

ADDRESSING ADVANCE DIRECTIVES IN RURAL PRIMARY CARE NORTH DAKOTA:
IMPLEMENTING A TOOL FOR HEALTHCARE PROVIDERS

A Dissertation
Submitted to the Graduate Faculty
of the
North Dakota State University
of Agriculture and Applied Science

By

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In Partial Fulfillment of the Requirements
for the Degree of
DOCTOR OF NURSING PRACTICE

Major Department:
Nursing

March 2019

Fargo, North Dakota

North Dakota State University
Graduate School

Title

Addressing Advance Directives in Rural Primary Care North Dakota:
Implementing a Tool for Healthcare Providers

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DOCTOR OF NURSING PRACTICE

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ABSTRACT

Advance directives are legal documents developed as a tool to allow patients to express their wishes and allow healthcare providers to educate and converse with their patients on disease prognosis and management. Advance directives promote shared decision making, thus enhancing quality medical decisions, improving quality of care at end-of-life, and under certain circumstances, even decreasing healthcare costs by refusing aggressive treatment (Garrido, Balboni, Maciejewski, Bao, & Prigerson, 2015; Hickman & Pinto, 2014). In the United States, less than 30% of the population have a completed advance directive (De Vleminck et al., 2013; Dunlay, Swetz, Mueller, Roger, 2012).

The purpose of this project was to increase advance directive rates by 20% at a rural clinic in patients older than 65 years of age with heart failure, stage IV cancer, end-stage renal disease, and/or chronic obstructive pulmonary disease. Advance directive rates and advance care planning facilitator rates were electronically gathered prior to two educational in-services. Educational in-services were given to a total of 24 healthcare professionals, and after each in-service, a confidence Likert scale survey was given to each participant. Four months after the first educational in-service, advance directive rates and advance care planning facilitators rates were electronically gathered.

Four months after the first educational in-service, advance directive rates remained unchanged with 211 of 490 (43%) patients having an advance directive. A total of 11 advance care planning facilitator referrals were made. Confidence Likert scale surveys found the education increased participants' knowledge of advance directives, confidence with initiating advance directive discussions, and likeliness of increasing advance care planning discussions.

ACKNOWLEDGEMENTS

I would not be here without all the support and guidance from several people in my life. I would like to take this time to acknowledge these people that supported and guided me throughout graduate school and completion of my final project.

I would like to thank my committee chair, Dr. Adam Hohman, for his guidance, support, and hours editing my final project. To the remainder of my committee members, Dr. Tina Lundeen, Dr. Mykell Barnacle, and Dr. Daniel Friesner, thank you for your advice and recommendations throughout this project. I would also like to extend a thank you to my liaison, Lois Ustanko, and to my project implementation site for your participation and time.

To my parents, family, and friends who have supported me not only throughout graduate school but, throughout life, I would not be the person I am today without you all in my life and am thankful for each one of you.

To my wife, Rachel, no words can express my gratitude for all of the sacrifices you have made during this process. All the love and support that you have given me while I pursued my dream of becoming a nurse practitioner are greatly appreciated.

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CHAPTER ONE. INTRODUCTION

Advance directives are legal documents allowing the expression of medical care preferences to family members, healthcare professionals, and friends. These documents are especially important because they allow patients to communicate personal life and death choices at a time at which they are unable to express such decisions autonomously (Ache, Harrold, Harris, Dougherty, & Casarett, 2014). Advance directives promote shared decision making, thus enhancing quality medical decisions, improving quality of care at end of life, and under certain circumstances, even decreasing healthcare costs by refusing aggressive treatment (Garrido, Balboni, Maciejewski, Bao, & Prigerson, 2015; Hickman & Pinto, 2014). However, for advance directives to work properly, the appropriate documents must be successfully completed. A systematic review has shown that many people start but do not complete the advance directive, making the end-of-life care decisions even harder for families (Garrido et al., 2015).

Background and Significance

The Patient Self Determination Act (PSDA) of 1991 was created to increase advance directive rates and facilitate advance care planning discussion (Silveira, Wiitala, & Piette, 2014). The PSDA requires that all Medicare-certified healthcare institutions ensure patients know about their right to complete an advance directive. Advance directives were introduced in the PSDA with the hope that adhering to patients' healthcare wishes would empower patients when they are unable to express themselves and make end-of-life comfortable for patients and their families. In addition, advance directives have the potential to prevent unnecessary procedures and thus reduce overall healthcare costs.

However, since the PSDA simply required healthcare institutions to inform patients about their right for advance care planning, the effectiveness of the PSDA is inconsistent. Rather than

educating and discussing advance directives and advance care planning with patients, institutions simply informed patients with a take home handout on advance directives resulting in lack of follow-up on advance directives and advance care planning (Silveira et al., 2014). The inconsistent use of the PSDA resulted in a lack of advance care planning transparency thus poor advance directive rates. Poor advance directive completion rates result in inadequate patient autonomy during end-of-life leading patients to receive a substandard quality of life rather than their honored preferences. Morhaim and Pollack (2013) found patients prefer to spend their last moments of life at home having a better quality of life. However, Morhaim and Pollack (2013) found only 22% of people died at home versus 58% at a hospital and 20% at a nursing home. Furthermore, 30% of Medicare's spending comes in the last year of a person's life with 50% of that money spent on care received in the acute care setting, which shows how ineffective the PSDA has really been (Morhaim & Pollack, 2013).

Problem Statement

The United States faces a growing health care crisis. By 2030 there will be greater than 72.1 million people 65 years and older. The geriatric population has the greatest percent of chronic disease and comorbidity requiring increased medical care and healthcare costs (Morhaim & Pollack, 2013). The common practice for many with chronic disease is to eventually have organ system failures that may require prolonged and possibly aggressive care; the care received may not align with patient wishes. Many patients lack the understanding of their prognosis; however, if providers were to have discussions of their disease prognosis, patients can be better informed allowing for individualized end-of-life treatment.

Advance directives were developed as a tool to allow patients to express their wishes and allow healthcare providers to educate and converse with their patients on disease prognosis and

management. However, despite the enactment of PSDA and an abundance of literature supporting advance directives, many patients still do not have a directive. In the United States, less than 30% of the population have a completed advance directive (De Vleminck et al., 2013; Dunlay, Swetz, Mueller, Roger, 2012). According to the project's participating institution's director of faith community nursing and health ministry (DFCNHM), the pre-project rate of advance directive completion was roughly 50% for all adult patients at the healthcare institution. The details of how well written or comprehensive the completed advance directives are is unknown. The institution originally had a goal rate of 80% advance directive completion for patients 65 years and older with chronic obstructive pulmonary disease (COPD), heart failure (HF), stage IV cancers, and end-stage renal disease (ESRD) completion by July 2018. However, the goal was considered too steep and changed to a rate of 50% advance directive completion for the same selected population.

CHAPTER TWO. LITERATURE REVIEW

The databases searched were the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, Cochrane Database of Systemic Reviews (CDSR), and Medline. The inclusion criteria for the databases included the terms: advance directive, end-of-life, costs, primary care, barriers, and geriatrics. Due to the institution's goal regarding patients 65 years and older having COPD, HF, stage IV cancers, and ESRD, database searches for advance directives were further narrowed to include ages 65 and older, COPD, HF, stage IV cancer, ESRD, academic journals, the geographic location of USA, and years 2008 to 2018. The Cochrane database search with the terms only advance directive, costs, and end-of-life resulted in seven trials. All but one of the Cochrane trials were at least 15 years old. Multiple research articles were reviewed, and most findings of the research were similar to the findings, which will be described in the literature review.

Advance Directives

The literature review resulted in a large amount of literature supporting the benefits of advance directives for the patient, the patient's family and friends, providers, and economic burden. A systematic review of randomized controlled trials found that advance care planning decreased hospitalization, decreased use of healthcare resources, and increased family satisfaction; however, Weathers et al. (2016) did not state exact numbers to the findings regarding increases and decreases. Silveira's, et al. (2014) study reported healthcare costs savings with evidence that supports advance directives saving Medicare dollars; however, Silveira et al. (2014) did not state an exact dollar amount related to the findings. Garrido et al. (2015) also reported that advance directives decreased heroic interventions (i.e. doing everything possible to remain alive) at end-of-life. Ache et al. (2014) noted hospice patients with an advance directive

live longer and were more likely to die at home or in a nursing home rather than in an inpatient facility. The use of more hospice services resulted in patients living longer and allowed families more time to anticipate and plan for the patient's death (Ache et al., 2014). Silveira et al. (2014) found advance directive completion has increased and deaths in hospitals, compared to outpatient facilities, have decreased (Silveira et al., 2014). Advance directives also aided in less family stress and decision making for end of life care of a loved one and provided better communication between families and the health care team (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007; Weathers et al., 2016). In 2012, the National Guideline Clearinghouse endorsed that all adults: have the right to express and decide what to be done with their bodies, are presumed capable decision makers until proven otherwise, and should be approached about their treatment preferences and wishes; therefore, patients should be asked about advance directives.

While there are great benefits of a completed advance directive, there lacks completion of advance directives especially in patients with serious illnesses. In the United States, less than 30% of the population have a completed advance directive, and patients with chronic disease, such as HF, COPD, ESRD, stage IV cancers, have only slightly higher completion rates (De Vleminck et al., 2013; Dunlay, Dunlay, Swetz, Mueller, Roger et al., 2012). Seventy percent of United States deaths are from chronic disease with 62% of these deaths being from heart disease, cancer, stroke, COPD, and diabetes (Benson & Aldrich, 2012). Advance directive completion rates for this patient populations remains low while patient mortality is high and there is an increased chance of undesirable hospitalization in these patient populations (Dunlay et al., 2012; Butler et al., 2015).

The following are findings of advance directive completion rates for heart failure, chronic obstructive pulmonary disorder, cancer, and end stage renal disease patients:

- While HF patients have a five-year mortality rate, a study involving 24,291 in-patient HF patients found 12.7% had a completed advance directive (Dunlay et al., 2012; Butler et al., 2015)
- 15% of 1,186 patients with pancreatic cancer were found to have a completed advance directive (Michael et al., 2013)
- Of 206,437 do-not-resuscitate (DNR) directives of cancer patients, 53% of the DNR directives signed by patients and 43% of the DNR directive signed by surrogates were done the day of the patient's death (Michael et al., 2013)
- 49% of 808 ESRD/dialysis patients with an average age of 68.6 were found to have a completed advance directive (Feely, Hildebrandt, Edakkanambeth, & Mueller, 2016)
- Of 9,164 patient-proxy-exit interviews conducted, patients with a diagnosis of lung disease or cancer had significantly higher odds of completing an advance directive within three months before death (Enguidanos & Ailshire, 2017)
- Patients completing an advance directive within the last three months of life wanted more aggressive/prolonging of life care (Enguidanos & Ailshire, 2017)
- Patients associated with significant higher chances of having a documented advance directive included: older age, female sex, Caucasian race, higher socioeconomic status, higher risk for adverse in-hospital outcomes, length of stay greater than or equal to five days, hospice discharge, palliative care consultation, and a DNR order (Butler et al., 2015; Feely et al., 2016)

Lastly, although substantial evidence supports the benefit of advance directives for patients and healthcare, certain circumstances do exist in which advance directives can hinder end-of-life care and place burden on decision makers. These circumstances include patients with

new cognitive impairment, patients with mental disability, or patients with poorly worded advance directives (James, Donna, Thomas, Noelle, & Nancy, 2012; Thompson, Barbour, & Schwartz, 2003). The validity of advance directives completed with cognitive or mental disabilities can be questioned; however, this is inconsistently assessed across clinicians (James et al., 2012). Circumstances where advance directives exist in the above patient population can cause treatment misunderstandings resulting in paradoxical over interventions or delayed care (Thompson et al., 2003).

Barriers

With change and implementation of practice change in healthcare, barriers to advanced directive completion will always be found. Both patient and healthcare barriers prevent adequate completion of advance directives. However, evidence found that providers and system barriers are more of a problem to advance directive completion than patient barriers (De Vleminck et al., 2013). De Vleminck et al. (2013) also found that patient barriers are harder to control as opposed to healthcare barriers. Provider and system barriers include time, knowledge, biases, leadership, reimbursement, electronic medical records, stress, anxiety, unknown disease prognosis, and communication (Conelius, 2010; De Vleminck et al., 2013).

There is uncertainty and a knowledge barrier of providers regarding how to discuss advance directives and advance care planning. Sixty to eighty percent of patients stated they are open to discussing advance directives; however, some providers believe patients should initiate the discussion (Conelius, 2010; De Vleminck et al., 2013). These providers believed if patients initiate advance care planning discussion, it means the patients have accepted their terminal illness (De Vleminck et al., 2013). Dube, McCarron, and Nannini (2015) found 65% of healthcare providers reported advance directive discussion with their patients at least some of the

time although 39% of healthcare providers reported not knowing a federal mandate requiring advance directives discussion with Medicare patients exists (Dube et al., 2015). Even though there is a barrier of provider uncertainty and knowledge of advance directives and advance care planning, 79% of healthcare providers felt additional advance directive education would increase advance care planning discussion with patients.

Time is the largest system barrier for advance directive discussion and completion. An advance directive discussion takes extensive time due to the sensitivity of the topic, exploring patient spirituality, discussing prognoses, and providing patient education (Dube et al., 2015). Advance directive discussions take time; however, De Vleminck et al. (2013) found that the average time healthcare providers spend discussing advance directives with patients was only 5.6 minutes and two-thirds of that time the provider is the one who is speaking.

