two participants answered “neither agree nor disagree.” When participants were asked in the post-survey, “after the education webinar, I know the benefits of advance care planning and advance directives,” eleven participants answered “strongly agree” and three participants answered “somewhat agree.”

Figure 3

Pre/Post Confidence in Initiating ACP and AD

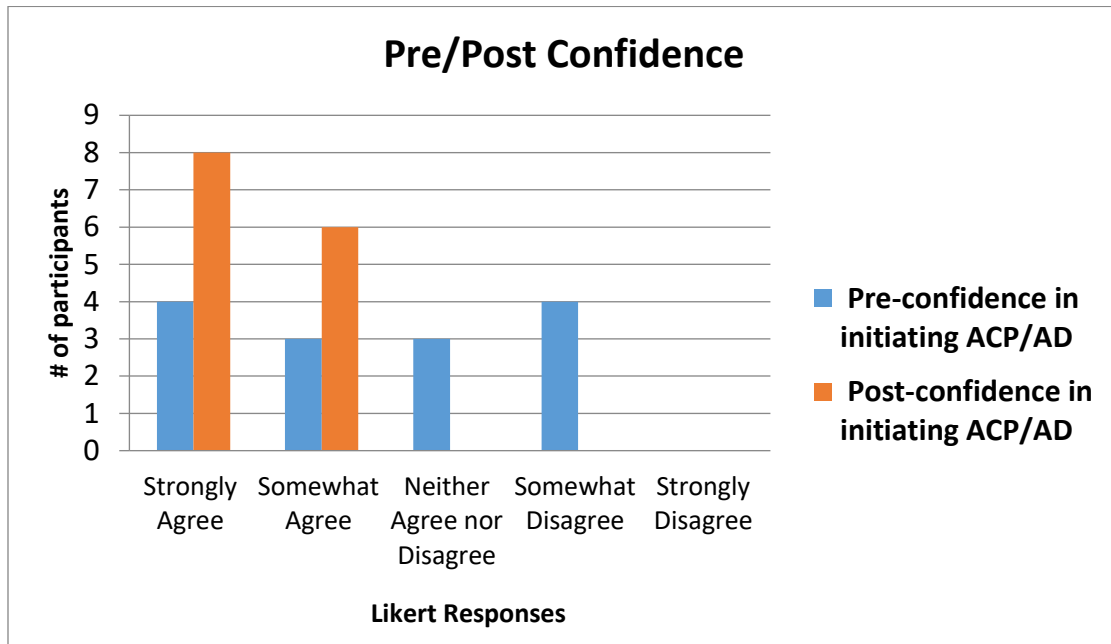


Figure 3 represents the responses from participants when asked in the pre-survey, “I feel confident in initiating advance care planning and advance directive discussions with patients,” four participants answered “strongly agree,” three participants answered “somewhat agree,” three participants answered “neither agree nor disagree,” and four participants answered “somewhat disagree.” When participants were asked in the post-survey, “after the education webinar, I feel confident initiating advance care planning and advance directive discussions with patients,” eight participants answered “strongly agree” and six participants answered “somewhat agree.”

Several questions were asked about experiences with documenting AD, initiating discussions, conversations regarding ACP or AD in participants’ practice settings, following AD preferences, and documentation of AD for patients. When participants were asked questions regarding existing knowledge and experience, 92.9% ($n=13$) reported having experience with conversations about advance care planning or advance directives and have initiated a discussion

about advance directives with a patient. Despite having these interactions, approximately 57.1% ($n=8$) reported no experience with documentation for advance directives. Post-survey questions seven, eight, nine, ten, and eleven are depicted in Table 2.

Table 2

Experience of Participants

Question		N=14	N%
7. Have you had conversations about advance care planning or advance directives in your practice setting?	Yes	13	92.9%
	No	1	7.1%
8. Have you been a witness (i.e., involved in documentation) for an advance directive for a patient?	Yes	6	42.9%
	No	8	57.1%
9. Have you initiated a discussion about advance directives with a patient?	Yes	13	92.9%
	No	1	7.1%
10. Have you provided treatment to patients whose advance directive indicated otherwise (i.e., family's goals of care didn't align with patient's)?"	Yes	4	28.6%
	No	10	71.4%
11. Have you observed others providing treatment to patients whose advance directive indicated otherwise?	Yes	6	42.9%
	No	8	57.1%

Objective Two

Objective two was to assess the healthcare providers' perceived knowledge of how to use the *Serious Illness Conversation Guide* (SICG) and its application to initiate advance care planning discussions. Questions regarding pre/post understanding of how to use the *Serious Illness Conversation Guide* were obtained. Figure 4 depicts the comparison between pre-education and post-education responses regarding a participant's understanding of how to use the *Serious Illness Conversation Guide*.

Figure 4

Pre/Post Knowledge of the Serious Illness Conversation Guide

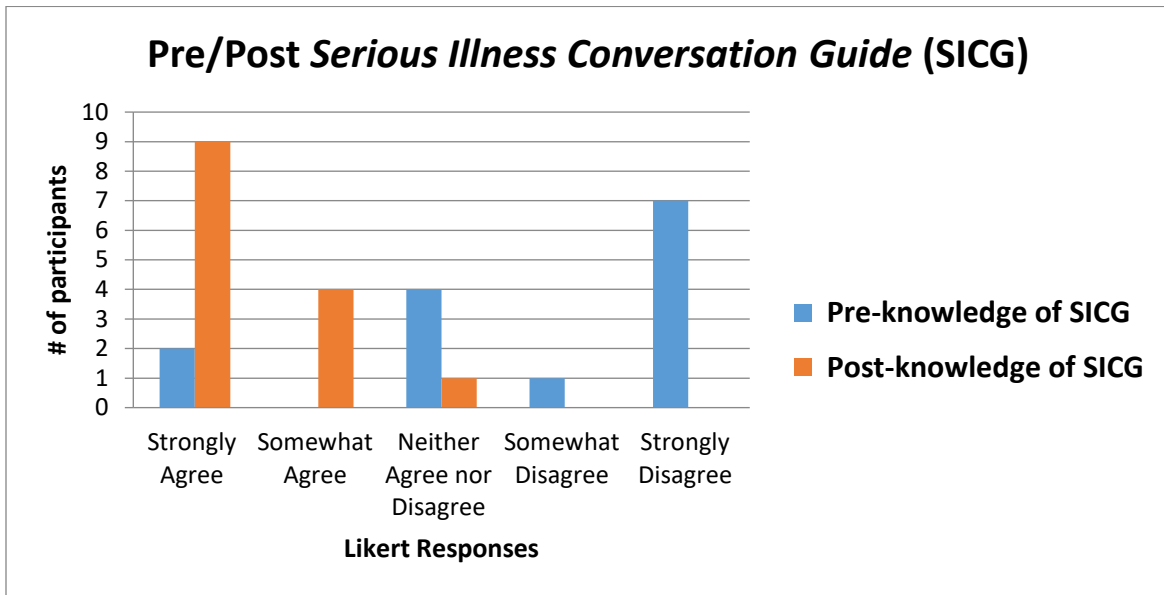


Figure 4 represents the responses from participants when asked in the pre-survey, “I understand how to use the *Serious Illness Conversation Guide* with patients,” two participants answered “strongly agree,” four participants answered “neither agree nor disagree,” one participant answered “somewhat disagree,” and seven participants answered “strongly disagree.” When participants were asked in the post-survey, “after the education webinar, I understand how to use the *Serious Illness Conversation Guide* with patients,” nine participants answered “strongly agree,” four participants answered “somewhat agree,” and one participant answered, “neither agree nor disagree.”

Objective Three

Objective three was to assess the healthcare providers’ knowledge of the role of advance care planning facilitators. Data regarding understanding of the role of advance care planning facilitators were obtained pre- and post-education.

Figure 5 depicts the contrast between responses pre-education and post-education regarding the participant's understanding of the role of ACP facilitators.

Figure 5

Pre/Post Understanding of the Role of ACP Facilitators

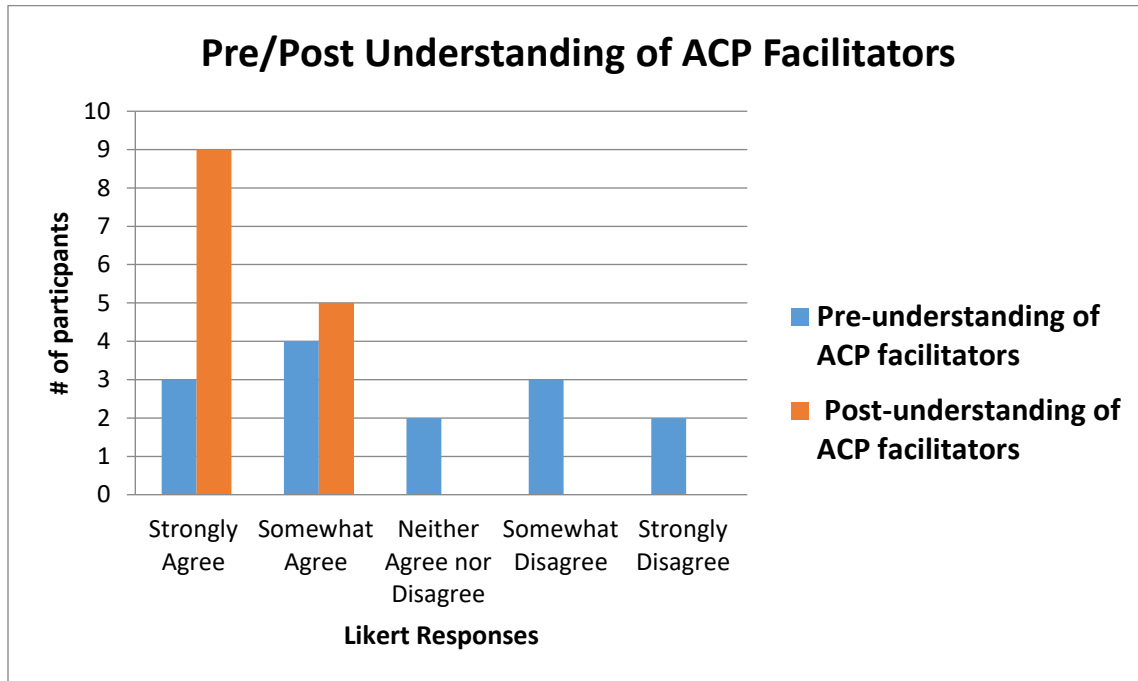


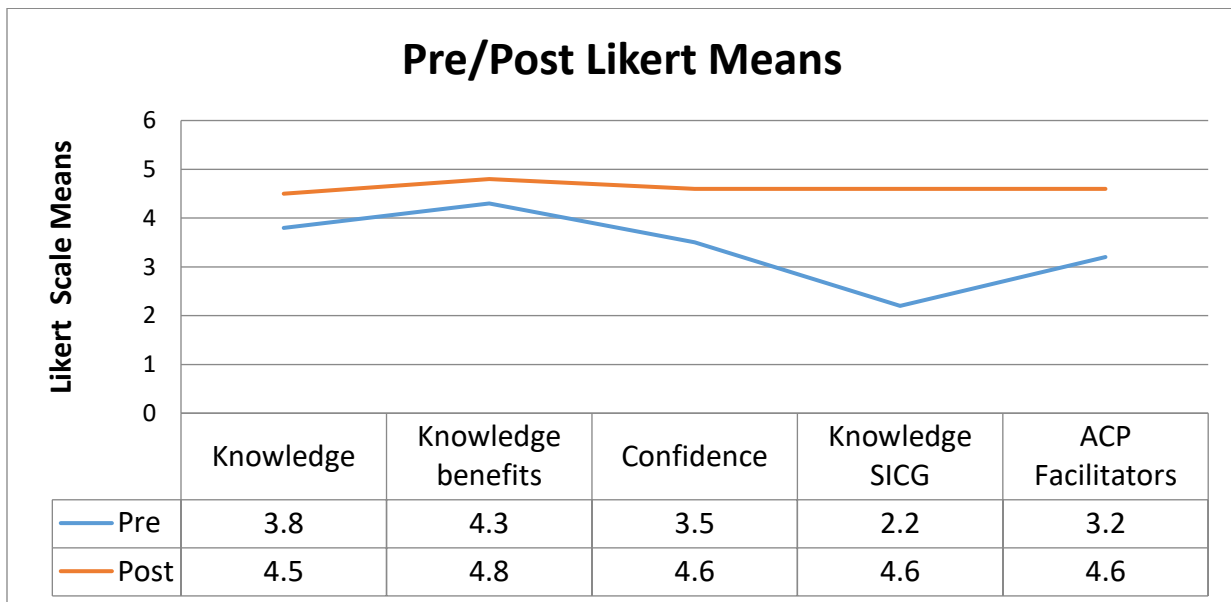
Figure 5 represents the responses from participants when asked in the pre-survey, “I understand the role of advance care planning facilitators,” three participants answered “strongly agree,” four participants answered “somewhat agree,” two participants answered “neither agree nor disagree,” three participants answered “somewhat disagree,” and two participants answered “strongly disagree.” When participants were asked in the post-survey, “after to the education webinar, I understand the role of advance care planning facilitators,” nine participants answered “strongly agree” and five participants answered “somewhat agree.”

Likert Means

The Likert scale items used a five-point numerical value which was assigned to each category for all items assessed for objectives one, two, and three. Strongly agree was given a five, somewhat agree was given a four, neither agree nor disagree was given a three, somewhat disagree was given a two, and strongly disagree was given a one. Mean values were taken from both pre-education and post-education for each question in regards to objectives one, two, and three. In Figure 6, the mean ranking for all participants increased from 3.8 to 4.5 for overall knowledge of ACP and AD, 4.3 to 4.8 for knowledge of benefits of ACP and AD, 3.5 to 4.6 for confidence in initiating ACP and AD, 2.2 to 4.6 for knowledge of the SICG, and 3.2 to 4.6 for understanding the role of ACP facilitators. Likert means are depicted in Figure 6 below.

Figure 6

Pre/Post Likert Means for Objectives One, Two, and Three



Education Webinar

Post-survey questions were obtained regarding the effectiveness of the education webinar. Post-survey questions twelve, thirteen, fourteen, and fifteen are depicted in Table 3 below which evaluated the effectiveness of the education webinar.

Table 3

Evaluation of Webinar Educational Content

Question		N=14	N%
12. Information presented was current and could be applied to own practice area.	Strongly Agree	10	71.4%
	Somewhat Agree	4	28.6%
13. The teaching/learning resources and instructed materials were effective and suited for the topic.	Strongly Agree	10	71.4%
	Somewhat Agree	4	28.6%
14. Administration and technology of online webinar was smooth and customer friendly.	Strongly Agree	9	64.3%
	Somewhat Agree	4	28.6%
	Neither Agree nor Disagree	1	7.1%
15. Instructions for participation and receiving continuing education credits were adequate.	Strongly Agree	10	71.4%
	Somewhat Agree	4	28.6%

Qualitative Data

One open-ended question was asked among participants regarding the effectiveness of the education webinar. A total of two participants of the fourteen provided additional comments regarding the effectiveness of the webinar. Post-survey question sixteen and participants' responses are depicted in Table 4 below.

Table 4

Qualitative Evaluation of Education Webinar

Question	Participant A	Participant B
16. Is there anything else related to advance directives and advance care planning you wished we discussed in the education webinar? Please leave a comment.	“The advance care planning and advance directive education provided by Hannah Murphy and Nancy Joyner was very helpful to me in my practice. I plan to incorporate the information and helpful tools during my discussions with patients about advance care planning during annual physical examinations.”	“Very nice job; easy to understand information”

CHAPTER 5. DISCUSSION AND RECOMMENDATIONS

Discussion

Objective One

The goal of objective one was “healthcare providers’ perceived knowledge, confidence, and understanding of advance care planning and advance directives will increase after completing the one-hour online education webinar.” The confidence Likert surveys aided in measuring objective one. Objective one was considered met if all participants answered either “strongly agree” or “somewhat agree” to all questions pertaining to the post-education survey. Objective one was met because all participants answered either “strongly agree” or “somewhat agree” on the post-survey to the questions mentioned. Likert scale question mean rankings revealed that knowledge increased from 3.8 (pre-education) to 4.5 (post-education), benefits increased from 4.3 (pre-education) to 4.8 (post-education), and confidence increased from 3.5 (pre-education) to 4.6 (post-education). As outlined in Figure 6, the data from the survey infers that the education webinar increased participants’ perceived knowledge, confidence, and understanding of advance care planning and advance directives as evidenced by an increase in post-survey Likert scale mean rankings compared to the pre-survey rankings.

Objective Two

The goal of objective two was “healthcare providers’ perceived knowledge of how to use the *Serious Illness Conversation Guide* and its application to initiate advance care planning discussion will increase after the one-hour online education webinar.” The confidence Likert scale surveys aided in measuring objective two. Objective two was considered met if all participants answered either “strongly agree” or “somewhat agree” to all questions pertaining to the post-education survey. Objective two was partially met because one participant on question

four of the post-survey did not answer “strongly agree” or “somewhat agree.” Despite failing to meet this specific goal, the mean for all participants’ knowledge of the *Serious Illness Conversation Guide* increased from 2.2 (pre-education) to 4.6 (post-education). Participants also answered “strongly agree” or “somewhat agree” on the post-education survey with a Likert mean of 4.6 for their intention to increase initiation of ACP discussions with patients (question six). The data from the survey infers that a majority (92.9%) of participants had an increase in understanding of how to use the *Serious Illness Conversation Guide* with patients as evidenced by an increase in post-education Likert scale question mean rankings. In addition to the means, all participants (100%) agreed to increasing discussions of ACP with patients.

Objective Three

The goal of objective three was “healthcare providers’ knowledge of the role of advance care planning facilitators will increase after a one-hour online education webinar.” The confidence Likert scale surveys aided in measuring objective three. Objective three was considered met if all participants answered either “strongly agree” or “somewhat agree” to all questions pertaining to post-education survey. Objective three was met because all participants answered either “strongly agree” or “somewhat agree” on the post-survey to question five. The mean ranking for all participants increased from 3.2 (pre-education) to 4.6 (post-education) for understanding of the role of ACP facilitators. The data from the survey infers the education webinar increased participants’ knowledge of the role of advance care planning facilitators.

Student Nurse Practitioners

Since the education webinar was made available on the NDNPA website, Nurse Practitioner (NP) students had access to the free 1.0 CE opportunity. Three out of fourteen participants were NP students. One participant answered “neither agree nor disagree” to question

four which stated, “after the education webinar, I understand how to use the *Serious Illness Conversation Guide* with patients.” Since the education and surveys in this PIP were developed for practicing providers, student responses to some of the survey questions may be from limited level of experience with advance care planning and advance directives.

Project Findings in Comparison to Literature Findings

The practice improvement project had similar findings to what was found in the literature review. Project findings were associated with healthcare providers rather than institutions or patient findings since the practice improvement project focused on provider practice changes rather than institution or patient changes. Findings from the project that were similar to the literature review findings included:

- Approximately 71.4% ($n=10$) of participants reported that patients who had an advance directive were more likely to receive goals of care that aligned with their preferences even when family’s goals of care didn’t align with the patient’s. Research findings further support that when the patient, family, and healthcare provider had a common understanding of the patient’s preferences, both the family and the provider had an increased likelihood to act together to enact those preferences even when the patients were to lose decisional capacity (O’Halloran et al., 2018).
- Likert means for confidence increased from 3.5 (pre-education) to 4.6 (post-education) further supporting that providing education to healthcare providers increases knowledge and confidence of ACP and AD with patients (Dube et al., 2015; Risk et al., 2019).
- Education needs to be provided for more available resources, such as ACP facilitators, for healthcare providers initiatives in healthcare systems to increase

completion of AD rates (Courtright et al. 2017; Dube et al., 2015). The mean ranking for all participants increased from 3.2 (pre-education) to 4.6 (post-education) for understanding the role of ACP facilitators.

- Providing education on tools, such as the *Serious Illness Conversation Guide*, helps to increase understanding and intention to initiate ACP discussions with patients (Bernacki et al., 2019). The Likert mean for all participants increased from 2.2 (pre-education) to 4.6 (post-education) for understanding of the *Serious Illness Conversation Guide*. After providing education, participants answered “strongly agree” or “somewhat agree” with a Likert mean of 4.6 for their intention to increase initiation of ACP discussions.
- Despite approximately 92.9% ($n=13$) of participants having had conversations about ACP or AD, more than half of participants, 57.1% ($n=8$) have not been involved in documentation for an advance directive for their patients. Feely et al. (2016) further supports the evident need for ACP documentation to increase AD rates.