Healthcare facilities should increase resources that aid in decreasing healthcare workers' biases and emotional distress and increase patient prognosis discussion, time spent discussing advance care planning and directives, and education of advance care planning and directives (Chong-Wen, Chan, & Chow, 2017; Courtright, 2017). Healthcare facilities are taking measures to train current employees, to include nurses, providers, and social workers, to become advance care planning facilitators. Advance care planning facilitators are certified in advance care planning, which allows them to have the knowledge and skills to facilitate advance directive discussion (Respecting Choices, n.d.). Schellinger, Sidebottom, and Briggs (2011) found 94.3% of 1,894 heart failure patients who were referred to advance care planning facilitators completed a directive. Schellinger's et al. (2011) finding is thought to be because of the study's disease specific advance care planning intervention, which used referrals to facilitators to discuss advance care planning with heart failure patients. It was also found patients that engaged with

advance care planning facilitators were more likely to use hospice (Schellinger et al., 2011). However, for advance care planning facilitators to participate in patient advance care planning, a referral from the patient's provider or hospital discharge provider inferring the patient wants or the patient's condition warrants advance care planning discussion is needed.

Healthcare facilities have tried offering more options for patient in completing advance directives. However, Courtright (2017) found more patient options did not increase advance directive completion rates and has made advance directives more difficult for patients to complete. Instead of incorporating patient options, healthcare facilities are creating system methods for increasing advance directive completion. Referrals to advance directive facilitators and incorporating advance care planning discussions notes into electronic medical records (EMR) are some examples of system methods implementation. More congruent advance directive discussions occur with EMR use due to frontline healthcare workers documenting and reviewing advance care planning discussion (Dube, McCarron, & Nannini, 2015; Hagen et al., 2015).

Facilitators

To facilitate advance directive and advance care planning discussion, patients want a trustful provider and clinical setting, and the primary care setting is found to be the best setting due to repeated patient contact and an established trustful relationship between the patient and provider (Dube et al., 2015). Conelius (2010) and O'Sullivan, Mailo, Angeles, and Agarwal (2015) found 56% of patients would prefer to discuss advance directives with their family providers at a clinic office visit rather than any other healthcare setting due to comfort from an established relationship. O'Sullivan et al. (2015) also found patients would prefer providers to initiate advance care planning and directive discussion as opposed to themselves initiating the

conversation. As discussed prior, provider barriers still exist in preventing advance directives from being completed; however, evidence has found nurses and social workers to be great facilitators in advance directive and advance care planning discussion.

There are many professionals in healthcare, including nurses that can facilitate completion of advance directives and advance care planning with proper education and guidance. Sixty-seven percent of healthcare staff believe nurses would be the most likely to initiate advance directive discussion, and a systematic meta-synthesis review on qualitative studies showed nurses can be more active in the patient's completion of advance directives (Conelius, 2010; Ke, Huang, O'Connor, & Lee, 2015). Nurses report that advance directives have more advantages than disadvantages, and nurses are well positioned to engage in advance directive conversations with patients (Ke et al., 2015). Barriers to advance directive completion perceived by nurses include older people, environment, time, culture, cost, and knowledge (Ke et al., 2015). Even though nurses can be great facilitators, advance care planning and advance directive education is needed for nurses because over 50% of nurses from an acute care setting did not fully understand advance directives (Conelius, 2010).

Just as nurses, social workers with the proper education and guidance can facilitate advance directives and advance care planning. Stein and Fineberg (2013) support social workers being qualified for aide in advance directive discussion and education. Social workers pay attention to diversity, social inequality, and are equipped to facilitate and promote education and understanding (Stein & Fineberg, 2013). Social workers are capable of being an educator, promotor, interpreter, and advocate for patients seeking advance directives (Chong-Wen et al., 2017). Despite being well-suited for the responsibility, Chong-Wen et al. (2017) found that social workers only get involved with advance directives and end-of-life discussions when

referred to by providers or nurses. Social workers are capable advance directive facilitators because of their knowledge base through bachelor and master degree programs, training in psychosocial care, and due to the ethical standards of their profession (Stein & Fineberg, 2013). Although social workers may not possess enough knowledge of life-sustaining measures, with the proper education and guidance they can facilitate advance directives and advance care planning (Chong-Wen et al., 2017).

Serious Illness Conversation Guide

The *Serious Illness Conversation Guide* is a structured set of questions focused on eight elements gathered from the best practice in palliative care (Araidne Labs, n.d.) and used as a guide for the *Serious Illness Care Program*. The *Serious Illness Conversation Guide* consists of eight elements for discussion: understanding, information preferences, prognosis, goals, fears/worries, function, trade-offs, and family (see Appendix A). The *Serious Illness Care Program* was created to address the challenges patients, families, friends, and healthcare teams face during a time of serious life-threatening illness (Araidne Labs, n.d.). The guide allows clinicians to engage and lead important conversations involving what is important to the patient. The goal of the *Serious Illness Care Program* is to learn and express the patient's goals, values, and priorities in order to inform their future care (Araidne Labs, n.d.). Ideally, the program and conversation lead by the *Serious Illness Conversation Guide* will guide clinicians and loved ones in a direction of care during a time of a patient's serious illness.

Although evidence using the *Serious Illness Conversation Guide* and *Serious Illness Care Program* is limited due to its recent implementation, there are preliminary results suggesting that the guide and program benefit patients and providers during times of serious illness. Ariadne Labs (n.d.) states, "preliminary results show serious illness conversations that happened in the

trial earlier in the illness, were of better quality and less anxiety and depression.” In the primary care setting, the program and guide lead to better and more frequent conversations, in fact the average conversation with a patient on serious illness was 22 minutes (Ariadne Labs, n.d.). Providers were also satisfied with the guide and program giving it a 4.7/5 satisfaction rating (Ariadne Labs, n.d.). The *Serious Illness Conversation Guide* and *Serious Illness Care Program* were beneficial in different patient settings and populations such as the emergency surgery setting, chronic critical illness setting, and in African American patients and families (Ariadne Labs, n.d.). Again, the literature review resulted in a large amount of literature supporting the benefits of advance directives for the patient, the patient’s family and friends, providers, and economic burden.

Theoretical Framework

Evidence based models and nursing theories can be used in the process of practice change. Theories can summarize existing knowledge, give meaning to empirical findings, provide structure and framework, and offer knowledge and means of data collection for nursing practice (Fain, 2015). Evidence based models guide and assist clinicians in the process of clinical change (Melnik & Fineout-Overholt, 2015). Merle Mishel’s middle range theory, *Uncertainty of Illness*, was chosen to guide this project. The Iowa Model of Evidence-Based Practice to Promote Quality Care was chosen as the model for project planning and is discussed in chapter three.

Mishel’s Uncertainty of Illness Theory

Mishel’s *Uncertainty of Illness Theory* works well in this advance directive project because of the project’s focus on patients with chronic diseases during end-of-life. During end-of-life, patients confront uncertainty caused by either a new diagnosis, a poor prognosis, or the

uncertainty of completing an advance directive. The *Uncertainty of Illness Theory* defines uncertainty as a cognitive state created when an individual cannot categorize an illness event, predict outcomes because of insufficient cues, or assign values to objects and events (Cypress, 2016). The theory was designed in the 1980's to assist in the healthcare practice of adults and children with cancer (Cypress, 2016).

Neville (2013) states “Mishel’s theory addresses three components: the antecedents of uncertainty, impaired cognitive appraisal, and coping with uncertainty in illness” (see Figure 1). The primary antecedent, the stimulus frame, can be influenced by both cognitive capacity and structure providers (Neville, 2003). Cognitive capacity and structure providers are both involved in advance care planning and advance directive completion. During their end of life, patient cognitive capacity can be impaired by physiologic, psychologic, or environmental factors, so the importance of an advance directive is vast (Neville, 2003). Structure providers are the resources available to an individual, and many times healthcare professionals, such as nurse practitioners or facilitators, are these professionals (Neville, 2003). Nurse practitioners and providers can reduce uncertainty for the individual during end-of-life and provide tools of assistance, such as advance directives.

The *Uncertainty of Illness Theory*’s three components of uncertainty, appraisal, and coping closely relate and apply to the *Serious Illness Conversation Guide*’s eight elements understanding, information preferences, prognosis, goals, fears/worries, function, trade-offs, and family. The *Serious Illness Conversation Guide* is a tool that clinicians can use to guide advance care planning and directive conversation. Discussing the prognosis, goals, fears/worries, and understanding of the patient’s chronic disease will alleviate the uncertainty the patient may have and aid in advance directive completion.

Lastly, providers not only relate to the *Uncertainty of Illness Theory* by being a structure for patients, providers can also relate to the theory by having uncertainty in themselves. The literature review described providers having:

- Uncertainty in patient’s prognosis
- Uncertainty in advance directive or advance care planning discussion
- Uncertainty in advance directive or advance care planning knowledge

The *Uncertainty of Illness Theory* can be applied to the provider barriers of uncertainty involved in advance directive completion identified in the literature review. Although providers may not have cognitive capacities that patient’s with serious illnesses have, structure providers are available for their aid in uncertainty of advance directive and advance care planning discussion. For example, advance care planning facilitators can act as structure providers by providing education for providers. Providers may see their uncertainties, identified in the literature, as a danger or opportunity. Whether viewed as a danger or opportunity, the provider must adapt. Through different applications, the *Uncertainty of Illness Theory* can be applied to both providers and patients facing uncertainty.

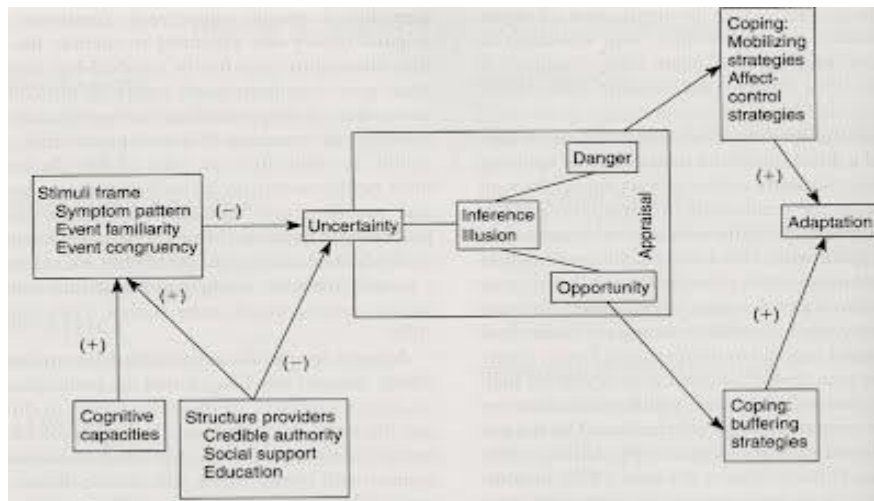


Figure 1. Uncertainty of Illness Theoretical Model (Mishel, n.d.)

CHAPTER THREE. PROJECT DESIGN AND OBJECTIVES

Objectives

1. Healthcare professionals will understand the institution's advance care planning initiatives (i.e. facilitators, conversations, and electronic referrals) by having five advance care planning facilitator referrals four months after the one-hour education in-service.
2. Healthcare professionals' perceived knowledge, confidence, and understanding of advance directive benefits will increase by attending a one-hour education in-service.
3. Healthcare professionals will understand how to use the *Serious Illness Conversation Guide* and its application to initiate advance care planning discussion.
4. The clinic will have a 20% increase in advance directive completion in patients with a diagnosis of chronic obstructive pulmonary disease, heart failure, stage IV cancers, and/or chronic kidney disease four months after the one-hour education in-service.

Design

Evidence-Based Model for Change

The Iowa Model of Evidence-Based Practice to Promote Quality Care guided project planning. The model has wide applicability and ease of use between multidisciplinary health care teams (Melnyk & Fineout-Overholt, 2015). The first step of the model is to identify questions or triggers relating from a clinical problem, current practice or new knowledge (Melnyk & Fineout-Overholt, 2015). The project's institution of implementation had a desire to change their advance directive practice and created a goal of 80% completion rate of advance directive in patients older than 65 years of age with HF, stage IV cancer, ESRD and/or COPD by July 2018. However, the institution considered the goal too high, therefore the goal was lowered to a 50%

completion rate by July 2018 for the same patient population. The literature review findings and the findings from the institution's previous advance care planning intervention findings were used to direct the project's intervention.

The second step of the model is making the identified problem or current practice a priority for change at the healthcare institution (Melnik & Fineout-Overholt, 2015). A rural clinic of the healthcare institution, which is where the co-investigator has completed clinical rotations, was selected as the project's site. At the participating healthcare institution, increasing advance directive rates was a priority. As stated above, the institution's advance directive goal was to reach 50% completion by July 2018 for patients older than 65 years of age with either HF, stage IV cancer, ESRD, and/or COPD. The institution's current advance directive rates were 5-10% below the goal. The third step of the model is forming a team (Melnik & Fineout-Overholt, 2015). Prior to the project, the participating institution already had faculty/team members in place working to improve advance directive rates. The institution was utilizing its palliative care team along with providers, social workers, and nurses to become certified advance care planning facilitators. The institution had implemented a two-step certification program that educated and trained facilitators in advance care planning and directive completion. The institution had previously implemented an electronic clinical pathway allowing providers to refer patients to advance care planning facilitators for advance care planning discussions and advance directive completion. Trained facilitators and clinical pathways were in place at the institution's rural clinic prior to this project, so the project's intervention was to provide education to the providers regarding the institution's advance directive goal, the facilitator referral process, and the clinic's advance care planning facilitator.

The fourth step of the model is having a sufficient base (Melnyk & Fineout-Overholt, 2015). As discussed earlier, there is an abundance of literature supporting the benefits of advance directives and the use of the *Serious of Illness Conversation Guide*. The literature review supported implementation of an advanced directive pilot intervention at the selected institution's rural clinic. The pilot intervention consisted of outcomes, evidenced-based provider education, evaluation of the process and outcomes, and recommended practice modifications for advance directive discussions.

The fifth step of the model is piloting a practice change with interventions that will result in outcomes in a controlled environment (Melnyk & Fineout-Overholt, 2015). The quality improvement project initial goal was to increase advance directive completion rates through practice change of the site's ten family medicine providers. The initial practice changes interventions planned to provided education and copies of *Serious Illness Conversation Guide* to the site's ten family medicine providers. However, after zero providers attended the first education in-service, all healthcare professionals, to include nursing and other ancillary staff, were included in the quality improvement project.