Findings that were discovered in the practice improvement project which were not found in the literature review included:

- Despite the benefits of having end-of-life conversations early in the disease course, literature findings suggest that patients have reported not discussing ACP or completing ADs with their physicians (McDonald et al., 2016; Young et al., 2017). According to McDonald et al. (2016), of 183 participants, only 2% reported previously discussing EOL wishes with their family physicians. Young et al. (2017) also reported that out of 400 heart failure patients, only 17% reported previously discussing EOL care with their physicians. In contrast to the McDonald and Young

studies, observation from this PIP suggests otherwise with approximately 92.9% ($n=14$) of participants reported having conversations in their practice settings and initiating discussions about AD with their patients. These results of this PIP may be in contrast to literature due to the small sample size and participants being practicing nurse practitioners or nurse practitioner students instead of physicians.

- Out of fourteen, the majority of participants ($n=9$) reported “strongly agree” or “somewhat agree” on having a baseline knowledge of ACP and AD. Another observation was that out of fourteen participants, the majority of participants ($n=12$) reported “strongly agree” or “somewhat agree” on having a baseline knowledge of the benefits of ACP and AD. Higher baseline knowledge and benefits of ACP and AD was found among participants even though literature findings suggest lack of baseline knowledge of ACP and AD (Dube et al., 2015; Fulmer et al., 2018; Blackwood et al., 2019).

Observations that were not made in the PIP but were found in the literature review are the *Serious Illness Conversation Guide* increasing and improving provider advance care planning conversations or advance directive completion rates. These observations may not have been found in the project because they were not directly assessed or measured within this PIP.

Limitations and Strengths

Limitations

Limitations found in this practice improvement project consisted of lack of participation from other healthcare providers (i.e. physicians and physician associates) and a limited advertising region. Since the project was approved for 1.0 CE through the NDBON, a potential limitation was the potential for selection bias as the target population of the NDNPA website is

nurse practitioners and nurse practitioner students, thus, having a potential lack of incentive and awareness for participation among physicians and physician associates (PAs). Although the NDNPA website was geared towards NPs, advertisement for the PIP was initiated at the NDNPA annual pharmacology conference, where physicians and PAs do attend. Since physicians and PAs obtain continuing medical education (CME) as form of license renewal, perhaps more participation would have occurred if 1.0 CME credit was obtained for the education webinar or providing the education webinar on multiple websites such as the American Medical Association (AMA) and the American Association of Nurse Practitioners (AANP).

Another limitation could be involving students within the healthcare profession. Although the assumption cannot be made that including NP students would have changed the PIP outcomes, the education and surveys were developed for practicing providers. By involving students within the survey, not all project outcomes were met due to the potential limited level of experience with advance care planning and advance directives.

The last limitation was the targeted participant region. Since the education webinar was posted on the NDNPA website, PIP findings were not largely diverse. NDNPA website represents advance practice nurses from North Dakota. Providing the education webinar on a national platform such as the American Association of Nurse Practitioners (AANP) website in the future could provide a larger, diverse, targeted audience.

Strengths

Strengths found in this practice improvement project consisted of consistency of responses, flexibility via online participation, and key stakeholder support. Fourteen participants completed both pre/post-implementation surveys. Although sample size from the project was small, data from pre/post-implementation surveys were consistent with a 100% completion rate.

Consistency of responses from participants resulted in an adequate assessment of the effectiveness of the education webinar and the enhancement of the individual participant's knowledge.

A second strength was the education implementation occurring online. Since the webinar was pre-recorded and resources were available for participants via links on the NDNPA website from September 30, 2021-December 30,2021, flexibility with participants' schedules was allowed. As noted by Heisler (2019), time and scheduling were noted barriers to traditional in-person education. However, with an online asynchronous format, time and scheduling were not barriers to participants in this project, thus, potentially increasing attendance.

Lastly, the education content was developed in correspondence with a key stakeholder. Obtaining support from an expert on the subject material helped to create content validity along with an applicable and effective education webinar. In addition to applicable education content, a multitude of optional resources for healthcare providers were obtained due to the key stakeholder support such as: books, conversation applications for electronic devices, articles, websites, conversation tools, and additional videos.

Recommendations

By utilizing education on ACP and AD, healthcare providers can adequately serve their patient population by breaking down common barriers which can lead to low AD completion rates. Although AD rates were not assessed in this project, results of the project did show improvement in healthcare providers' perceived knowledge, confidence, and understanding of benefits of ACP and AD. Results also suggested that resources provided for healthcare providers, such as the *Serious Illness Conversation Guide*, will help healthcare providers in the clinic setting initiate ACP discussions with patients, especially in patients greater than 65 living with

chronic disease. As previously mentioned, follow-up research should be obtained on how providing ACP and AD education directly affects AD rates among patients over 65 years old, living with chronic disease. Although objectives from this project did not measure AD completion rates, future research should continue to provide ACP and AD resources and education for healthcare providers.

Future education should continue to be led and created by key stakeholders and subject matter experts as well as certified advance care planning facilitators. The co-investigator of future project implementations should continue to obtain advance care planning facilitator certification from resources such as Respecting Choices. Education should continue to be supplemented from Ariadne Labs, the creator of the *Serious Illness Conversation Guide*, to provide evidence-based PowerPoints, videos demonstrating conversations, and case study scenarios.

Another recommendation based on the findings of this project, would be to continue to provide education online for healthcare providers. According to Heisler (2019), a limitation with in-person education was provider attendance due to scheduling conflicts and time barriers. Since the NDNPA website was chosen for online attendance, another option for future implementation would be to choose an organization with national representation of healthcare providers such as the American Association of Nurse Practitioners (AANP) or the American Medical Association (AMA). Although the AANP or AMA would be optimal platforms for implementation, willingness to work with students is a perceived barrier. In addition to choosing an implementation website with national representation of healthcare providers, education should be accredited for at least 1.0 CME instead of 1.0 CE to promote incentive for not just nurses and

nurse practitioners but to encompass other healthcare providers, such as physicians and physician associates.

Dissemination

Prior to implementation, the project proposal had already been presented during poster sessions to undergraduate nursing students, fellow graduate nursing students, and nurse practitioners. Poster presentation sites included the North Dakota Nurse Practitioner Association (NDNPA) 2021 Pharmacology Conference, where the co-investigator presented on benefits behind ACP and AD in primary care.

After project implementation, dissemination will occur during another poster session for undergraduate and graduate nursing students at North Dakota State University on May 4, 2021, where project findings will be presented. Publication in journals such as the Journal of American Association of Nurse Practitioners (JAANP), American Journal of Nursing (AJN), and the Online Journal of Issues in Nursing (OJIN) will also be pursued to allow an expanded dissemination to audiences of primary care providers who may be interested in learning more about ACP and AD in practice. The education webinar, *Advance Care Planning and Advance Directives*, and project results will also be distributed to the NDSU DNP program.

Application to the Advanced Practice Nurse Role

Advanced practice registered nurses (APRNs) must continue to expand their roles practice improvement, leadership, and advocacy for their patients. As a Doctor of Nursing Practice (DNP) prepared provider, eight essentials have prepared graduates to become competent in emerging problems and to design health interventions at aggregate, systems, and organization levels (American Association of Colleges of Nursing, 2019). In addition to the advanced education, DNP prepared APRNs have attributes of leadership and organization development

that further shapes them to become successful leaders (Kapu & Jones, 2016). Part of the program outcomes of the DNP curriculum at NDSU aims to utilize technology and evidence-based intervention strategies, to promote health, improve health disparities, and improve quality of healthcare delivery (North Dakota State University, 2020). The implementation of an ACP and AD practice improvement project ultimately, embodies these outcomes.

The PIP involved the development of evidence-based education, implementation of surveys, data analysis, and recommendations for practice. Additionally, the project met its main objectives and delivers recommendations for future research on the topic, as well as suggestions for resources which can be used to improve an NP's understanding of the importance of ACP and AD. Practice improvement project findings suggest that healthcare providers who completed the online education webinar increased their overall knowledge, confidence, and understanding of ACP and ADs. Findings from this project can be used to create awareness among APRNs and other providers regarding the gaps in advance directives and advance care planning knowledge and practice. Knowledge obtained through this project can ultimately, better equip healthcare providers in the primary care setting to meet patient needs, especially regarding quality of care at EOL.

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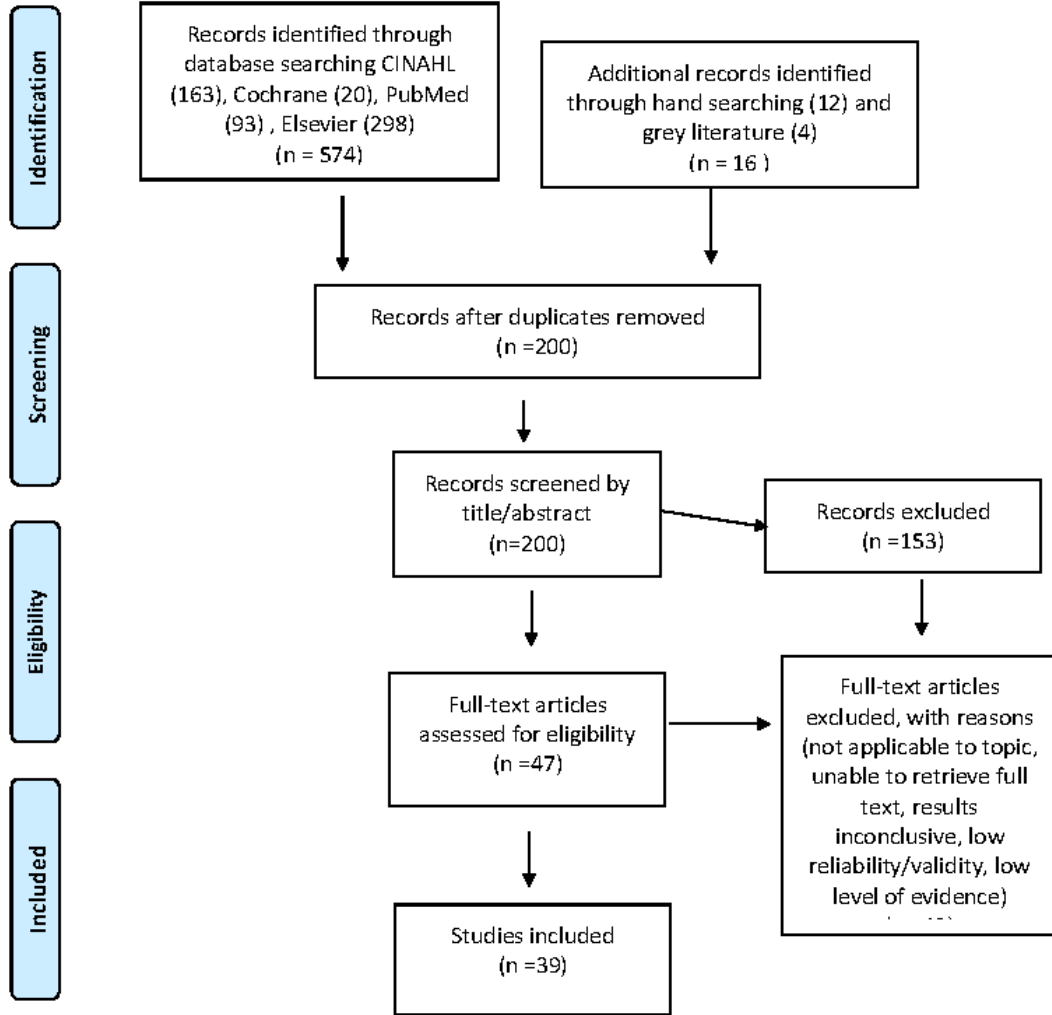
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APPENDIX A. PRISMA FLOW DIAGRAM



PRISMA 2009 Flow Diagram



APPENDIX B. SERIOUS ILLNESS CONVERSATION GUIDE

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. <i>Set up the conversation</i> Introduce the idea and benefits Ask permission	SET UP “I’m hoping we can talk about where things are with your illness and where they might be going — is this okay? ”
2. <i>Assess illness understanding and information preferences</i>	ASSESS “What is your understanding now of where you are with your illness?” “How much information about what is likely to be ahead with your illness would you like from me?”
3. <i>Share prognosis</i> Tailor information to patient preference Allow silence, explore emotion	SHARE Prognosis: “I’m worried that time may be short.” or “This may be as strong as you feel.”
4. <i>Explore key topics</i> Goals Fears and worries Sources of strength Critical abilities Tradeoffs Family	EXPLORE “What are your most important goals if your health situation worsens?” “What are your biggest fears and worries about the future with your health?” “What gives you strength as you think about the future with your illness?” “What abilities are so critical to your life that you can’t imagine living without them?” “If you become sicker, how much are you willing to go through for the possibility of gaining more time?” “How much does your family know about your priorities and wishes?”
5. <i>Close the conversation</i> Summarize what you’ve heard Make a recommendation Affirm your commitment to the patient	CLOSE “ It sounds like _____ is very important to you.” “Given your goals and priorities and what we know about your illness at this stage, I recommend... ” “ We’re in this together. ”
6. <i>Document your conversation</i>	

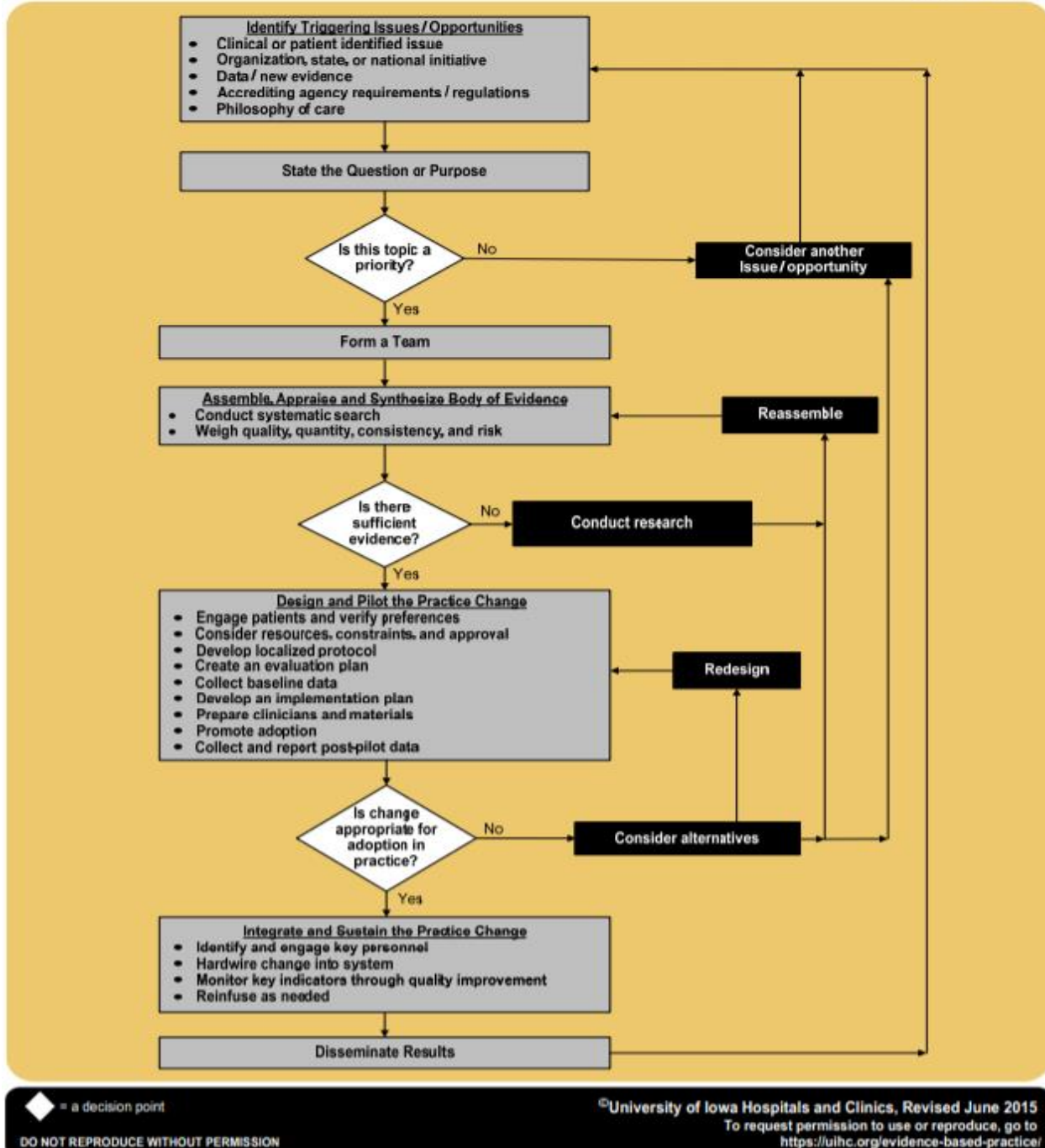


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APPENDIX C. IOWA MODEL

The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care



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APPENDIX D. PERMISSION TO USE IOWA MODEL

Permission to Use The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care



Kimberly Jordan - University of Iowa Hospitals and Clinics
s <survey-bounce@survey.uiowa.edu>
Fri 12/18/2020 6:12 PM
To: Weishoff, Hannah



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APPENDIX E. LETTER OF SUPPORT



March 26, 2021

To Hannah Murphy,

It is with great honor for me to support your efforts in your project. "Advance Care Planning and Advance Directives: Implementing Online Education for Healthcare Providers". The goal of Honoring Choices® North Dakota is to disseminate the awareness, education, and the importance of Advance Care Planning (ACP). Your project will be instrumental in getting the word out to nurse practitioners and other healthcare professionals.


There are some excellent tools to use, including the Serious Illness Conversation Guide (SICG) from Ariadne Labs and their Serious Illness Program. This program and guide is evidence-based and recognized nationally. The guide is easy to use and can be used in guiding ACP conversations in the primary care setting. The average conversation takes 20-30 minutes.

Some great ice breakers for ACP conversations include Go Wish Card game, Hard Choices For Loving People booklet and What Matters to Me Workbook. To continue the conversation, other tools include Vital Talks Tip App and My Directives mobile. There are also some helpful websites [including Honoring Choices® North Dakota](#), [The Conversation Project](#), [Serious Illness Care Program through Ariadne Labs](#), and the [National Healthcare Decisions Day](#).

However, many of the conversations takes more time. There are ACP facilitators that have been trained throughout the state that can be utilized as a resource to help for the extensive time that is needed to finish the conversation and complete a healthcare directive.

I am looking forward to working with you to complete this very necessary online education for providers. I do think this is a worthy project that will advocate and help address this very difficult national issue, especially during the time of COVID-19 pandemic. Thank you for being yet another advocate.

Sincerely,

 Nancy Joyner, APRN-CNS, ACPNP

Instructor - First Steps ACP Facilitator Training
POLST Trainer
HCND's POLST Coordinator
702 Belmont Road
Grand Forks, ND 58201
218.779.5037
nancy.joyner@honoringchoicesnd.org
<http://www.honoringchoicesnd.org/>

VISION

The health care choices a person makes become the health care the person receives.

Mission

To assist communities develop a successful advance care planning process.

APPENDIX F. SURVEY

DEMOGRAPHICS

What is your profession?

- a. Physician
- b. Nurse Practitioner
- c. Physician Associate
- d. Other (Please Explain): _____

What is your age?

- a. 20-29
- b. 30-39
- c. 40-49
- d. 50-59
- e. 60-69
- f. 70+

What is your gender?

- a. Male
- b. Female
- c. Prefer not to say

Please specify your area of specialty.

- a. Family Medicine
- b. Critical Care
- c. Neurology
- d. Cardiology
- e. Pulmonology
- f. Emergency Medicine
- g. OB/GYN
- h. Pediatrics
- i. Internal Medicine
- j. Oncology
- k. Palliative
- l. Hospice
- d. Other:_____

How many years have you been practicing?

- a. <1 year
- b. 1-3 years
- c. 4-6 years
- d. 7-9 years
- e. 10- 12
- f. > 12 years

PRESURVEY

1. I have sufficient knowledge on advance care planning and advance directives.
 - a. Strongly disagree
 - b. Somewhat disagree
 - c. Neither agree nor disagree
 - d. Somewhat agree
 - e. Strongly agree

2. I know the benefits of advance care planning and advance directives.
 - a. Strongly disagree
 - b. Somewhat disagree
 - c. Neither agree nor disagree
 - d. Somewhat agree
 - e. Strongly agree

3. I feel confident in initiating advance care planning and advance directive discussions with patients.
 - a. Strongly disagree
 - b. Somewhat disagree
 - c. Neither agree nor disagree
 - d. Somewhat agree
 - e. Strongly agree

4. I understand how to use the *Serious Illness Conversation Guide* with patients.
 - a. Strongly disagree
 - b. Somewhat disagree
 - c. Neither agree nor disagree
 - d. Somewhat agree
 - e. Strongly agree

5. I understand the role of advance care planning facilitators.
 - a. Strongly disagree
 - b. Somewhat disagree
 - c. Neither agree nor disagree
 - d. Somewhat agree
 - e. Strongly agree

POSTSURVEY

1. After the education webinar, I have sufficient knowledge on advance care planning and advance directives.

- a. Strongly disagree
- b. Somewhat disagree
- c. Neither agree nor disagree
- d. Somewhat agree
- e. Strongly agree

2. After the education webinar, I know the benefits of advance care planning and advance directives.

- a. Strongly disagree
- b. Somewhat disagree
- c. Neither agree nor disagree
- d. Somewhat agree
- e. Strongly agree

3. After the education webinar, I feel confident in initiating advance care planning and advance directive discussions with patients.