The sixth step of the model is evaluation of the data gained from the practice change interventions and decision of adopting or modifying the intervention for future practice (Melnyk & Fineout-Overholt, 2015). Data used to evaluate the project intervention were advance directive rates, surveys results, and advance care planning facilitator referral rates. Advance directive rates were gathered electronically prior, mid, and after the practice change interventions for the patient population 65 years and older with either a diagnosis of HF, COPD, stage IV cancer, and/or ESRD. Surveys were distributed at the educational sessions to all participating healthcare professionals and analyzed by the co-investigator, a quality improvement advisor from the

institution, and a statistician from North Dakota State University. Advance care planning facilitator referral rates were gathered electronically after the practice change interventions. Recommendations for future practice was given to the institution; however, it was the institution's decision of adopting or modifying the intervention for future practice.

The seventh step of the model is dissemination of the project's results (Melnyk & Fineout-Overholt, 2015). Dissemination was completed with the institution at a poster symposium along with students in the North Dakota State University Doctor of Nursing Practice program through a lecture.

Pre-Project Interventions and Project Site

Pre-project, the institution had implemented a variety of interventions at various pilot sites during the institution's "phases" of initiative to increase advance directive rates. Phase one and two of the institution's advance directive initiative was known; however, future phases were unknown. Phase one and two interventions included:

- Identification of clinic implementation sites
- Implementation of huddles
- Education of advance care planning facilitators
- Implementation of advance directives in the "Health Maintenance" section of patient's 65 years and older EMR
- Creation of an electronic clinical referral process

Daily morning provider/nurse huddles included identification of patients 65 years and older that had COPD, HF, stage IV cancer, and/or ESRD with appointments that day, and whether they had advance directives in their electronic medical record. Implementation of huddles resulted in improvement of advance directive rates after six to nine months; however, the exact increase of

advance directive rates was not analyzed for this project. Registered nurses and/or social workers from the participating sites were trained and certified as advance care planning facilitators through completion of online modules and attendance of an in-person eight-hour course. For patients who met the institution’s advance directive population of focus, an advance directive tab was added in the “health maintenance” section of the patient’s EMR (see Figure 2).

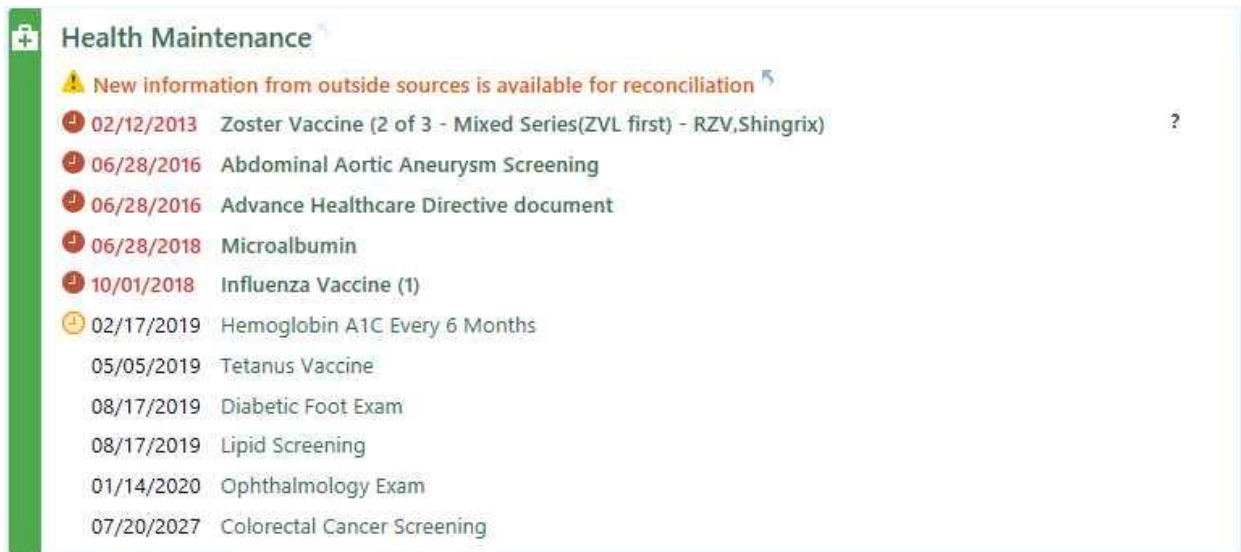


Figure 2. Health Maintenance

An electronic clinical pathway was created for creating and receiving advance directive referrals and charting (see Figure 3). The implementation of facilitators and the electronic pathway were underway as this project was being implemented, so referral rates were not analyzed prior to the project’s implementation.

Figure 3. Electronic Referral Pathway

The rural community has a population of 11,152; however, the clinic’s number of patients meeting the project’s required patient population was unknown (Suburban Stats, 2018). The institution had selected older than 65 years of age with HF, stage IV cancer, ESRD, and/or COPD as the project target population. The institution had an initial goal of 80% advance directive completion rates by July 2018 for the selected population; however, the institution considered the goal too high, therefore the goal was lowered to a 50% completion rate by July 2018 for the same patient population.

The project’s rural clinic was selected as the implementation site because of previous stakeholder buy-in, the clinic’s involvement in phase two of the institution’s advance care planning initiative, and the site had one licensed social worker who was certified in advance care planning. While various interventions had been implemented at the selected institution prior to this project, the initial goal of the project was to provide a one-hour educational in-service discussing the institution’s advance care planning initiative, benefits of advance directive completion, and a guide to engage patients with serious illnesses in end-of-life discussion and

disease management. The in-service also included education on the *Serious Illness Conversation Guide*, electronic clinical pathways for making advance care planning facilitator referrals, and coding capabilities. Approval for use of the *Serious Illness Conversation Guide* for the project was received from Ariadne Labs (see Appendix E).

Institutional Need

The institution had a known need of increasing advance directive rates and made it a priority to increase its advance directive rates. The institution selected patients 65 years and older with COPD, HF, stage IV cancer, and/or ESRD as the project's population. The institution's initial goal was an 80% advance directive completion rates by July 2018 for patients older than 65 years of age with HF, stage IV cancer, ESRD, and/or COPD. However, the institution considered the goal too high, therefore the goal was lowered to a 50% completion rate by July 2018 for the same patient population. The institution approached the co-investigator about completing a practice improvement project to increase advance directive rates.

The institution had not completed needs assessments with its various implementations at the selected site as the institution based their advance care planning implementations off literature findings and previous advance care planning implementation findings. For this project, the literature review and the institution's previous advance care planning intervention findings guided the project implementation. In the literature review, findings of education, confidence, and time were barriers for provider's in assisting patients with the completion of advance directives. Findings from the implementation of huddles and facilitators with the institution revealed nurses and social workers aided in the increase of having advance care planning conversations. Identifying patients who are at need of advance care planning will aide in increasing conversations and advance directive rates. The project's education in-service content

and discussion stressed the importance of having advance care planning conversations with HF patients. Heart failure patients at the project's site were found to be the largest patient population meeting the project's requirements and had the lowest advance directive completion rate.

Education Content Development

During the development of the project, the co-investigator met with an advance care planning facilitator and completed an advance directive to better understand the process of completing a directive. The co-investigator spent between one hour with the facilitator discussing wishes and treatment goals if something were to happen where the co-investigator could no longer voice his wishes. Although the co-investigator does not have a condition that meets the requirement of this project's target population, the co-investigator experienced first-hand the time required to have difficult discussions necessary to complete an advance directive.

In addition, the co-investigator became a certified advance care planning facilitator by completing the Last Steps Advance Care Planning Facilitator online modules and attending an eight-hour Last Steps Advance Care Planning Facilitator class at the institution (see Appendix G). The class was led by an experienced certified advance care planning facilitator. The class 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 class and modules cost were \$250; however, the institution's Advance Care Planning Department covered the cost.

The development of the educational in-service was accomplished through 10 meetings which occurred in-person, via email, or speaking via Skype or telephone with the institution's DFCNHM. The meetings were needed to practice advance care planning discussion and formulate the educational in-service's content. The educational in-service content also came

from similar evidence-based presentations given prior by the institution's DFCNHM to providers and nursing staff. The co-investigator also integrated evidence from the literature review and Ariadne Labs to complete the in-service educational content. Evidence from the literature review and Ariadne Labs consisted of content related to:

- Barriers
- Definitions of advance directives and advance care planning
- Average time a provider may spend discussing advance care planning with a patient
- *Serious Illness Conversation Guide* improving conversations
- Prognosis phrases
- Video of a provider demonstrating an advance care planning conversation using the *Serious Illness Conversation Guide*

A geriatric provider employed by the institution was shadowed by the co-investigator to gain insight and experience firsthand about advance care planning conversations. The geriatric provider was an expert in the use of the *Serious Illness Conversation Guide* and has helped implement the use of the *Serious Illness Care Program* at a different institution.

Education-Inservice

In an attempt to increase provider attendance to the one-hour educational in-service, the institution supplied a meal for the participating healthcare professionals. The meal was paid for by the institution's advance care planning department at an unknown cost. The institution's clinic director emailed the providers one month before and the morning of the in-services. The co-investigator and the institution's DFCNHM, who is a certified advance care planning facilitator, provided the education in-services. The educational in-service consisted of a PowerPoint presentation regarding advance directives and a review of the *Serious Illness Conversation*

Guide. Copies of the PowerPoint in-service education content and copies of the *Serious Illness Conversation Guide* were printed by the advance care planning department at an unknown cost and given to the participants at the beginning of the in-service.

After the educational in-services, hard-copy surveys were administered to the attending participants and collected by the co-investigator. The survey evaluated participant demographics including age, gender, type of staff, and years of practice. The survey questions evaluated pre and post education knowledge, benefits, confidence, and initiation of advance directives and advance care planning conversations (see Appendix B). The survey was developed using content from Dr. Mary Jezewski's Knowledge, Attitudinal, Experiential Survey on Advance Directive (KAESAD) instrument, the institution's previous advance care planning implementations, and evidence from the literature review. Approval was obtained from Dr. Mary Jezewski for use of the KAESAD instrument in this project. A copy of the instrument, permission to use the instrument, and the instrument's validity was provided in an email (see Appendix C). The instrument's reliability and validity were established by pilot test/retest and was reviewed by an expert panel consisting of disciplines from nursing, medicine, law, and bioethics. The instrument had been used in previous oncology, intensive-care, and emergency department related studies. The instrument consists of eight principal components and 115 items. Due to the length of the KAESAD instrument and for the purpose of this project's survey, only select content was used from the instrument. The content selected from the instrument was determined based on the project's objectives.

Serious Illness Conversation Guide

Serious Illness Conversation Guides were laminated for the clinic's providers and nursing staff as an initiative to trigger advance directive discussions and increase advance

directive rates. Each provider was given a laminated pocket copy of the *Serious Illness Conversation Guide* and a larger laminated *Serious Illness Conversation Guide* to hang in their exam rooms. These copies were printed and paid for by the institution.

Resources

The largest resources needed for the project included participants' time with the education in-service and the time of coordination of the project with the institution's DFCNHM. The institution's informatics team was needed to gather advance directive and referral data prior to the education in-service and at the four-month mark. *Serious Illness Conversation Guide* handouts and lamination for the education in-service, provider's pockets, and provider rooms were printed by the institution at an unknown cost. An incentive meal was provided by the institution's Advance Care Planning Department at an unknown cost. The co-investigator attended the Last Steps Advance Care Planning Facilitator course which was paid for by the institution. For institutional employees to complete the course, the cost is \$160, and for non-institutional employees to complete the course, the cost is \$250.

Protection of Human Subjects

Participants of the dissertation project included the institution's ten family medicine providers, other healthcare professionals at the project site, and retrospective data gathering of advance directive data from patient charts. Each provider sees approximately 10 to 30 patients from across the life span per day. Data regarding how many of these daily patients met the criteria for the project was unattainable. However, the project participants did not involve children.

Implied consent of the participants was obtained by voluntary attendance of the in-service and voluntary completion of the survey. At the time of implied consent, participants were

informed of the benefits of the project which included improving advance directive completion rates, improving personal knowledge about advance directives, and improving advance care planning discussions. Participants could withdraw from participation of the in-service education and survey at any time. There was little risk for participating providers; however, emotional distress could be a minimal potential effect due to the nature of advance directive conversations. Participants' confidentiality was lost while attending the in-services as they were all in the same room; however, all data was gathered without participant identifiers and reported as cohort data. All participant data gathered was stored on a password protected and facial recognition computer with only the co-investigator's accessibility.

Institutional Review Board Approval

An Institutional Review Board (IRB) approval by North Dakota State University was obtained. Approval for protocol #PH19008 was received from North Dakota State University's IRB board (see Appendix F). The participating institution decided IRB approval was not needed from their institution.

CHAPTER FOUR. EVALUATION

Evaluation of the evidence-based practice improvement project consisted of EMR data and survey analysis by the co-investigator, a quality improvement advisor from the institution, and a statistician from North Dakota State University to decide whether the project's four objectives were met.

Evaluation of Objective One

Healthcare professionals will understand the institution's advance care planning initiatives (i.e. facilitators, conversations, and electronic referrals) by having five advance care planning facilitator referrals four months after the one-hour educational in-service. Objective one was evaluated by electronically extracting advance care planning facilitator referral rates four months after the education in-service. Objective one was considered met if there were greater than five referrals.

Evaluation of Objective Two

Healthcare professionals' perceived knowledge, confidence, and understanding of advance directive benefits will increase by attending a one-hour education in-service. Objective two was considered met if all healthcare professionals answered strongly agree or somewhat agree to all post-education related questions. Objective two was evaluated by administering the confidence Likert scale survey post-educational in-services (see Appendix B). The survey was a confidence Likert scale survey that used strongly agree, somewhat agree, neutral, somewhat disagree, or strongly disagree to answer the questions related to the education content. The Likert scale survey 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, neutral 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.