- a. Strongly disagree
- b. Somewhat disagree
- c. Neither agree nor disagree
- d. Somewhat agree
- e. Strongly agree

4. After the education webinar, I understand how to use the *Serious Illness Conversation Guide* with patients.

- a. Strongly disagree
- b. Somewhat disagree
- c. Neither agree nor disagree
- d. Somewhat agree
- e. Strongly agree

5. After the education webinar, I understand the role of advance care planning facilitators.

- a. Strongly disagree
- b. Somewhat disagree
- c. Neither agree nor disagree
- d. Somewhat agree
- e. Strongly agree

6. After the education webinar, I will increase advance care planning discussions with patients.

- a. Strongly disagree
- b. Somewhat disagree
- c. Neither agree nor disagree

- d. Somewhat agree
- e. Strongly agree

7. Have you had conversations about advance care planning or advance directives in your practice setting? Yes or No

8. Have you been a witness (i.e., involved in documentation) for an advance directive for a patient? Yes or No

9. Have you initiated a discussion about advance directives with a patient? Yes or No

10. Have you provided treatment to patients whose advance directive indicated otherwise (i.e., family's goals of care don't align with patient's)? Yes or No or prefer not to answer

11. Have you observed others providing treatment to patients whose advance directive indicated otherwise? Yes or No or prefer not to answer

12. Information presented was current and could be applied to own practice area.

- a. Strongly disagree
- b. Somewhat disagree
- c. Neither agree nor disagree
- d. Somewhat agree
- e. Strongly agree

13. The teaching/learning resources and instructed materials were effective and suited for the topic.

- a. Strongly disagree
- b. Somewhat disagree
- c. Neither agree nor disagree
- d. Somewhat agree
- e. Strongly agree

14. Administration and technology of the online webinar was smooth and customer-friendly.

- a. Strongly disagree
- b. Somewhat disagree
- c. Neither agree nor disagree
- d. Somewhat agree
- e. Strongly agree

15. Instructions for participation and receiving continuing education credits were adequate.

- a. Strongly disagree
- b. Somewhat disagree
- c. Neither agree nor disagree
- d. Somewhat agree
- e. Strongly agree

16. Is there anything else related to advance directives and advance care planning you wished we discussed in the education webinar?

Comments:

POSTTEST

1. Advance care planning (ACP) benefits include all of the following except:
 - a. Higher rates of completion of advance directives
 - b. Increased hospitalization at end of life
 - c. Increased alignment of patients wishes
 - d. Less intensive treatments at end of life

Answer: b. Increased hospitalization at end of life

2. True or False. 21% of patients are open to talk about ACP and 60% of providers report talking about ACP or end-of-life care.

Answer: False- 60% patients are open to talk about ACP, only 21% providers report talking about ACP or end-of-life care.

3. Advance directive (AD) is all of the following except:
 - a. Legal document
 - b. Medical order
 - c. Appoints a person to speak for patients when they are unable
 - d. Different in every state
 - e. Includes person's values, beliefs, and preferences

Answer: b. Medical order

4. What are the 5 D's of when to update an advance directive?
 - a. Decline, Delirium, Divorce, Diagnosis, Death
 - b. Divorce, Decline, Decade, Determination, Death
 - c. Determination, Divorce, Death, Diagnosis, Decline
 - d. Divorce, Decline, Decade, Death, Diagnosis

Answer: d. Divorce, Decline, Decade, Death, Diagnosis

5. Which barrier is the most common in advance care planning and completion of advance directives?
 - a. Knowledge
 - b. Leadership support
 - c. Time
 - d. System

Answer: c. Time

6. Who is appropriate to have advance care planning conversations with?
 - a. Individuals over 65 years old
 - b. Seriously ill
 - c. Healthy adults
 - d. Adolescents
 - e. All of the above

Answer: e. All of the above

7. Steps of the *Serious Illness Conversation Guide* includes all of the following except:
- Set up the conversation
 - Understanding death
 - Assess understanding and preferences
 - Share prognosis
 - Explore key topics
 - Close the conversation

Answer: b. Understanding death

8. Honoring Choices of North Dakota is all of the following except:
- Online resource for providers
 - Assists communities to develop successful ACP process
 - For profit organization
 - Offers professional outreach and education

Answer: c. For profit organization

9. When is it best to refer a patient to an ACP facilitator?
- First visit about ACP and AD
 - After primary care provider has had initial ACP discussion with patient
 - Before talking to primary care provider about new serious illness
 - When patients need medical questions answered about prognosis
 - Always since providers can't make appointments for ACP

Answer: b. After primary care provider has had initial ACP discussion with patient

10. True or False. The PSDA requires that health care facilities advise patients of their rights regarding advance directives.

Answer: True

APPENDIX G. SURVEY PERMISSION LETTER

Hannah

You have my permission to use the KAESAD and I have attached the instrument with the validity and reliability results. We have three articles one for emergency nurses published in Applied Nursing Research and one with critical care nurses that was published in Critical Care Nurse and oncology nurses published in Oncology Nursing Forum. KEEP IN MIND THAT THIS INSTRUMENT WAS DEVELOPED FOR RNS NOT THE GENERAL PUBLIC. The reliability and validity does not apply to groups other than RNs. If you change the wording or change the scales in any way, the reliability and validity of the scales is compromised,

Please read the r & v and note the low Cronbach alphas for the attitudes as a total scale. Thus we did individual item analysis for the attitude items (percent of agreement). You do not need to reverse score to do individual item analysis.

Note that the answers to the questions about state laws will vary according to state or country so you will have to determine the correct answers for your situation. Also the demographics will need to be adjusted to fit your sample [I am sending the oncology instrument which is the same as the critical care and emergency nurses except for a couple of demographic items which you change to suit your sample]. Please understand if you change items or wording of items in any of the sub scales, the reliability and validity of the scale is invalid.

You have my permission to reproduce and use the KAESAD instrument for your project. You may NOT publish the KAESAD instrument in any articles you write nor attach it to any thesis or dissertation report. You can publish a few examples of items if you wish.

The expectation is that you will eventually share your findings with us.

Please respond via email that you agree with the statements above. If you have additional questions, please email me.

Good luck with your project.

Mary Ann Jezewski, RN, PhD, FAAN
Professor Emeritus
University at Buffalo, SUNY
School of Nursing

APPENDIX H. WEBINAR FLYER



Advance Care Planning and Advance Directives Webinar
September 30, 2021-December 30, 2021

Available on North Dakota NDNPA Website

Presented by

Hannah Murphy, RN, BSN, DNP-S &
Nancy Joyner, MS, CNS-BC, APRN, ACHPN®

Objectives:

1. Describe the benefits of advance care planning (ACP) and advance directives (AD).
2. Identify the barriers to ACP and AD completion.
3. Identify how and when to use the *Serious Illness Conversation Guide* in ACP
4. Describe the role of ACP facilitators
5. Describe Honoring Choices® and ACP resources available



Who Should Attend: Nurse Practitioners, Physician Associates, Physicians, and others who facilitate ACP

When: Online virtual webinar available on North Dakota Nurse Practitioner Association website from September 30, 2021- December 30, 2021

How to obtain your 1.0 CE credit:

1. Complete pre-test/survey
2. Watch the one-hour webinar
3. Pass the post-test with an 80%
4. Complete post-survey
5. You will then be directed to a webpage to print off your certificate



*Will be available after December 30, 2021 on NDNPA website for the full year.

*Link to free online webinar: <https://ndnp.enpnetwork.com/page/37726-additional-ce-opportunities>

*For more information please contact: hannah.weishoff@ndsu.edu

APPENDIX I. CONSENT



School of Nursing
1919 N University Dr, Fargo, ND 58102
NDSU Dept. 2670
PO Box 6050
Fargo, ND 58108-6050
701.231.7395

Advance Care Planning and Advance Directives: Implementing Online Education for Healthcare Providers

Dear participant,

My name is Hannah Murphy, I am a Graduate Student in the Doctor of Nursing Practice program at North Dakota State University, and I am conducting a research project to see if providing healthcare provider education on advance care planning and advance directives will improve advance care planning conversations and increase patient advance directive rates. It is my hope, that with this research, we will find a way to help improve healthcare providers' perceived knowledge, confidence, and understanding in both initiating and facilitating advance care planning conversations, especially in the primary care setting.

Because you are a healthcare provider, you are invited to take part in this research project. Your participation is entirely your choice, and you may change your mind or quit participating at any time, with no penalty to you. By filling out both pre/post tests and surveys, you are giving your consent to participate in this study and attesting that you are at least 18 years of age.

By taking part in this research, you may benefit by understanding more regarding advance care planning and advance directives. However, you may not get any benefit from being in this study. Benefits to others are likely to include increased knowledge on benefits of advance care planning (ACP) and advance directives (AD), barriers to ACP and AD completion, how and when to use Serious Illness Conversation Guide, role of ACP facilitators, Honoring Choices[®] of North Dakota, and ACP resources available.

It is not possible to identify all potential risks in research procedures, but we have taken reasonable safeguards to minimize any known risks. These known risks include: emotional or psychological distress related to the questions asked during the survey.

This survey should take 15 to 30 minutes to complete. It is entirely electronic, anonymous, and will be returned to the data collection team immediately. You will receive a free, 1.0 CE credit upon completion of both surveys as well as the pre/posttest. All questionnaires will be kept confidential. The questionnaires are anonymous and contain no personal identifying information. Participant information will be used to measure the effectiveness of providing advance care planning education to healthcare providers. In addition, the de-identified questionnaire results may be used in a future publication in a healthcare journal. [Insert statement here about IRB approval from North Dakota State University].

If you have any questions about this project, please contact Hannah Murphy at 406-697-4111 or hannah.weishoff@ndsu.edu, or contact my advisor, Adam Hohman at 701-231-8016 or adam.hohman@ndsu.edu.

You have rights as a research participant. If you have questions about your rights or complaints about this research, you may talk to the researcher or contact the NDSU Human Research Protection Program at 701.231.8995, toll-free at 1-855-800-6717, by email at ndsu.irb@ndsu.edu, or by mail at: NDSU HRPP Office, NDSU Dept. 4000, P.O. Box 6050, Fargo, ND 58108-6050.

Thank you for your taking part in this research. If you wish to receive a copy of the results, please contact me at hannah.weishoff@ndsu.edu visit the North Dakota Nurse Practitioner Association's (NDNPA) website in January of 2022 for results and recommendations.

Please click below to complete the survey.

Thank you for your time,

Hannah Murphy, DNP-S
Adam Hohman, DNP, APRN, FNP-BC

APPENDIX J. IRB APPROVAL



08/23/2021

Dr. Adam G Hohman
Nursing

Re: IRB Determination of Exempt Human Subjects Research:
Protocol #IRB0003818, "Advance Care Planning and Advance Directives: Implementing Online Education for Healthcare Providers"

NDSU Co-investigator(s) and research team:

- Adam G Hohman
- Hannah Aundrea Murphy

Approval Date: 08/23/2021

Expiration Date: 08/22/2024

Study site(s): Research will be conducted over a 3 month period. Participants will participate from the comfort of their own home and work through completion of a free, one-hour education webinar on their own time.

Funding Agency:

The above referenced human subjects research project has been determined exempt (category 1) in accordance with federal regulations (Code of Federal Regulations, Title 45, Part 46, *Protection of Human Subjects*).

Please also note the following:

- The study must be conducted as described in the approved protocol.
- Changes to this protocol must be approved prior to initiating, unless the changes are necessary to eliminate an immediate hazard to subjects.
- Promptly report adverse events, unanticipated problems involving risks to subjects or others, or protocol deviations related to this project.

Thank you for your cooperation with NDSU IRB procedures. Best wishes for a successful study.

NDSU has an approved FederalWide Assurance with the Department of Health and Human Services: FWA00002439.

APPENDIX K. PERMISSION TO USE ARIANDE LAB RESOURCES



Nora Downey <ndowney@ariadnelabs.org>

Mon 1/11/2021 4:11 PM

To: Weishoff, Hannah



Hi Hannah,

[Congratulations](#) on your upcoming dissertation work!

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I hope this helps!

All the best,

Nora

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APPENDIX L. ACP FACILITATOR CERTIFICATE



Respecting Choices®
PERSON-CENTERED CARE



Facilitator Certification

This certifies that

Hannah Murphy

has successfully completed the Respecting Choices certification requirements
and therefore qualifies as a Respecting Choices

Advanced Steps ACP Certified Facilitator

Stephanie Anderson

Stephanie Anderson, DNP, RN
Executive Director, Respecting Choices®

March 17, 2021

Date

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APPENDIX M. ESTIMATED COST FOR IMPLEMENTATION

Educational Materials	Estimated Cost		Total: \$375.00 USD
	NDBON CE Accreditation	\$100	
	ACP facilitator certification course	\$275	

Note. This table was adapted from Roush’s (2019) budget example on p. 59; Care Planning Facilitator Course cost retrieved from past dissertation project by Heisler (2019); NDBON CE Accreditation from receipt.

APPENDIX N. WEBINAR PRESENTATION

Advance Care Planning & Advance Directives: Implementing Online Education for Healthcare Providers

Hannah Murphy, RN, DNP-S
Nancy Joyner, MS, CNS-BC, APRN, ACHPN®
(Attribution to Lois Ustanko, MSN and Ryan Heisler, DNP, CNP)

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Objectives

At the end of this in-service, participants will be able to:

- Describe the benefits of advance care planning (ACP) and advance directives (AD)
- Identify the barriers to ACP and AD completion
- Identify how and when to use the Serious Illness Conversation Guide in advance care planning
- Describe role of ACP facilitators
- Describe Honoring Choices and ACP resources available

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Disclaimer

- Graduate student NDSU
- Conducting a research project
- Providing healthcare provider education on ACP and AD
- Hope to improve ACP and AD rates



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Dissertation Project

- ICU background
- NDSU graduation requirement for DNP
- Prior dissertation Ryan Heisler found a need
- Problem: lack of provider training and education about advance care planning and advance directives
- Purpose: to increase healthcare providers' knowledge of facilitating ACP conversations and completion of ADs



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Just as birth concludes a pregnancy, death concludes life



In America we fight hard against age, illness and death

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Advance Care Planning (ACP): Definition

A process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences.

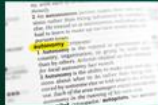


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(Sudore et al., 2017)

Advance Directive (AD): Definition

The documents a person completes while still in possession of decisional capacity about how treatment decisions should be made on the behalf in the event they lose the capacity to make such decisions. They are legal tools directing treatment decision-making and/or appoint surrogate decision-makers.



(Silveira, Arnold & Givens, 2021)

Advance Care Planning

- Power to produce a written plan (Advance Directive/Healthcare Directive)
- 60% of patients stated that they are open to talk about ACP; however, only 21% percent of providers reported talking frequently about matters related to ACP or end-of-life care (Fulmer et al., 2018; Risk et al., 2019).



"It always seems too early until it is too late"

Advance Directives

- The Patient Self Determination Act (PSDA) 1990
- Two thirds of Americans have not completed an advance directive and 70 percent of Americans (more than 1.7 million) die of chronic diseases (Kung 2008; Penn Medicine News, 2017)

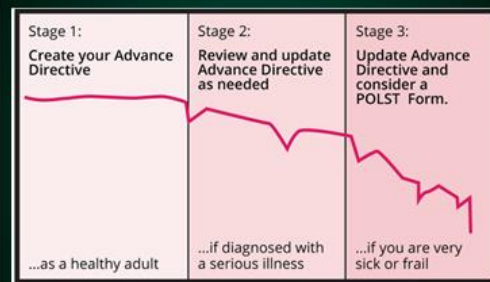


What is POLST

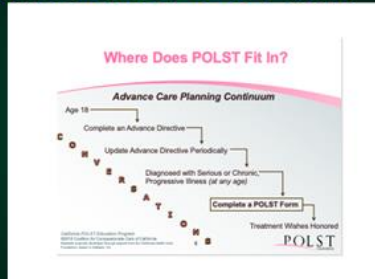
- A national movement, implemented at the state level, that supports patient autonomy regarding treatment preferences during a medical emergency.
- A **process**. Part of advance care planning, which helps the patient live the best life possible.
- **Conversation**. about medical conditions, treatment options, and what the patient wants
- A **medical order form** that travels with the patient (called a POLST form).
- Voluntary, not for everyone

Advance Directive vs. POLST

	Advance Directives	POLST Form
What is it?	Legal Document	Medical Order
Who should have this document?	All adults	Anyone (regardless of age) who is seriously ill or frail
Why would I need this?	To tell others who you want to make medical decisions for you, if you can't communicate. Tell others what medical treatments you would want, your values, what you care about.	Order providers to give specific treatments during an emergency. Supports the patient across care settings
Who fills it out?	The individual	Health care professional (after discussion with patient)
Can I use it to appoint my surrogate?	Yes	No
Can emergency responders use it?	No	Yes—it tells them if the patient was CPR and if the patient wants to go to the hospital
Is the document easily found?	Not always. Be sure you give a copy of your advance directive to your provider and surrogate.	Yes. You have a copy, your provider has a copy, and it may also be in a registry.



Where does POLST fit in?



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ACP Benefits

- ACP significantly improves multiple outcomes, particularly for patients with serious illness:
 - Higher rates of completion of ADs
 - Increased alignment of patient's wishes by clinicians and families/loved ones
 - Reduction of hospitalization at end of life
 - Less intensive treatments at end of life
 - Increased utilization of hospice services
 - Increased likelihood patient will die in preferred place



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When to Discuss

- At annuals even when healthy
- At initial diagnosis of serious illness
- As illness progresses
- Functional decline
- Follow-up hospitalization
- Illness is no longer responsive to treatment
- When treatment is causing more harm than benefit
- The 5 D's: decade, divorce, diagnosis, death, decline



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What are the barriers?

- Barriers are faced at several levels: individual, interpersonal, provider, and system.
- Lack of knowledge
- Time (most common)
 - Despite lack of time necessary to provide information (federal mandate)
 - Should take at minimum, 30 minutes
 - Use of ACP facilitators significantly improves rates of ADs



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The elephant in the room ...



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Who should you have ACP conversations with?

- All adults (over 18)
- Minimally, 65 years and older
 - Especially, those living with chronic disease, serious illness (i.e. COVID) and frailty
- Individuals with stage IV cancer or lung disease were more likely to complete an AD within last three months before death (Enguidanos & Ailshire, 2017).
- 63% of patients living with stage IV lung cancer had ACP conversations in the inpatient setting rather than in primary care (Mack et al., 2012)
- Among patients living with ESRD, 49% had an advance directive but only 10% addressed dialysis (Feely et al., 2016)

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ACP Heart Failure

- 21% of 24,291 individuals admitted with heart failure had an AD and more than 80% of patients did not have ADs documented in their medical record (Butler et al., 2015; Dunlay et al., 2012).
- When patients know the possible trajectory of their illness, they can plan better.



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Palliative Care: Definition

Specialized medical care focused on providing relief from symptoms, stress of a serious illness, and goal is to improve quality of life for both the patient and the family.



(Conversation Project, 2021)

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Conversation in CHF Patients

Communication Step	Example
Explaining the nature and course of the heart failure	"Heart failure is a chronic disease where your heart becomes weaker and doesn't pump very strongly."
Eliciting patient preferences for care	"One option might be to insert a device in your heart that will use electricity to help your heart to beat normally. How do you feel about this?"
Encouraging documentation of preferences	"In case you get sick and come to the hospital again but cannot talk for yourself, it is helpful to have your wishes for care documented in the medical record so doctors can see and follow them."