Survey questions that evaluated objective two were:

- Question five, “prior to the education in-service, I had sufficient knowledge on advance directives.”
- Question six, “after the education in-service, I have sufficient knowledge on advance directives.”
- Question seven, “prior to the education in-service, I knew the benefits of advance directives.”
- Question eight, “after the education in-service, I know the benefits of advance directives.”
- Question nine, “prior to the education in-service, I felt confident discussing advance directives and advance care planning with patients.”
- Question ten, “after the education in-service, I feel confident discussing advance direct and advance care planning with patients.”
- Question fifteen, “is there anything else related to advance directives and advance care planning you wished we discussed in the education in-service?”

Evaluation of Objective Three

Healthcare professionals will understand how to use the *Serious Illness Conversation Guide* and its application to initiate advance care planning discussion. Objective three was considered met if all healthcare professionals answered strongly agree or somewhat agree to all post-education related questions. Objective three was evaluated by administering the confidence Likert scale survey post-educational in-services (see Appendix B). The survey was a confidence

Likert scale survey that used strongly agree, somewhat agree, neutral, somewhat disagree, or strongly disagree to answer the questions related to the education content. The Likert scale survey 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, neutral 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.

Survey questions that evaluated objective three were:

- Question eleven, “prior to the education in-service, I had advance care planning discussions with patients.”
- Question twelve, “after the education in-service, I will increase advance care planning discussions with patients.”
- Question thirteen, “prior to the education in-service, I felt confidence initiating advance directive discussion.”
- Question fourteen, “after the education in-service, I feel confident initiating advance directive discussion.”

Evaluation of Objective Four

The clinic will have a 20% increase in advance directive completion in the patient population with a diagnosis of chronic obstructive pulmonary disease, heart failure, stage IV cancers, and/or chronic kidney disease four months after the one-hour education in-service. Objective four was evaluated by electronically extracting advance directive rates for the patient population 65 years and older with either a diagnosis of HF, COPD, stage IV cancer, and/or

ESRD. The rates were gathered prior, mid, and post-project, and objective four was considered met if there was a greater than 20% increase in post-project rates compared to pre-project rates.

CHAPTER FIVE. RESULTS

The initial one-hour education in-service was conducted on August 30, 2018 at the rural clinic with 13 participants. Of these participants zero providers were in attendance. The clinic supervisor reported that two providers were on vacation, two providers are part-time, and that an hour time slot was not blocked off for attendance of the education in-service. Due to the attendance of zero providers, all participating healthcare professionals, to include nursing and other ancillary staff, were included in the survey responses and data analysis.

After discussion with the project's committee chair and the clinic's supervisor, a second education in-service was given on October 30, 2018 during the clinic's mandatory monthly provider meeting. However, there was a limited time frame of fifteen minutes at the October 30, 2018 provider meeting in which the education time had to be completed due to time constraints of the provider meeting. The same education content used in the August 30, 2018 education in-service was used in the October 30, 2018 education in-service (see Appendix H). However, during the October 30, 2018 in-service elaboration on select content was shortened as compared to the one-hour in-service. Content that was not elaborated on included the definitions of advance directives and advance care planning, phrases used when discussing prognosis, and heart failure. The video demonstrating a conversation between a provider and a patient using the *Serious Illness Conversation Guide* was also not included in the October 30, 2018 in-service. In addition to the second education in-service, a twelve-minute voice over PowerPoint of the content used during the in-services was developed and sent to the clinic supervisor for distribution to the providers. Lastly, follow-up interviews with providers on their use of *Serious Illness Conversation Guide* was not done due to zero providers attending the August 30, 2018

education in-service. The only individual follow-up that occurred was with the site’s advance care planning facilitator.

Demographic of Participants

The developed project’s confidence Likert scale survey was given in-person to a total of 24 participating staff members combined after the education in-services on August 30, 2018 and October 30, 2018. Total response rate of the survey was 87.5%. Figure 4 contains the demographic results.

	August 30, 2018 In-Service	October 30, 2018 In- Service	Total In-services
Type of Participant			
Physicians	0	5	5
Nurse Practitioners	0	1	1
Physician Assistants	0	2	2
Licensed Clinical Social Workers	0	1	1
Registered Nurses	4	0	4
Licensed Practical Nurses	5	0	5
Licensed Social Workers	1	0	1
Receptionist Supervisors	1	0	1
Not Applicable Participants	0	1	1
Total Participants:	11	10	21
Sex of Participant			
Males	0	4	4
Females	11	6	17
Total Participants	11	10	21
Age of Participant			
Age 60-69	1	2	3
Age 50-59	1	4	5
Age 40-49	5	1	6
Age 30-39	2	2	4
Age 25-29	2	1	3
Total Participants	11	10	21
Participants’ Years of Experience			
Greater 12 Years’ Experience	8	6	14
Between 10-12 Years’ Experience	1	1	2
Between 7-9 Years’ Experience	2	1	3
Between 4-6 Years’ Experience	0	1	1
Between 1-3 Years’ Experience	0	1	1
Total Participants	11	10	21

Figure 4. Demographics

Survey Results

Of the eleven participants on August 30, 2018, eleven participants (100%) completed the surveys. A North Dakota State University statistician determined inferential statistical analysis was unable to be completed on the survey, so only descriptive data analysis was completed with the survey. Figure 5 contains the survey (see Appendix B) results from the August 30, 2018 education in-service.

August 30, 2018 In-Service Survey Results							
Question	Strongly Agree (5)	Somewhat Agree (4)	Neutral (3)	Somewhat Disagree (2)	Strongly Disagree (1)	Total	Likert Scale Mean
#5. Prior Knowledge of Advance Directives	0	7	4	0	0	11	3.6
#6. After Knowledge of Advance Directives	5	6	0	0	0	11	4.5
#7. Prior Benefits of Advance Directives	5	6	0	0	0	11	4.5
#8. After Benefits of Advance Directives	11	0	0	0	0	11	5
#9. Prior Confidence of Advance Directive and Advance Care Planning	1	6	3	1	0	11	3.6
#10. After Confidence of Advance Directive and Advance Care Planning	6	4	1	0	0	11	4.5
#11. Prior Discussion of Advance Care Planning	3	4	3	0	1	11	3.6
#12. After Discussion of Advance Care Planning	7	4	0	0	0	11	4.6
#13. Prior Initiation of Advance Directive Discussion	2	4	3	1	1	11	3.5
#14. After Initiation of Advance Directive Discussion	5	5	1	0	0	11	4.4

Figure 5. August 30, 2018 In-Service Survey Results

Figure 6 contains the August 30, 2018 education in-service survey results related to post-education questions. Of the eleven participants on August 30, 2018, eleven participants (100%) completed the surveys. The survey illustrates the post-education responses to question five, six, seven, eight, nine, ten, eleven, twelve, thirteen, and fourteen.

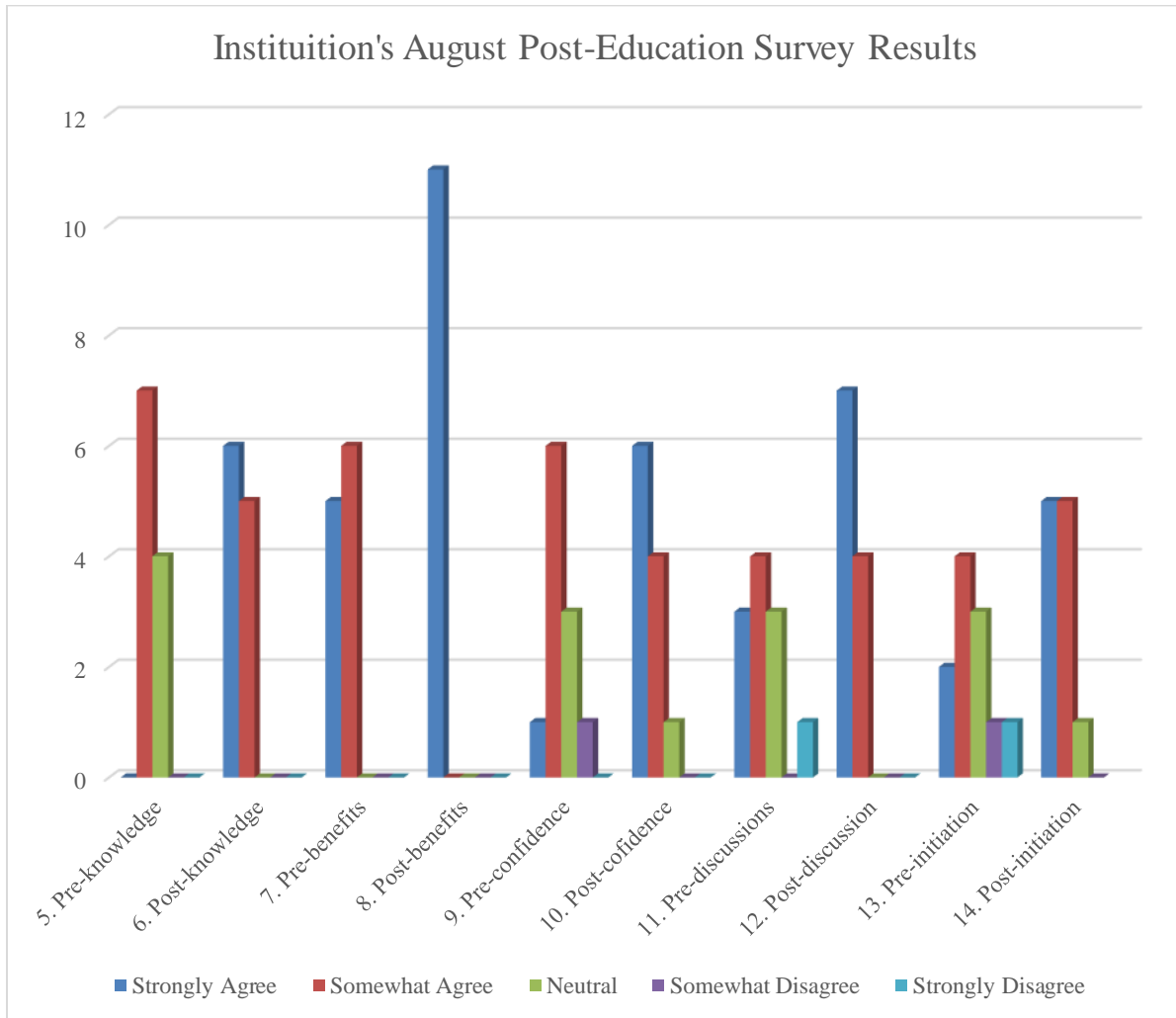


Figure 6. Institution's August Post-Education Survey Results; Zero Providers

Figure 7 contains the survey (see Appendix B) results from the October 30, 2018 education in-service. Of the thirteen participants on October 30, 2018, ten participants (80%) completed the surveys. A North Dakota State University statistician determined inferential statistical analysis was unable to be completed on the survey, so only descriptive data analysis

was completed with the survey. In the comment section of the survey, one participant, whom answered physician, stated they were a Psy. D. and stated, “did not think survey answers are relevant as they do not discuss patient prognosis or physical issues unless part of therapy process.”

October 30, 2018 In-Service Survey Results							
Question	Strongly Agree (5)	Somewhat Agree (4)	Neutral (3)	Somewhat Disagree (2)	Strongly Disagree (1)	Total	Likert Scale Mean
#5. Prior Knowledge of Advance Directives	3	4	1	2	0	10	3.8
#6. After Knowledge of Advance Directives	4	6	0	0	0	10	4.4
#7. Prior Benefits of Advance Directives	6	3	1	0	0	10	4.5
#8. After Benefits of Advance Directives	7	3	0	0	0	10	4.7
#9. Prior Confidence of Advance Directive and Advance Care Planning	6	2	0	0	2	10	3.8
#10. After Confidence of Advance Directive and Advance Care Planning	7	1	2	0	0	10	4.5
#11. Prior Discussion of Advance Care Planning	4	2	0	1	3	10	3.3
#12. After Discussion of Advance Care Planning	6	2	1	0	1	10	4.2
#13. Prior Initiation of Advance Directive Discussion	3	4	0	1	2	10	3.5
#14. After Initiation of Advance Directive Discussion	6	3	0	0	1	10	4.3

Figure 7. October 30, 2018 In-service Survey Results

Figure 8 contains the October 30, 2018 education in-service survey results related to post-education questions. Of the thirteen participants on October 30, 2018, ten participants (77%) completed the surveys. The survey illustrates the post-education responses to question five, six, seven, eight, nine, ten, eleven, twelve, thirteen, and fourteen.

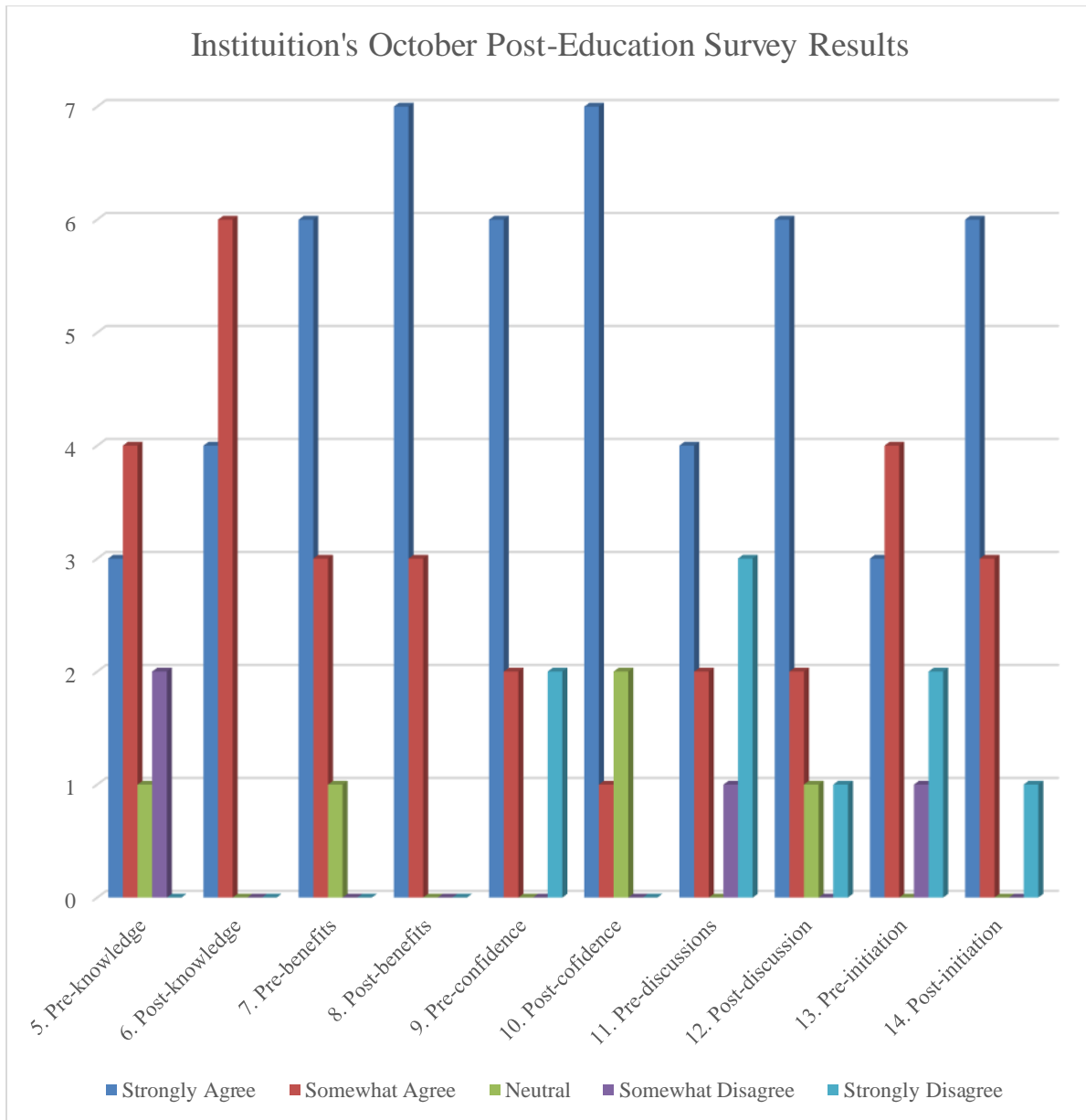


Figure 8. Institution’s October Post-Education Survey Results; Providers attended

Figure 9 contains combined survey responses from participants of the August 30, 2018 and October 30, 2018 education in-services. Total response rate of the survey was 87.5%. A North Dakota State University statistician determined inferential statistical analysis was unable to be completed on the survey, so only descriptive data analysis was completed with the survey.

August 30, 2018 and October 30, 2018 In-Services Survey Results							
Question	Strongly Agree (5)	Somewhat Agree (4)	Neutral (3)	Somewhat Disagree (2)	Strongly Disagree (1)	Total	Likert Scale Mean
#5. Prior Knowledge of Advance Directives	3	11	5	2	0	21	3.7
#6. After Knowledge of Advance Directives	9	12	0	0	0	21	4.4
#7. Prior Benefits of Advance Directives	11	9	1	0	0	21	4.8
#8. After Benefits of Advance Directives	18	3	0	0	0	21	4.9
#9. Prior Confidence of Advance Directive and Advance Care Planning	7	8	3	1	2	21	3.8
#10. After Confidence of Advance Directive and Advance Care Planning	13	5	3	0	0	21	4.5
#11. Prior Discussion of Advance Care Planning	7	6	3	1	4	21	3.5
#12. After Discussion of Advance Care Planning	13	6	1	0	1	21	4.4
#13. Prior Initiation of Advance Directive Discussion	5	8	3	2	3	21	3.5
#14. After Initiation of Advance Directive Discussion	11	8	1	0	1	21	4.3

Figure 9. August 30, 2018 and October 30, 2018 In-Services Survey Results

Figure 10 contains a comparison of family medicine provider participants survey results to the non-family medicine providers/non-providers survey results. Seven participants were family medicine providers and fourteen were non-family medicine providers/non-providers. Total response rate of the survey was 87.5%. A North Dakota State University statistician determined inferential statistical analysis was unable to be completed on the survey, so only descriptive data analysis was completed with the survey.

Comparison of Family Medicine Providers to Non-Family Medicine Providers/Non-Providers														
Question	Strongly Agree (5)		Somewhat Agree (4)		Neutral (3)		Somewhat Disagree (2)		Strongly Disagree (1)		Total		Likert Scale Mean	
	P	N	P	N	P	N	P	N	P	N	P	N	P	N
#5. Prior Knowledge of Advance Directives	2	1	4	7	0	5	1	1	0	0	7	14	4	3.58
#6. After Knowledge of Advance Directives	3	6	4	8	0	0	0	0	0	0	7	14	4.4	4.4
#7. Prior Benefits of Advance Directives	6	5	1	8	0	1	0	0	0	0	7	14	4.9	4.3
#8. After Benefits of Advance Directives	7	11	0	3	0	0	0	0	0	0	7	14	5	4.8
#9. Prior Confidence of Advance Directive and Advance Care Planning	5	2	2	6	0	3	0	1	0	2	7	14	4.7	3.4
#10. After Confidence of Advance Directive and Advance Care Planning	6	7	1	4	0	3	0	0	0	0	7	14	4.9	4.3
#11. Prior Discussion of Advance Care Planning	4	3	2	4	0	3	1	0	0	4	7	14	4.3	3.1
#12. After Discussion of Advance Care Planning	5	8	1	5	1	0	0	0	0	1	7	14	4.6	4.4
#13. Prior Initiation of Advance Directive Discussion	3	2	3	5	0	3	1	1	0	3	7	14	4.1	3.1
#14. After Initiation of Advance Directive Discussion	5	6	2	6	0	1	0	0	0	1	7	14	4.7	4.1

P= family medicine providers; N= non-family medicine providers/non-providers

Figure 10. Comparison of Participants

Referrals

The institution’s clinical pathway which allows providers or nurses to refer patients to the clinic’s advance care planning facilitator was made live July 2018, so data analysis started with the month of July 2018. A North Dakota State University statistician determined inferential statistical analysis was unable to be completed on the referral numbers, so only descriptive data analysis was completed. The month of July had zero referrals while the month of August had two referrals; the first education in-service was given August 30, 2018 (see Figure 11). The months of September 2018 and October 2018 had four referrals each. The month of November 2018 had one referral. The month of December 2018 had zero referrals as of December 8, 2018. The advance care planning facilitator stated most of the referrals came from the same provider and nurse team. The advance care planning facilitator also stated many of the referrals were received verbally rather than electronically.

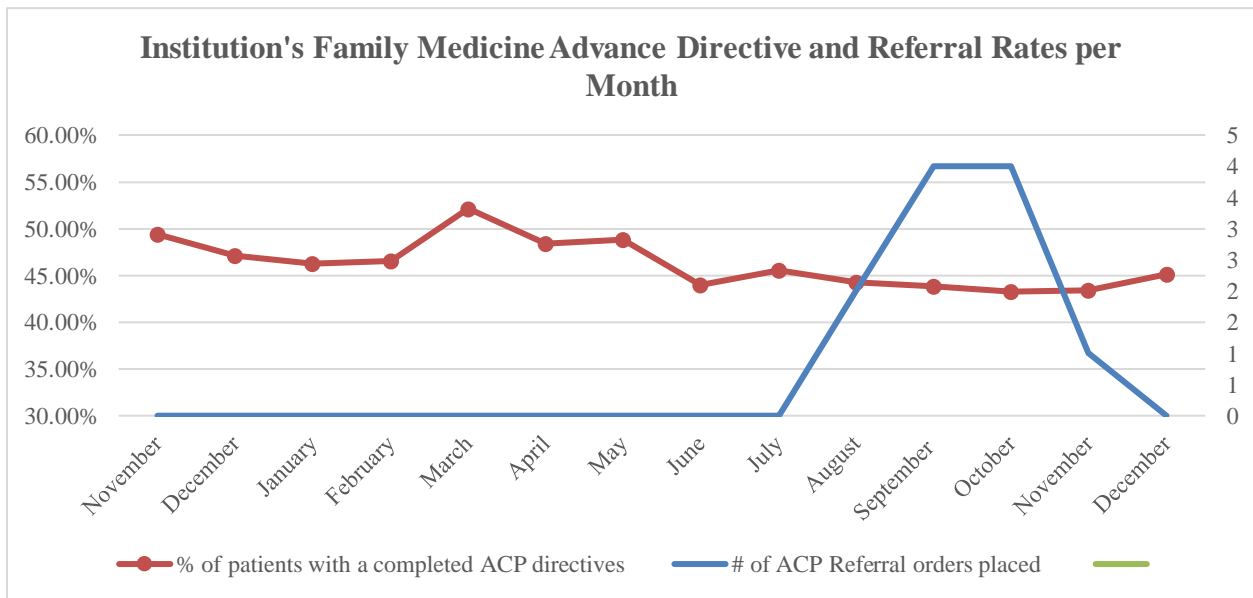


Figure 11. Institution’s Family Medicine Advance Directive and Referral Rates per Month

Advance Directives

Data was collected pre-project, mid-project, and post-project (see Figure 12). The pre-project data was collected for only the month of July 2018 using a monthly total. The July 2018 data was collected incongruently with the project design resulting in only the month of July 2018 data gathered rather than July 2017-July 2018. The mid-project data, which was collected two months after the August 2018 education in-service, was collected from October 2017 to October 2018 using a running total. October 2017 to October 2018 was selected for the mid-project data as it was two months after the first education in-service, two months before the project end date, and two months before the second in-service, which was primarily providers. The post-project data was collected for January 2018 to December 2018 using a running total. A North Dakota State University statistician determined inferential data analysis was unable to be completed, so only descriptive data analysis was completed.

The pre-project data was analyzed for the month of July 2018. The month had 279 patients that met the criteria of 65 years and older and having a diagnosis of COPD, HF, stage IV cancers, and/or ESRD (see Figure 10). Of the 279 patients seen in July with at least one of the diagnoses, 128 patients (45.9%) had an advance directive in their EMR. Of the 128 patients with an advance directive, 45 of 103 (43.7%) patients with COPD had a completed advance directive, 45 of 198 (22.7%) patients with HF had a completed advance directive, zero of one (0%) patient with a stage IV cancer had a completed advance directive, and four of nine (44.4%) patients with ESRD had a completed an advance directive.

The mid-project data was analyzed for October 2017 to October 2018 and analyzed prior to the second education in-service held on October 30, 2018. Total patients were not analyzed; only rates of patients with the project's selected diagnoses were analyzed. The rates of advance

directive completion were 43.5% for COPD patients, 22.1% for HF patients, 50% for stage IV cancer patients, and 37.5% for ESRD patients (see Figure 12).

The post-project data was analyzed for January 2018 to December 2018. For the year, the institution's family medicine had 479 total patients with the criteria of being 65 years and older with a diagnosis of COPD, HF, stage IV cancers, and ESRD (see Figure 12). Of the 490 patients between December 2017 to December 2018, 211 (43%) patients had an advance directive in their EMR. Of the 211 patients with an advance directive, 44 of 101 (43.6%) with COPD had a completed advance directive, 44 of 199 (22.1%) patients with HF had a completed advance directive, 27 of 54 (50%) patients with stage IV cancer had a completed advance directive, and three of eight (37.5%) patients with ESRD had a completed advance directive.

Figure 11 shows advance directive completion rates for patients 65 years and older with a diagnosis of COPD, HF, stage IV cancer, and/or ESRD on a per month basis seen in the clinic from November 2017 to December 2018. The month of July 2018 (pre-project) had a completion rate of 45.5%. The month of October 2018 (mid-project) had a completion rate of 43.3%. The month of December 2018 (post-project) had a completion rate of 45%. The month of September had a completion rate of 43.81% and November had a completion rate of 43.4%.

Institution's Family Medicine			
Pre-Project		Mid-Project	Post-Project
July 10, 2018 279 Total Patients >65 with Diagnoses 128 of the 279 (45.9%) Patients have Advance Directives		October 2017 To October 2018	January 2018-December 2018 490 Total Patients >65 with Diagnoses 211 of the 490 (43.1%) Patients have Advance Directives
Diagnosis	Patients	Patients	Patients
COPD on problem list	103	-	101
COPD on problem list and advance directive	45	-	44
Percent	43.7%	43.5%	43.6%
Heart failure on problem list	198	-	199
Heart failure on problem list and advance directive	45	-	44
Percent	22.7%	21.9%	22.1%
Stage 4 cancer on problem list	1	-	54
Stage 4 cancer on problem list and advance directive	0	-	27
Percent	0%	37.5%	50%
ESRD on problem list	9	-	8
ESRD on problem list and advance directive	4	-	3
Percent	44.4%	52.6%	37.5%

Figure 12. Advance Directive Rates Pre, Mid, and Post In-Service

For comparison to the patient population of this project (i.e. 65 years and older with either COPD, HF, stage IV cancer, and/or ESRD), data was gathered and analyzed for patients 65 years and older with an advance directive regardless of condition. From January 1, 2018 to December 14, 2018, a running total of 2,251 patients 65 years and older were attributed to the institution's family medicine clinic. Of the 2,251 patients, 698 (31%) patients had an advance directive in their medical record. In comparison for the site's patient population, patients 65

years and older with COPD, HF, stage IV cancer, and/or ESRD had an advance directive completion rate of 43.06% while patients 65 years and older regardless of diagnoses had an advance directive completion rate of 31%.

CHAPTER SIX. DISCUSSION AND RECOMMENDATIONS

Discussion

The project's design needed to be revised due to unforeseen circumstances. Initially one education in-service was to be given; however, because zero providers attended the August 30, 2018, a second education in-service was held on October 30, 2018. Survey results from the providers were going to be the only survey results used. However, due to the limited number of provider participants, surveys were given to other education in-service healthcare professional participants. Lastly, due to the limited number of provider participants, the project's objectives had to be altered from being a provider focused population to a healthcare professional focused population.