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ACP Heart Failure

NYHA I No symptoms even with moderate intensity exercise	NYHA II Reduced capacity for moderate intensity exercise	NYHA III Severe decreased physical capacity, breathlessness except at rest	NYHA IV Symptomatic ever at rest, uncomfortable with activity
ACP should be developed	Review ACP as need r/t symptoms	Wouldn't be surprised if dies within 12 months begin thinking about writing POLST orders	

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Serious Illness: Definition

A health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life or excessively strains their caregiver



(Kelley & Bollens-Lund, 2018)

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Serious Illness Conversation Guide


- Created to address the challenges patients, families, friends, and healthcare teams face during a time of serious life-threatening illness
 - Guide allows clinicians to engage and lead important conversations involving what's important to the patient.
 - Goal is to learn and express the patient's goals, values, and priorities and inform their future care
- Primary care setting: lead to better and more frequent conversations → average conversation was 22 minutes

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Serious Illness Conversation Guide	
CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. Set up the conversation Introduce yourself Prepare for future decisions Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?" "What is your understanding of where you are with your illness?" "How much information about what is ahead do you want to share with your illness?"
2. Assess understanding and preferences	"I want to start with my understanding of where things are with your illness." Introduction: "I can see that it is probably what you would expect with your illness. I hope you will continue to feel well for a long time but I'm worried that you could get sick suddenly and I think it is important to prepare for that possibility." Theme: "While we aren't in this situation, I'd be worried that there may be a point in the future when you need to make decisions about your care." Question: "I hope that this is not the case, but I'm worried that this may be in front of you at some point. How do you feel about that?" Theme: "What are your most important goals if your health situation worsens?" Question: "What are your biggest fears and worries about the future with your illness?" Question: "What gives you strength or hope about the future with your illness?" Question: "What abilities are so critical to your life that you can't imagine being without them?" Question: "If you become sicker, how much are you willing to go through for the possibility of getting better?" Theme: "How much does your family know about your priorities and wishes?"
3. Close the conversation Summarize Reassess understanding Check in with patient Offer commitment	"I've heard you say that _____ is really important to you. Keeping that in mind, and what we know about your illness, I understand that we _____ may help us make sure that your treatment goals reflect what is important to you." "How does this plan seem to you?" "I'll do everything I can to help you through this."
4. Document with key clinicians	

Role of the Provider

- Engage the patient in ACP
- Discuss prognosis
- Refer to facilitator
- Reassess and review directive and orders
- Document



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Case Study

Skills Practice Case: Advanced CHF (Clinician Role)

BACKGROUND

- 72-year-old retired teacher/husband
- CHF with EF of 15%, diabetes, congestive heart failure
- Just been released from hospital
- Two hospitalizations this year for CHF exacerbations
- Has a cardiologist for advanced heart failure therapies
- Needs help with shopping
- Difficulty walking her city blocks
- Strained and love with spouse, adult children do not live locally

SETTING

- Advanced Heart Failure Clinic

NOTE: This is a simulation for a discussion using the Serious Illness Conversation Guide to understand more about her/his values, goals, and the type of care he/she would want as the illness progresses.

AS YOU PREPARE TO MEET WITH MR. NILES SMITH, YOU CONSIDER THE FOLLOWING:

- Mr. Niles Smith has advanced CHF and multiple comorbidities
- Prognosis: Given the hospitalizations and functional challenges, you estimate her/his prognosis as likely less than 1 year, but death could be sudden and without warning.

The goal of the discussion today is to explore wishes for future care using the Serious Illness Conversation Guide. The focus should be on values and goals for the months ahead rather than procedures and therapies.

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Case Study Responses

How are things going?	I'm getting by.
Set-up	Whatever you want doc. You're the boss.
Understanding	I know I have a bad heart and I just don't feel like I want to. Some things are harder than they used to be. My husband helps me to get around with me now.
Information	I want to know everything.
Preferences	Is that really me?
Prognosis	She said, "Turn away from the clinician and put your head down and handle over your state. Be happy in 10-15 minutes after the clinician leaves alone."
Communication	I've been feeling weaker but that never is a big deal. I know this is important though. I've been worried about this for a while.
Goals	I want to be able to play cards with my friends. I want to spend more time with my family.
Fears/Worries	I worry about suffocating. That happened before I went into the hospital and it was terrifying. I think feeling more independent on the topics and hands.
Strengths	My spouse and my friends give me strength. They help me get through.
Function	I couldn't interact with my spouse. I couldn't want to be like that. That is the most important thing. I'm not running marathons or anything so if things get worse (probably) I'd be OK.
Tradeoffs	If going to the hospital means I can feel better when I get a shot of breath and have more time with my family, I would do it. I have a couple of times when I just sit and wait. I wouldn't want to put my spouse through that.
Family Understanding	I signed the proxy form already. It is my spouse. I didn't want to worry the kids about all of this. They're living their lives.

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1. Set Up the Conversation

- Introduce purpose
- Prepare for future decisions
- Ask permission



"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?"

Set-up Whatever you want doc. You're the boss.

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2. Assess Understanding and Preferences

ASSESS	<p>"What is your understanding now of where you are with your illness?"</p> <p>"How much information about what is likely to be ahead with your illness would you like from me?"</p>
Understanding	I know I have a bad heart and I just don't feel like I used to. Some things are harder than they used to be. My husband/wife has to run errands with me now.
Information Preferences	I want to know everything.



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3. Share Prognosis

- Frame as a "wish...worry", "hope...worry" statement
- Allow silence, explore emotion

SHARE	<p>"I want to share with you my understanding of where things are with your illness..."</p> <p>Uncertain: "It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility."</p> <p>OR</p> <p>Time: "I wish we were not in this situation, but I am worried that time may be as short as ____ (specify as a range, e.g. days to weeks, weeks to months, months to a year)."</p> <p>OR</p> <p>Function: "I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult."</p>
Prognostic Communication	<p>Is that really true?</p> <p>[Be sad. Turn away from the clinician and put your head down and hands over your eyes. Re-engage in 15-30 seconds after the clinician allows silence.]</p> <p>I've been feeling weaker but that news is a lot to take in. I know this is important though. I've been worried about this for a while.</p>

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Prognosis Phrases

- Time Prognosis
 - Discuss prognostic information as a range: Days to weeks, weeks to months, months to years
- Functional Prognosis
 - "I think that your leg swelling may get better, but I think you will still need oxygen and I'm worried that this may be as strong as you feel."
- Unpredictable Prognosis
 - "Heart disease is unpredictable OR It can be difficult to predict what will happen with your illness. People can live well for years, but sometimes things can happen quickly. I think we need to be prepared for a crisis, or sudden event, in which we may be confronted by some difficult decisions."

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4. Explore key topics

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family



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4. Explore key topics (cont.)

EXPLORE	<p>"What are your most important goals if your health situation worsens?"</p> <p>"What are your biggest fears and worries about the future with your health?"</p> <p>"What gives you strength as you think about the future with your illness?"</p> <p>"What abilities are so critical to your life that you can't imagine living without them?"</p> <p>"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"</p> <p>"How much does your family know about your priorities and wishes?"</p>
Goals	I want to be able to play cards with our friends. I want to spend more time with my family.
Fears/Worries	I worry about suffocating. That happened before I went into the hospital and it was terrifying. I hate feeling more dependent on my spouse and friends.
Strengths	My spouse and my friends give me strength. They help me get through.
Function	If I couldn't interact with my spouse, I wouldn't want to live like that. That is the most important thing. I'm not running marathons or anything so if things get worse physically I'd be ok.
Tradeoffs	If going to the hospital means I can feel better when I get short of breath and have more time with my family, I want that. If there comes a time when I'm just a vegetable, I wouldn't want to put my spouse through that.
Family Understanding	I signed the proxy form already, it is my spouse. I don't want to worry the kids about all of this. They're living their lives.

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5. Close the conversation

- Summarize
- Make a recommendation
- Check in with patient
- Affirm commitment



CLOSE	<p>"I've heard you say that ____ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ____ This will help us make sure that your treatment plans reflect what's important to you."</p> <p>"How does this plan seem to you?"</p> <p>"I will do everything I can to help you through this."</p>
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Role of ACP Facilitators

- Advance care planning facilitators are certified to facilitate advance directive discussion.
- Spend >1.5hrs with patient following a script
- 94.3% of 1,894 heart failure patients referred to advance care planning facilitators had a health directive (Schellinger et al. 2011)
- Studies found patients prefer to have ACP conversations with their trusted provider (O'Halloran et al., 2018); O'Sullivan et al., 2015)



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Honoring Choices® North Dakota

- <https://www.honoringchoicesnd.org>
- Vision: The health care choices a person makes becomes the health care the person receives
- Goal: To assist communities develop a successful advance care planning process
- Objectives:
 1. Promote advance care planning through community and professional outreach and education
 2. Promote standardization of advance care planning
 3. Establish base of financial support

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Key Take Aways

- Benefits of ACP & AD overview
- Barriers to ACP & AD reviewed
- Comprehensive review of Serious Illness Conversation Guide
- Role of ACP facilitators
- Honoring Choices and ACP resources



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APPENDIX O. TOOLKIT

Descriptions of ACP Toolkit Resources

Books:

Being Mortal: Medicine and What Matters in the End by Atul Gawande

- Gawande’s book reveals suffering produced by medicine’s neglect of the wishes people might have beyond mere survival through eye-opening research and gripping stories of his own patients and family. This book, which has already changed the national conversation on aging and death, shows how the ultimate goal is not a good death but a good life—all the way to the very end.
- https://www.amazon.com/Being-Mortal-Illness-Medicine-Matters/dp/1781253943/ref=sr_1_1?dchild=1&keywords=Being+Mortal%3A+Medicine+and+What+Matters+in+the+End+by+Atul+Gawande&qid=1630778395&s=books&sr=1-1

Extreme Measures: Finding a Better Path to the End of Life by Jessica Nutik Zitter, MD

- *Extreme Measures* charts Zitter’s journey from wanting to be one kind of hero to becoming another—a ICU doctor who prioritizes the patient’s values and preferences in an environment where the default choice is the extreme use of technology. In her work Zitter has learned what patients fear more than death itself: the prospect of dying badly. She builds bridges between patients and caregivers, formulates plans to allay patients’ pain and anxiety, and enlists the support of loved ones so that life can end well, even beautifully.
- <https://www.amazon.com/Extreme-Measures-Finding-Better-Path/dp/1101982551>

Gone From My Sight: The Dying Experience by Barbara Karnes, RN

- Author, Barbara Karnes is a hospice pioneer and nurse who provides non-medical language for patients and their families about what to potentially expect in the last months, weeks, days, hours, and minutes of death.
- https://www.amazon.com/Gone-My-Sight-Dying-Experience/dp/B00072HSCY/ref=sr_1_1?dchild=1&keywords=Gone+From+My+Sight%3A+The+Dying+Experience+by+Barbara+Karnes%2C+RN&qid=1630778749&s=books&sr=1-1

Hard Choices for Living People: CPR, Feeding Tubes, Palliative Care, Comfort Measures, and the Patient with a Serious Illness by Hank Dunn

- This book offers honest, practical, reliable advice and information, as well as help with the emotional and spiritual concerns families and patients face during the most difficult time of life. Over 3.5 million copies of *Hard Choices* have been sold and are being used in more than 5,000 hospitals, nursing homes, hospice programs, and faith communities.