Objective One

Objective one was healthcare professionals will understand the institution's advance care planning initiatives (i.e. facilitators, conversations, and electronic referrals) by having five advance care planning facilitator referrals four months after the one-hour education in-service. Objective one was considered met if there was greater than five advance care planning facilitator referral rates four months after first education in-service. There was no referral data for comparison as the electronic clinical pathway was implemented in July 2018, making the pre-project referral rate unmeasurable. The referral process was discussed with participants at both education in-services. A total of 11 advance care planning facilitator referrals were made; however, two referrals were made before the August 30, 2018 education in-service. Objective one was considered met as the objective was to have greater than five referrals. Post-referral rates, excluding the two referrals made before the education, revealed nine referrals from August 30, 2018 to December 2018. Referral rates were inconclusive of whether nurses or providers

were making the referrals; however, the institution's advance care planning coordinator stated "most" referrals are from the same provider/nurse team.

Objective Two

Objective two was healthcare professionals' perceived knowledge, confidence, and understanding of advance directive benefits will increase by attending a one-hour education in-service. The confidence Likert scale surveys aided in measuring objective two. The survey questions that evaluated objective two were:

- Question five, "prior to the education in-service, I had sufficient knowledge on advance directives."
- Question six, "after the education in-service, I have sufficient knowledge on advance directives."
- Question seven, "prior to the education in-service, I knew the benefits of advance directives."
- Question eight, "after the education in-service, I know the benefits of advance directives."
- Question nine, "prior to the education in-service, I felt confident discussing advance directives and advance care planning with patients."
- Question ten, "after the education in-service, I feel confident discussing advance direct and advance care planning with patients."
- Question fifteen, "is there anything else related to advance directives and advance care planning you wished we discussed in the education in-service?"

Objective two was considered met if all healthcare participants answered either strongly agree or somewhat agree to all questions pertaining to post-education on the survey given at both

education in-services. The questions that pertained to post-education were question six, question eight, and question ten. Objective two was not considered met because three healthcare professional participants did not answer strongly agree or somewhat agree to question ten. That said, the mean ranking for all participants increased from 3.7 for question nine (pre-education) to 4.5 for question ten (post-education). The data from the survey infers the education in-services increased participants' knowledge regarding advance directives, patient benefits of advance directives, and confidence with advance directives as evidenced by an increase in post-education Likert scale question mean rankings.

Objective Three

Objective three was healthcare professionals will understand how to use the Serious Illness Conversation Guide and its application to initiate advance care planning discussion. The confidence Likert scale surveys aided in measuring objective three. The survey questions that evaluated objective three were:

- Question eleven, “prior to the education in-service, I had advance care planning discussions with patients.”
- Question twelve, “after the education in-service, I will increase advance care planning discussions with patients.”
- Question thirteen, “prior to the education in-service, I felt confidence initiating advance directive discussion.”
- Question fourteen, “after the education in-service, I feel confident initiating advance directive discussion.”

Objective three was considered met if all healthcare participants answered either strongly agree or somewhat agree to all questions pertaining to post-education on the survey given at both

education in-services. The questions that pertained to post-education were question twelve and question fourteen. Objective three was not met because two participants did not answer strongly agree or somewhat agree to question twelve and three participants did not answer strongly agree or somewhat agree to question fourteen. Although question twelve had two participants not answer strongly agree or somewhat agree, the mean for all participants increased from 3.5 for question eleven to 4.4 for question twelve. While question fourteen had three participants not answer strongly agree or somewhat agree, the mean for all participants increased from 3.5 for question thirteen to 4.3 for question fourteen. The data from the survey infers the education in-services increased participants' confidence with initiating advance directive discussion and will increase the participants' discussions of advance care planning with patients as evidenced by an increase in post-education Likert scale question means.

Objective Four

Objective four was the clinic will have a 20% increase in advance directive completion in patients with a diagnosis of chronic obstructive pulmonary disease, heart failure, stage IV cancers, and/or chronic kidney disease four months after the one-hour education in-service. Objective four was considered met if the clinic's advance directive completion rate increased greater than 20% in the selected population. Objective four was not met as there was not an advance directive completion rate increase of 20% or greater. The July 2018 data cannot have valid comparison to the January 2018 to December 2018 data due to different collection methods. Data analysis of the July 2018 to January to December 2018 demonstrates a decrease in advance directive rates from a pre-project advance directive rate of 45.9% to a post-project advance directive rate of 43%. The number of patients analyzed were also different, as the pre-project number of the target population was 279 and the post-project number population was

490. Since the patient populations were collected by different methods, the large increase (56.9%) in the total target patient population could account for the decrease in advance directive rates. When analyzing the monthly advance directive rates, which was a more valid comparison, advance directive rates remained unchanged from July 2018 (45.5%) to December 2018 (45.1%) (Figure 3). Even with the emphasis of the education in-service content on heart failure patients, advance directive rates for heart failure patients also remained unchanged, (a pre-project rate of 22.7% and a post-project rate of 22.1%).

Non-Family Medicine Healthcare Professionals

The participation of non-family medicine healthcare professionals (i.e. receptionists, social workers, nurses, psychologists, psychiatrists) in the education in-service was an unexpected outcome of this practice improvement project. However, non-family medicine healthcare professionals may be part of a solution to meeting the institution's advance directive rate goal. One participant from the August 30, 2018 education was a non-family medicine healthcare professional. One participant answered neutral to two survey questions pertaining to post-education. Three participants from the October 30, 2018 education were non-family medicine healthcare professionals and on multiple survey questions pertaining to post-education, there were one to three participants who answered either neutral or strongly disagree. However, an assumption cannot be made that the non-family medicine healthcare professionals answering neutral or strongly disagree would have changed the outcomes of objectives one, two, and three. The project's education and survey were developed for providers, so the non-family medicine healthcare professionals' survey responses may be from limited level of involvement or lack thereof advance directive discussions.

Project Findings in Comparison to the Literature Findings

The practice improvement project had similar findings that were found in the literature review. The project findings were associated with healthcare professionals and institutions rather than patient findings due to the practice improvement project focusing on system and provider practice changes rather than patient changes. Findings from the project that were similar to the literature review findings are:

- System and healthcare professional barriers included providers' time, healthcare professionals' knowledge on advance directives, providers' uncertainty with disease prognosis, and complications with healthcare communication
- Advance directive rates from the project were similar to those of the literature findings
- Healthcare facilities were training healthcare professionals to become advance care planning facilitators
- Nurses, social workers, and other healthcare professionals were capable of having advance care planning discussion with patients; however, more education is needed for them
- EMR use resulted in more congruent advance directive discussions due to use of facilitators with the referral process

Findings that were not found in the project but were found in the literature review are the *Serious Illness Conversation Guide* increasing and improving provider advance care planning conversations with patients and system/provider barriers being biases, leadership, and reimbursement. These findings may not have been found in the project because they were not

directly assessed. Lastly, the project did not assess patient findings of advance directive completion, so the project had no patient reportable findings as compared to the literature review.

Limitations

Limitations found in this practice improvement project consisted of inconsistent data collection, the short time frame of the project, the short education in-service time during the October 2018 education in-service, and zero providers attended the August 2018 in-service. First, the pre-project advance directive rates were collected for patients only seen in the clinic for the month of July 2018 rather than a running total in which the post-project data advance directive rates were collected. The monthly data collection was less accurate because of the limitations imposed by only a monthly patient volume collection as opposed to fluctuations in patient volumes being seen the remainder of the year. The monthly total also counted patients multiple times if they were seen more than once during that month. In comparison, the running total only counted a patient being seen once in the entire year. The institution's quality improvement advisor, who collected most of the data, reported that converting the month of July 2018 data to a running annual total of July 2017 to July 2018 could not be done.

A second limitation was the short time frame of the practice improvement project. The initial education in-service was given August 30, 2018, which only allowed four months to assess for a change in advance directive rates. Given zero providers attended the August 30, 2018 education in-service, a second education in-service had to be given at a mandatory provider meeting on October 30, 2018, which shortened the assessment interval of advance directives to 1.5 months.

Thirdly, the short education in-service time at the October 30, 2018 was another limitation to the practice improvement project. The education in-service content was prepared to

be given over 60 minutes. However, at the October 30, 2018 education in-service, the content had to be given over 15 minutes requiring a brief overview on certain content.

The fourth limitation was the provider attendance of the August 30, 2018 education in-service. Zero providers attended the first education in-service on August 30, 2018 despite a paid lunch meal from 12:00 p.m. to 1:00 p.m. and sending out two email reminders from the clinic supervisor. The supervisor also reported that two providers were on vacation, two providers are part-time, and that an hour time slot was not blocked off on providers' schedules for attendance of the education in-service.

Lastly, patients were a variable in this project. Objectives one and four relied on patient participation and willingness to accept the referral process and advance directive discussions. Objectives one related to referrals, so patients had to be willing to be referred to an advance care planning facilitator. Objective four related to advance directive rates, so patients had to be willing to upload or provide a copy of their advance directive. If a copy of the patient's advance directive was not in their EMR, they were not counted as having a completed advance directive,

Recommendations for Project Site

Based on the project's findings, future recommendations should include:

- Continuing the current set advance directive rate goal of 50%
- At least one mandatory 60-minute education in-service supplemented with an advance care planning discussion role-play and an online module to be completed prior to the in-service
- Further education on advance directives and advance care planning discussion techniques using Ariadne Labs and Respecting Choices content
- Mandatory education attendance for advance directive in-services for all clinic staff

- Further training on advance care planning referrals and documentation instructed by the institution's informatics team discussing provider notes, referral process, and billable services
- Consistent data collection using an annual running total collection method
- Including non-ancillary staff in future advance directive education, advance care planning interventions, and provider scheduling

Although advance directive rates were unchanged in this project, a recommendation was made to maintain the institution's current advance directive goal. Currently the institution has a goal of 50% advance directive completion for patients 65 years of age and older with a diagnosis of COPD, HF, stage IV cancers, or ESRD. There are no current general practice guidelines or required advance directive rates by national institutes; however, according to the DFCNHM, advance directives may be a Center for Medicare and Medicaid Services quality core measure in the future. The 2018 annual advance directive rate for the project's selected patient population and site was 43.06%. Although the advance directive rate did not increase, referrals are being made and over time a change in rates will likely be seen as previous institution interventions took approximately nine months to have an impact on advance directive completion rates.

Although the objectives of this project were not to make all participants certified advance care planning facilitators, the project outcomes may suggest a needed increase in the length of time spent on advance directive and advance care planning training. The training could be created in online modules relating to advance directives and advance care planning in which CME hours could be obtained and/or increasing the length of the education in-service. Lengthening the time of the in-service may allow staff to participate with hands on role play of

advance directive and advance care planning discussion while using the *Serious Illness Conversation Guide*.

Future education may be led and created by the site's certified advance care planning facilitator and could be supplemented with additional education content from Respecting Choices or Ariadne Labs. Ariadne Labs, the creator of the *Serious Illness Conversation Guide*, has other resources that facilities can use when implementing interventions related to advance care planning. Other resources that Ariadne provides are developed evidence-based PowerPoints, videos demonstrating conversations, podcasts, and case study scenarios. Respecting Choices created the advance care planning facilitator classes and has resources for implementation services, consultation services, and curriculum for facilitators.

Another recommendation based on the findings of this project would be mandating future education in-services and identifying provider attendance barriers to training. If no attendance barriers are identified, a recommendation should be made to make future advance directive and advance care planning training mandatory. Another suggestion that the institution is considering is adding advance care planning and the *Serious Illness Conversation Guide* to the new hire provider orientation.

The institution does not have a goal for the number of advanced directive referrals. A recommendation should be made that the site creates a goal for the number of advance care planning facilitator referrals for the first quarter of 2019. During a follow-up conversation with the site's advance care planning facilitator in December 2018, she reported "most" referrals came verbally and from the same provider/nurse team. A recommendation should be made that the site creates either a separate education in-service or lengthens the advance directive and advance care planning education in-service to allow more time spent on the referral process, charting, and

coding of advance care planning visits. Future education needs to emphasize that the institution's referral pathway for advance care planning facilitators was developed to complete patient advance directives, accurate data analysis, billing, and to view nurses, providers, and facilitators advance care planning notes.

Due to the non-consistent data collection, a recommendation should be made for re-analyzing the advance directive rates comparing future data to the running total analysis of the December 2017-December 2018 data. The institution's quality improvement advisor recommends a running total analysis rather than a monthly analysis due to accuracy and reliability.

Lastly, an incidental finding of a knowledge deficit regarding advance directives was noted for non-ancillary staff. A recommendation should be made to include non-ancillary staff in future advance directive interventions. The benefits of having ancillary staff included in future interventions may include:

- Improved provider/patient scheduling regarding advance care planning.
- Queuing advance care planning discussion for patient and/or providers if an advance directive is not found in medical chart.
- General knowledge that could reach family and community members.

Dissemination

The co-investigator presented the pre and mid-term data from the project during a poster symposium held October 25, 2018 for the institution and was entered under the institution's Advance Care Planning Department. The poster was developed and presented by the co-investigator. The cost of the poster was covered by the institution. There were over 110 posters

in six categories with multiple judges evaluating the posters with presenters disseminating their project's findings. The poster was entered in the Quality of Life category and won its category.

The co-investigator also disseminated the project findings and its education material to students in the North Dakota State University Doctor of Nursing Practice program. The dissemination took place February 13, 2018 on the campus of North Dakota State University. The dissemination was 60 minutes long and was presented in a PowerPoint format.

Implications for Practice/Future Research

Implication for practice of this project include increased provider and ancillary staff's knowledge, confidence, and discussion of advance directives and advance care planning resulting in enhanced patient benefits. The project also educated the staff on the institution's goals of advance directives, advance care planning, and the referral process to the advance care planning facilitator. The clinic was able to identify their advance directive rates and identified heart failure patients to be at a great need for advance directives. Heart failure patients accounted for the largest patient population included in the institution's advance directive goal while meeting less than 50% of the institution's goal.

Future research and practice improvement projects should include a site needs assessment, consistent data collection, mandatory attendance of education in-services, and project replication at similar rural sites. A site needs assessment would help individualize practice improvement projects which would make the project more successful and help identify the site's barriers to meeting their advance directive goals. Project replication at similar rural sites would allow for better generalization and increase validity and reliability of this project.

Application for Doctor of Nursing Practice Roles

As a Doctor of Nursing (DNP) prepared provider, advanced practice registered nurses (APRNs) must continue to expand their roles in practice improvement, leadership, and advocacy for their patients. The eight essentials of DNP education have prepared graduates to be competent in defining actual and emerging problems and design health interventions at aggregate, systems, and organization levels (American Association of Colleges of Nursing, 2019). DNP prepared APRNs possess the quality and competent skills in organization, systems, and community assessment techniques and expert understanding of nursing and biological and behavioral sciences (American Association of Colleges of Nursing, 2019). Evidence has been found supporting that DNP prepared APRNs have advanced education and skills in system leadership and organization development that propels them to become successful leaders (Kapu & Jones, 2016).

Lastly, the project findings indicate that the providers who attended the education in-service increased their advance care planning and advance directive knowledge and increased their discussions and confidence with advance care planning and advance directives. Although the data cannot be directly applied to nurse practitioners with certainty due to the limited number of nurse practitioner participants and anonymous survey responses in this project. 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.

REFERENCES

- Ache, K., Harrold, J., Harris, P., Dougherty, M., & Casarett, D. (2014). Are advance directives associated with better hospice care? *Journal of the American Geriatrics Society*, 62(6), 1091-1096. doi:10.1111/jgs.12851
- American Association of Colleges of Nursing. (2019). DNP essentials. Retrieved from <https://www.aacnnursing.org/DNP/DNP-Essentials>
- Ariadne Labs. (n.d.). Serious illness care. Retrieved from <https://www.ariadnelabs.org/areas-of-work/serious-illness-care/research/>
- Benson W.F. & Aldrich N. (2012). Advance care planning: Ensuring your wishes are known and honored if you are unable to speak for yourself. Retrieved from www.cdc.gov/aging
- Bernacki R. & Block S. Communication about Serious Illness Care Goals: A Review and Synthesis of Best Practices. *JAMA Intern Med*; 174(12): 1994-2003
- Bernacki, R., Paladino, J., Lamas, D., Hitchings, M., Lakin, J., Neville, B., Lipsitz, S...Block, S. (2015). Delivering more, earlier, and better goals-of-care conversations to seriously ill oncology patients. *Journal of Clinical Oncology*, 33(29). doi: 10.1200/jco.2015.33.29_suppl.39
- Butler J., Binney Z., Kalogeropoulos A., Owen, M., Clevenger, C., Gunter, D., Georgiopoulou, V., & Quest, T. (2015). Advance directives among hospitalized patients with heart failure. *JACC Heart Failure* 3(2),112–121.
- Chong-Wen, W., Chan, C. W., & Chow, A. M. (2017). Social workers' involvement in advance care planning: a systematic narrative review. *BMC Palliative Care*, 171-20. doi:10.1186/s12904-017-0218-8

- Conelius, J. (2010). A literature review: advance directives and patients with implantable cardioverter defibrillators. *Journal of the American Academy of Nurse Practitioners*, 22(5), 250-255. doi:10.1111/j.1745-7599.2010.00499.x
- Courtright, K. R., Madden, V., Gabler, N. B., Cooney, E., Kim, J., Herbst, N., & ... Halpern, S. D. (2017). A Randomized Trial of Expanding Choice Sets to Motivate Advance Directive Completion. *Medical Decision Making*, 37(5), 544-554. doi:10.1177/0272989X16663709
- Cypress, B. S. (2016). Understanding uncertainty among critically ill patients in the intensive care unit using mishel's theory of uncertainty of illness. *Dimensions of Critical Care Nursing*, 35(1), 42-49. doi:10.1097/DCC.0000000000000152
- De Vleminck, A., Houttekier, D., Pardon, K., Deschepper, R., Van Audenhove, C., Vander Stichele, R., & Deliens, L. (2013). Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review. *Scandinavian Journal of Primary Health Care*, 31(4), 215-226. doi:10.3109/02813432.2013.854590
- Dube, M., McCarron, A., & Nannini, A. (2015). Advance Care Planning Complexities for Nurse Practitioners. *Journal for Nurse Practitioners*, 11(8), 766-773. doi:10.1016/j.nurpra.2015.05.011
- Dunlay, S., Swetz, K., Mueller, P., Roger, V. (2012). Advance directives in community patients with heart failure. *Circulation: Cardiovascular Quality & Outcomes*, 5(3), 283-289. doi:10.1161/CIRCOUTCOMES.112.966036
- Enguidanos, S., & Ailshire, J. (2017). Timing of advance directive completion and relationship to care preferences. *Journal of Pain & Symptom Management*, 53(1), 49–56. <https://doi-org.ezproxy.lib.ndsu.nodak.edu/10.1016/j.jpainsymman.2016.08.008>

- Fain, J.A. (2015). *Reading, understanding, and applying nursing research. (4th ed.)*. Philadelphia, PA: F.A. Davis.
- Feely, M. A., Hildebrandt, D., Edakkanambeth Varayil, J., & Mueller, P. S. (2016). Prevalence and contents of advance directives of patients with ESRD receiving dialysis. *Clinical journal of the American Society of Nephrology: CJASN*, *11*(12), 2204-2209.
- Garrido, M. M., Balboni, T. A., Maciejewski, P. K., Bao, Y., & Prigerson, H. G. (2015). Quality of life and cost of care at the end of life: The role of advance directives. *Journal of Pain & Symptom Management*, *49*(5), 828-835. doi:10.1016/j.jpainsymman.2014.09.015
- Hagen, N. A., Howlett, J., Sharma, N. C., Biondo, P., Holroyd-Leduc, J., Fassbender, K., & Simon, J. (2015). Advance care planning: identifying system-specific barriers and facilitators. *Current Oncology*, *22*(4), e237-45. doi:10.3747/co.22.2488
- Hickman, R. L., & Pinto, M. D. (2014). Advance directives lessen the decisional burden of surrogate decision-making for the chronically critically ill. *Journal of Clinical Nursing*, *23*(5/6), 756-765. doi:10.1111/jocn.12427
- James, F., Donna, D., Thomas, L., Noelle, C., & Nancy, M. (2012). The effect of advance directives on end-of-life cost experience. *Journal of Health Care for the Poor & Underserved*, *23*(3), 1137-1156. doi:10.1353/hpu.2012.0098
- Kapu, A. & Jones, P. (2016). Team concepts. APRN transformational leadership. *Nursing Management*, *47*(2), 19–22. <https://doi-org.ezproxy.lib.ndsu.nodak.edu/10.1097/01.NUMA.0000479443.75643.2b>
- Ke, L., Huang, X., O'Connor, M., & Lee, S. (2015). Nurses' views regarding implementing advance care planning for older people: a systematic review and synthesis of qualitative studies. *Journal of Clinical Nursing*, *24*(15/16), 2057-2073. doi:10.1111/jocn.12853

- Melnyk, B. M. & Fineout-Overholt, E. (2015). *Evidenced-based practice in nursing and healthcare: A guide to best practice (3rd ed.)*. Philadelphia, PA: Wolters Kluwer.
- Michael, N., O'Callaghan, C., Clayton, J., Pollard, A., Stepanov, N., Spruyt, O., ... Ball, D. (2013). Understanding how cancer patients actualise, relinquish, and reject advance care planning: implications for practice. *Supportive Care in Cancer, 21*(8), 2195–2205.
<https://doi-org.ezproxy.lib.ndsu.nodak.edu/10.1007/s00520-013-1779-6>
- Mishel, M. (n.d.). Uncertainty of illness. Retrieved from
<https://sites.google.com/a/northgeorgia.edu/merle-mishel-middle-range-nursing-theorist/home/uncertainty-of-illness>
- Morhaim, D. K., & Pollack, K. M. (2013). End-of-Life Care Issues: A Personal, Economic, Public Policy, and Public Health Crisis. *American Journal of Public Health, 103*(6), e8-e10. doi:10.2105/AJPH.2013.301316
- National Guideline Clearinghouse (2012). Guideline summary: Advance directives. In: Evidence-based geriatric nursing protocols for best practice. Retrieved from
<https://www.guideline.gov/summaries/summary/43915>
- Neville, K. (2003). Uncertainty in illness: An integrative review. *Orthopaedic Nursing, 22*(3), 206-214.
- O'Sullivan, R., Mailo, K., Angeles, R., & Agarwal, G. (2015). Advance directives: survey of primary care patients. *Canadian Family Physician, 61*(4), 353-356.
- Respecting Choices. (n.d.). The role of the advance care planning facilitator. Retrieved from
<https://respectingchoices.org/types-of-curriculum-and-certification/facilitator-certification/>

- Schellinger, S., Sidebottom, A., & Briggs, L. (2011). Disease specific advance care planning for heart failure patients: Implementation in a large health system. *Journal of Palliative Medicine, 14*(11), 1224-1230. <https://doi.org/10.1089/jpm.2011.0105>.
- Silveira, M. J., Wiitala, W., & Piette, J. (2014). Advance directive completion by elderly Americans: A decade of change. *Journal of the American Geriatrics Society, 62*(4), 706-710. doi:10.1111/jgs.12736
- Stein, G. L., & Fineberg, I. C. (2013). Advance Care Planning in the USA and UK: A Comparative Analysis of Policy, Implementation and the Social Work Role. *British Journal of Social Work, 43*(2), 233-248. doi:10.1093/bjsw/bct013
- Suburban Stats. (2018). Population demographics. Retrieved from <https://suburbanstats.org/population/minnesota/list-of-counties-and-cities-in-minnesota>
- Teno, J., Gruneir, A., Schwartz, Z., Nanda, A., & Wetle, T. (2007). Association between advance directives and quality of end-of-life care: a national study. *Journal of The American Geriatrics Society, 55*(2), 189-194. doi:10.1111/j.1532-5415.2007.01045.x
- Thompson, T., Barbour, R., & Schwartz, L. (2003). Health professionals' views on advance directives: a qualitative interdisciplinary study. *Palliative Medicine, 17*(4), 403-409.
- Weathers, E., O’Caoimh, R., Cornally, N., Fitzgerald, C., Kearns, T., Coffey, A., and O’Sullivan, R. (2016). Advance care planning: A systematic review of randomized controlled trials conducted with older adults. *Maturitas, 91*, 101-109. doi:10.1016/j.maturitas.2016.06.016

APPENDIX A. SERIOUS ILLNESS CONVERSATION GUIDE

Serious Illness Conversation Guide

CLINICIAN STEPS

- Set up**
 - Thinking in advance
 - Is this okay?
 - Combined approach
 - Benefit for patient/family
 - No decisions today
- Guide** (right column)
- Summarize and confirm**
- Act**
 - Affirm commitment
 - Make recommendations to patient
 - Document conversation
 - Provide patient with Family Communication Guide

CONVERSATION GUIDE

Understanding What is your understanding now of where you are with your illness?

Information preferences How much information about what is likely to be ahead with your illness would you like from me?

FOR EXAMPLE

Some patients like to know about time, others like to know what to expect, others like to know both.

Prognosis *Share prognosis, tailored to information preferences*

Goals If your health situation worsens, what are your most important goals?

Fears / Worries What are your biggest fears and worries about the future with your health?

Function What abilities are so critical to your life that you can't imagine living without them?

Trade-offs If you become sicker, how much are you willing to go through for the possibility of gaining more time?

Family How much does your family know about your priorities and wishes?

(Suggest bringing family and/or health care agent to next visit to discuss together)

Draft R4.2 12/10/13

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**APPENDIX B. ADDRESSING ADVANCE DIRECTIVES IN RURAL PRIMARY CARE IN
NORTH DAKOTA: IMPLEMENTING A TOOL FOR HEALTHCARE PROVIDERS**

Survey

1. What is your age?
 - a. 25-29
 - b. 30-39
 - c. 40-49
 - d. 50-59
 - e. 60-69
 - f. 70-79

2. What is your gender?
 - a. Male
 - b. Female

3. Are you a:
 - a. Physician
 - b. Nurse Practitioner
 - c. Physician Assistant
 - d. Social Worker
 - e. Registered Nurse

4. How many years have you been practicing?
 - a. 1-3 years
 - b. 4-6 years
 - c. 7-9 years
 - d. 10- 12
 - e. > 12 years

5. Prior to the education in-service, I had sufficient knowledge on advance directives.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neutral
 - d. Somewhat disagree
 - e. Strongly disagree

6. After the education in-service, I have sufficient knowledge on advance directives.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neutral
 - d. Somewhat disagree
 - e. Strongly disagree

7. Prior to the education in-service, I knew the benefits of advance directives.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neutral
 - d. Somewhat disagree
 - e. Strongly disagree
8. After the education in-service, I know the benefits of advance directives.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neutral
 - d. Somewhat disagree
 - e. Strongly disagree
9. Prior to the education in-service, I felt confident discussing advance directives and advance care planning with patients.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neutral
 - d. Somewhat disagree
 - e. Strongly disagree
10. After the education in-service, I feel confident discussing advance direct and advance care planning with patients.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neutral
 - d. Somewhat disagree
 - e. Strongly disagree
11. Prior to the education in-service, I had advance care planning discussions with patients.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neutral
 - d. Somewhat disagree
 - e. Strongly disagree
12. After the education in-service, I will increase advance care planning discussions with patients.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neutral
 - d. Somewhat disagree
 - e. Strongly disagree

13. Prior to the education in-service, I felt confidence initiating advance directive discussion.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neutral
 - d. Somewhat disagree
 - e. Strongly disagree

14. After the education in-service, I feel confident initiating advance directive discussion.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neutral
 - d. Somewhat disagree
 - e. Strongly disagree

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

Comments:

APPENDIX C. SURVEY PERMISSION LETTER

Ryan

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.