- https://www.amazon.com/Hard-Choices-Loving-People-Palliative/dp/099726120X/ref=sr_1_1?dchild=1&keywords=Hard+Choices+for+Living+People%3A+CPR%2C+Feeding+Tubes%2C+Palliative+Care%2C+Comfort+Measures%2C+and+the+Patient+with+a+Serious+Illness+by+Hank+Dunn&qid=1630778510&s=books&sr=1-1

The Conversation: A Revolutionary Plan for End-of-Life Care by Angelo E. Volandes, M.D.

- Through the stories of seven patients with very different end-of-life experiences, Dr. Volandes demonstrates that what people who are approaching the end of their lives need most is one simple thing: The Conversation. He argues for radical re-envisioning of the patient-doctor relationship and offers ways for patients and their families to talk about end-of-life care to ensure that patients will be in charge of the way they live their last days.
- https://www.amazon.com/Conversation-Revolutionary-Plan-End-Life/dp/1620408554/ref=sr_1_1?dchild=1&keywords=The+Conversation%3A+A+Revolutionary+Plan+for+End-of-Life+Care+by+Angelo+E.+Volandes%2C+M.D.&qid=1630778450&s=books&sr=1-1

Apps:

-MyDirectives MOBILE

- The MyDirectives experience helps you record and share your medical treatment goals, preferences and priorities with family, friends, caregivers and medical personnel
- Download from App store: <https://apps.apple.com/us/app/mydirectives-mobile/id931433126>

-VitalTalk Tips app

- The VitalTalk Tips app enables physicians, nurses, and other clinicians to improve their communication skills for patients who have a serious illness. This app includes a special set of communication skill tips, focused on the moments where clinicians most often get stuck. You can flip through the tips by topic (serious news, prognosis, family conferences, goals of care, and more), or just get a daily tip as a notification. Read the tip (it'll take <10 seconds), try it out, and over time, your inner communication ninja will emerge.
- Download from App store: <https://apps.apple.com/us/app/vitaltalk-tips/id1109433922>

PDFs:

- *Choosing Words Wisely in Communication with Patients with Heart Failure and Families* by Anne M. Kelemen, LICSW, George Ruiz, MD, MBA, and Hunter Groninger, MD

- In this work, the investigators unpack language commonly used in advanced HF care and provide explicit suggestions to better provide such pivotal communication. In conclusion,

specific phrasing may significantly impact patient experiences and outcomes. Communication that focuses on the disease itself and the therapy or intervention in question may help remove the patient from potential negative emotions, thus facilitating more objective shared decision-making with the clinician.

- [Choosing Words Wisely in Communication With Patients With Heart Failure and Families \(sciencedirectassets.com\)](#)

-Clinician Reference Guide

- This guide goes more into depth on explaining the Serious Illness Conversation Guide as seen in the webinar. Use this free booklet by Ariadne Labs for more guidance and explanation of each step to have effective conversations.
- https://implementation.aria.ariadnelabs.net/wp-content/uploads/2018/03/Implementing%20Checklist/01-prepare/01-2-select-sites/Clinician%20Reference%20Guide_%20Updated%2010.23.17.pdf

- “End-of-Life Care Conversations: Medicare Reimbursement FAQs” by Institute for Healthcare Improvement and Conversation Ready

- The changes in Medicare reimbursement policy that went into effect January 2016 provide an opportunity for more clinicians and patients to engage in conversations about preferences for care at the end of life. However, many people are confused about where to start. Whether you are uncertain about the new rules for CMS reimbursements or about starting those conversations with patients, this document will help you understand this new landscape for end-of-life care conversations.
- <https://theconversationproject.org/wp-content/uploads/2016/06/CMS-Payment-One-Pager.pdf>

-Serious Illness Conversation Guide

- Print off and laminate this free conversation tool by Ariadne Labs for your office. This tool will help you guide Serious Illness Conversations with your patients. We encourage you to use this tool and take notes as you discuss advance care planning with your patients.
- [https://implementation.aria.ariadnelabs.net/wp-content/uploads/2018/03/About/Serious%20Illness%20Conversation%20Guide%20\(7\).pdf](https://implementation.aria.ariadnelabs.net/wp-content/uploads/2018/03/About/Serious%20Illness%20Conversation%20Guide%20(7).pdf)

Websites:

-Aria website: <https://www.ariadnelabs.org/aria/>

- Available to anyone interested in improving quality in health care, Aria provides members access to free webinars, publications, and implementation resources to accompany tools from Ariadne Labs’ Serious Illness Care.

-Cake: <https://www.joincake.com/blog/category/advance-directives-and-living-wills/>

- Website for the community about topics in advance care planning such as end-of-life planning, loss and grief, and mortality.

-Conversation Project: <https://theconversationproject.org/>

- The Conversation Project is a public engagement initiative with a goal to have every person's wish for end-of-life care expressed and respected.

-Honoring Choices North Dakota website: <https://www.honoringchoicesnd.org/>

- Free online resource for the community to help be successful in the advance care planning and advance directive completion process.

-National Healthcare Decisions Day: <https://theconversationproject.org/nhdd/>

- National Healthcare Decisions Day (NHDD) exists to inspire, educate and empower the public and providers about the importance of advance care planning. NHDD is an initiative to encourage patients to express their wishes regarding healthcare and for providers and facilities to respect those wishes, whatever they may be.

-PREPARE for your care: <https://prepareforyourcare.org/welcome>

- Online education on advance care planning using a step-by-step program with several videos and easy to read documents on how to fill out and complete an advance directive. A great option for patients who are willing to learn about advance directives online instead of in-person with an advance care planning facilitator.

Conversation Tools:

-Go Wish card game: <https://codaalliance.org/go-wish/>

- A deck of 36 cards similar to the traditional playing cards available in multiple languages. These cards help guide participants in identifying wishes, values and preferences and to ensure that those wishes are met. Players are introduced to several phrases representing various activities and wishes. Participants sort cards into important stacks and then rank their top 10 wishes most important to them. These cards can be used in advance care planning conversations, end-of-life trainings or seminars, prior to filling out an advance directive, and upon diagnosis of life-threatening illnesses or after serious accidents.

-Hello Common Practice card game: <https://commonpractice.com/products/hello-game>

- *Hello* is a conversation game that is easy, non-threatening way to start a conversation with your family and friends about what matters most to you. This game includes 5 Questions Booklets 30 Thank-you chips Instruction Sheet Tips for inviting your friends and family to play.

Videos:

<https://www.youtube.com/watch?v=NAInRHicgWs>

- Zubin Damania, MD is a Stanford-trained hospital doctor and host of The ZDoggMD Show. He developed this music video to help describe the difficult journey doctors face during the end-of-life process with their patients.

<https://www.youtube.com/watch?v=TJiY8duVgz0>

- A documentary series on Netflix featuring Dr. Jessica Zitter and her journey with patients in the ICU. This series is filled with real-life patient stories and shows viewers the emotional journeys and end-of-life decisions as doctors, patients, and families face harrowing choices.

-Serious Illness Conversation Guide Demonstration (12 minutes)

https://www.youtube.com/watch?v=fhwa9f5O_U4

- Dr. Jo Paladino demonstrates a 12-min conversation using the Serious Illness Conversation Guide with a COPD patient.

-Serious Illness Care: What if we don't know the prognosis?

<https://www.youtube.com/watch?v=GC-FZ-h6qmQ>

- In this video, Michael Nathan, MD, discusses how to have a serious illness conversation with a patient when you don't know the prognosis or if the patient has an uncertain disease prognosis.

APPENDIX P. EXECUTIVE SUMMARY

Advance Care Planning and Advance Directives: Implementing online education for healthcare providers

Introduction

Two thirds of Americans have not completed an advance care directive and 70 percent of Americans (more than 1.7 million) die of chronic diseases. Approximately 60% of patients stated that they are open to talk about advance care planning (ACP); however, only 21% percent of providers reported talking frequently about matters related to ACP or end-of-life care. This project focused on increasing ACP conversations by implementing an online education webinar for healthcare providers.

Purpose

Advance directives (ADs) summarize goals or preferences for future care regarding life-sustaining treatment and designates a surrogate decision-maker in the event a patient is unable to make healthcare decisions. These legal documents are especially important for providing patient autonomy and allowing people to communicate their medical care preferences to family, friends, and healthcare professionals. Research revealed that providers lack training and education about ADs and ACP conversations, leading to discomfort in skills, confidence, and knowledge about having these essential discussions. The purpose of this practice improvement project was to increase healthcare providers' knowledge of facilitating ACP conversations, and completion of ADs among patients living with a chronic disease, over the age of 65, seen within the primary care setting.

Project Design

A one-hour education webinar and ACP toolkit was posted for voluntary participation among healthcare providers on the NDNPA website over a 3-month period. Education focused on increasing participants' knowledge, confidence, and understanding of ACP and AD, increasing understanding of ACP facilitators, and increasing understanding of the *Serious Illness Conversation Guide*. Likert scale surveys were administered to each participant electronically via Qualtrics pre/post education to measure the effectiveness of the online webinar.

Results & Conclusions

A total of 14 healthcare professionals participated in a one-hour educational webinar posted on the NDNPA website over a three-month time period between September 30, 2021 and December 30, 2021. Confidence Likert scale surveys found the education increased participants' knowledge, confidence, and understanding of ACP and AD. Research findings also found an increase in understanding of the *Serious Illness Conversation Guide* and an increase in both confidence and likeliness of increasing and initiating ACP conversations with patients. Observations of this study supports the benefit and importance of providing ACP education for healthcare providers.

Recommendations

- Follow-up research on how providing ACP and AD education directly affects AD rates among patients over 65 years old, living with chronic disease.
- Continue to provide ACP and AD resources and education for healthcare providers.
- Future education should continue to be led by key stakeholders, subject matter experts, and certified ACP facilitators.
- Continue to provide education online for healthcare providers.
- Choose an implementation website with national representation and accredited for at least 1.0 CME.