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 D. THEORY PERMISSION LETTER

Ryan,

Attached please find the requested information.

The best of luck to you!

Regards,

Eileen Ferrarie



Request Form - MUIS-Adult

I request permission to copy the Adult Uncertainty in Illness Scale for use in my research entitled,

In exchange for this permission, I agree to submit to Dr. Mishel, upon completion of the study a printout of the uncertainty data on a 3.5 inch disk containing the data with the data dictionary. The data must contain information on each subject's age, sex, education, and diagnosis, along with data on each subject's response to each item on the *Uncertainty Scale*. This data will be used to establish a normative data base for clinical populations. No other use will be made of the data submitted. Credit will be given to me in reports of normative statistics that make use of the data I submitted for pooled analyses. Credit will be given to me in any reports referring to my findings.

(Signature)

Date

Positions and full address of Investigator

Permission is hereby granted to copy the MUIS for use in the research described above.

Merle H. Mishel

(Date)

Please send two signed copies of this form to Merle H. Mishel, PhD, FAAN; School of Nursing, CB #7460 Carrington Hall, University of North Carolina, Chapel Hill, NC, 27599-7460

APPENDIX E. SERIOUS ILLNESS CONVERSATION GUIDE PERMISSION LETTER

Dear Ryan,

Thank you for contacting Ariadne Labs about use of the Serious Illness Conversation Guide and where to access articles on use of the Guide.

You are welcome to use and cite the Conversation Guide in your dissertation! Specifics on how to do so are at the end of my response. As for articles related to the use of the Guide, they are freely available on our online portal called the [Community of Practice](https://portal.ariadnelabs.org/) (<https://portal.ariadnelabs.org/>). It will require making a sign in and requesting membership for the Serious Illness Care Community of Practice, which will be fairly quick. Once in the Community of Practice, articles can be accessed under the "Resources" menu, under the category "Articles and Publications."

Depending on the needs of your dissertation, one recent article on adapting serious illness care conversations for African American communities is currently only available on the main Ariadne Labs website, linked [here](https://www.ariadnelabs.org/areas-of-work/serious-illness-care/resources/#Research) (<https://www.ariadnelabs.org/areas-of-work/serious-illness-care/resources/#Research>).

Please let me know if there are ever issues with Community of Practice resources access, logging-in, etc.

If you have any other questions or concerns related to the Guide, please feel free to contact me or my colleague, Francine Maloney, who is CC'ed to this email.

Very best,
Kaeng

APPENDIX F. IRB APPROVAL LETTER



July 25, 2018

Dr. Adam Hohman
Nursing

Re: IRB Determination of Exempt Human Subjects Research:
Protocol #PH19008, "Addressing Advance Directive in Rural Primary Care North Dakota: Implementing a Tool for Healthcare Providers"

Co-investigator(s) and research team: Ryan Heisler
Date of Exempt Determination: 7/25/2018 Expiration Date: 7/24/2021
Study site(s): Sanford Clinic, Wahpeton, ND
Sponsor: n/a

The above referenced human subjects research project has been certified as exempt (category #2b) in accordance with federal regulations (Code of Federal Regulations, Title 45, Part 46, Protection of Human Subjects). This determination is based on the revised protocol submission (received 7/12/2018) with oral script (received 7/25/2018).

Please also note the following:

- If you wish to continue the research after the expiration, submit a request for recertification several weeks prior to the expiration.
- 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.
- Notify the IRB promptly of any adverse events, complaints, or unanticipated problems involving risks to subjects or others related to this project.
- Report any significant new findings that may affect the risks and benefits to the participants and the IRB.

Research records may be subject to a random or directed audit at any time to verify compliance with IRB standard operating procedures.

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

A handwritten signature in purple ink that reads "Kristy Shirley".

Kristy Shirley, CIP, Research Compliance Administrator

For more information regarding IRB Office submissions and guidelines, please consult http://www.ndsu.edu/research/integrity_compliance/irb/. This Institution has an approved FederalWide Assurance with the Department of Health and Human Services: FWA00002439.

INSTITUTIONAL REVIEW BOARD

NDSU Dept 4000 | PO Box 6050 | Fargo ND 58108-6050 | 701.231.8995 | Fax 701.231.8098 | ndsu.edu/irb

Shipping address: Research 1, 1735 NDSU Research Park Drive, Fargo ND 58102

NDSU is an SCD/AA university.

APPENDIX G. FACILITATOR CERTIFICATION



APPENDIX H. IN-SERVICE PRESENTATION

Addressing Advance Directives in Rural Primary Care North Dakota: Implementing a Tool for Healthcare Providers

Ryan Heisler, RN, DNP-S
Lois Ustanko, RN, MS, MHA

NDSU

Objectives

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

- Know the benefits of advance care planning and advance directives
- Identify the barriers to advance care planning and advance directive completion
- Identify Sanford's advance care planning initiative
- Discuss advance care planning facilitators
- Know how and when to use the Serious Illness Conversation Guide in advance care planning

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Disclaimer

- Hi, my name is Ryan Heisler. I am a graduate student in the Department of Nursing at North Dakota State University, and I am conducting a research project to see if providing healthcare provider education on advance directives and advance care planning will increase patient advance directive rates and increase and improve advance care planning conversations. It is our hope, that with this research, we will find a way to increase advance directive rates and increase and improve advance care planning conversations.

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Dissertation Project

- Grandpa had severe COPD
- ICU background
- NDSU graduation requirement for DNP
- Collected data on advance directives and facilitator referrals rates prior to education → four months after education will gather data again
 - Patients with COPD, stage 4 cancers, heart failure, ESRD
- Analyze and compare data →
 - Was there an increase in advance directive rates?
 - Was there an increase in facilitator referrals?

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What is Advance Care Planning?

Advance Care Planning (ACP) is:

- An organized process of communication to help individuals understand, reflect upon, and discuss goals for future healthcare decisions in the context of their values and beliefs.
- It has the power to produce a written plan (**Advance Directive**) that prepares others to make healthcare decisions consistent with the patient's preferences.
- The earlier the better.

NDSU

What is an Advance Directive?

- Written instructions that communicate the patient's wishes about the care and treatment they do or do not want to receive if they reach the point where they can no longer speak for themselves. Every state now recognizes advance directives.
- 56% of patients would prefer to discuss advance directives with their family providers at a clinic office visit rather than any other healthcare setting
 - Patients prefer providers to initiate discussion

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AD and ACP Benefits

- Patient continues to have a say in their medical care, even if they become too sick to speak for themselves.
- Patients have peace of mind, knowing that they are more likely to receive the medical treatment they would want, and to not receive the treatment they would not want.
- Family and friends are relieved of the burden of having to make decisions without knowing patient preferences.
 - Less stress, anxiety, and depression
- Evidence shows conversations with providers about future treatments leads to better end of life care as patients transition to comfort care.
- Reduces avoidable hospitalizations and transfers between health care settings
 - Thirty percent of Medicare's spending comes in the last year of life with 50% spent on care received in the acute care setting
 - Home insurance

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When to Discuss

- At annuals
- 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 as more harm than benefit
- The 5 D's: decade, divorce, death, decline, diagnosis

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Wahpeton's Pre-Education Data

- Attributed Primary Care Provider
 - Attributed vs General
 - Wahpeton's has 2, 218 patients 65 year of age and older attributed to its 9 providers
- Advance Care Planning Facilitators
 - Wahpeton has 0 referrals thus far
 - Ability to schedule was activated in June
 - Regional education given 7/25/18

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Wahpeton Family Medicine	
279 Total Patients >65 with Diagnoses	
128 of the 279 (45.88%) Patients have Advance Directives	
Diagnosis	Patients
COPD on problem list	103
COPD on problem list and advance directive	45
Percent	43.69%
Heart failure on problem list	198
Heart failure on problem list and advance directive	45
Percent	22.73%
Stage 4 cancer on problem list	1
Stage 4 cancer on problem list and advance directive	0
Percent	0%
ESRD on problem list	9
ESRD on problem list and advance directive	4
Percent	44.44%

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What are the barriers?

- Provider and system barriers include time, knowledge, biases, leadership, reimbursement, electronic medical records, stress, anxiety, unknown disease prognosis, and communication.
 - Time has been found to be the largest system barrier
 - Healthcare providers spend on average 5.6 minutes discussing advance directives with patients

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ACP at Sanford

- ACP Facilitators
- Referral Process
 - Order set
 - Scheduling workque
 - Receptionist calls patient
 - Shows up facilitators Epic schedule

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Role of Advance Care Planning Facilitators

- Advance care planning facilitators are certified in advance care planning allowing them to have the knowledge and skills to facilitate advance directive discussion.
 - Explores the patient's story to gain insight into values, goals, and beliefs
 - Notes and questions for providers
- Spend >1.5hrs with patient following a script
- It was found 94.3% of 1,894 heart failure patients referred to advance care planning facilitators had a health directive.
- Also, it was found patients that engaged with advance care planning facilitators were more likely to use hospice.
- Ally Kugler, LSW is a ACP facilitator

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ACP Heart Failure

- Research has found 87.5% of patients would have liked to have had discussions about their expectations and preferences and 80.6% would have liked discussion about their prognosis
- Research found patients attempt to gain control over their lives and illness by getting information about how it is likely to progress → when patients know the possible trajectory of their illness, they can plan better.
- Recommend that patients and families be introduced to a palliative care team at the earliest possible time after diagnoses of heart failure.

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ACP Heart Failure

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

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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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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 → dying is a personal experience
- Primary care setting: lead to better and more frequent conversations → average conversation was 22 minutes

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Serious Illness Conversation Guide

1. Setup the conversation
2. Assess understanding and preferences
3. **Share prognosis**
4. **Explore key topics (worries, goals, tradeoffs)**
5. Close the conversation
6. Document your conversation
7. Communicate with clinicians

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Serious Illness Conversation Guide

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. Set up the conversation <ul style="list-style-type: none"> - 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? "
2. Assess understanding and preferences	"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. Share prognosis <ul style="list-style-type: none"> - Share prognosis - Frame as a "wish...worry", "hope...worry" statement - Allow silence, explore emotion 	"I want to share with you my understanding of where things are with your illness..." 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." OR Firm: "I wish we were not in this situation, but I am worried that time may be as short as ____ (express as a range, e.g. days to weeks, weeks to months, months to a year)." OR 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."
4. Explore key topics <ul style="list-style-type: none"> - Goals - Fears and worries 	"What are your most important goals if your health situation worsens?" "What are your biggest fears and worries about the future with your health?"



Prognosis

- The key to prognosis is not pinpointing time of death. Instead, it is to help patients prepare in case time is short.
- It allows the patient to make informed medical decisions
 - Generally, patients want to know
 - Doesn't cause stress or anxiety
 - Doesn't cause them to die sooner
- Patients are generally overly-optimistic about their prognosis worsening their preparation for end of life
 - Do not provide premature reassurance

Heart Failure
<http://depts.washington.edu/whfrn/veddy/12004/heights700>
 Dr. Winston
<https://ecognition.ucsf.edu/>

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."

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."

Prognosis Phrases

- Be direct in making your recommendation: Say
 - "I recommend...." Rather than using a "menu" approach of options.
 - "Half of people like you, who have been admitted to the hospital for heart failure, will die in a year."
 - "For someone of your age, with your set of medical conditions and ability to take care of yourself from day to day, most of them pass away at 5 years."

Institute for Healthcare Improvement



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Coding

- 99497
 - First 30 minutes
 - Needs to be > 16 minutes
 - Patient, family, and/or surrogate
 - Discussed ACP including advance directives and
 - Completion of advance directives is not required
- 99498
 - Next 30 minutes
 - List code separately

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References

- Aclis, K., Harold, J., Hama, P., Dougherty, M., & Casaroff, D. (2014). Are advance directives associated with better hospice care? *Journal of the American Geriatrics Society*, 62(6), 1001-1006. doi:10.1111/jgs.12851
- Ahluwalia, S.C., Levin, J.R., Lorenz, K.A., & Gordon, H.S. (2013). "There's no cure for this condition": How physicians discuss advance care planning in heart failure. *Patient Education and Counseling*, 92(2), 209-215.
- Ahluwalia, S.C., Levin, J.R., Lorenz, K.A., & Gordon, H.S. (2012). Missed opportunities for advance care planning communication during outpatient clinic visits. *Journal of General Internal Medicine*, 27(4), 445-451.
- Cornelius, J. (2010). A literature review: advance directives and patients with implantable cardioverter defibrillators. *Journal Of The American Academy Of Nurse Practitioners*, 22(5), 250-255. doi:10.1111/j.1745-7599.2010.00498.x
- De Vries, A., Hofmeier, D., Reijnders, K., Decheppe, R., Van Audenhove, C., Vander Stichele, R., & Deliens, L. (2013). Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review. *Scandinavian Journal Of Primary Health Care*, 31(4), 215-226. doi:10.3109/02813432.2013.854590
- Gordon, N.A., O'Riordan, D.L., Oracup, K.A., De Marco, T., & Parlati, S.Z. (2017). Let Us Talk About It: Heart Failure Patients' Preferences Toward Discussions about Prognosis, Advance Care Planning, and Spiritual Support. *Journal of Palliative Medicine*, 20(1), 79-93.

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References

- Kheirbek, R.E., Alami, F., & Citron, B.A. et al. (2013). Trajectory of illness for Patients with Congestive Heart Failure. *Journal of Palliative Medicine*, 16(5), 478-484.
- Morhaim, D.K., & Pollack, K.M. (2013). End-of-Life Care Issues: A Personal, Economic, Public Policy and Public Health Crisis. *American Journal Of Public Health*, 103(6), e8-e10. doi:10.2195/ajph.2013.301316
- Mazzafarani, D., Benjamin, E.J., Go, A.S., et al. on behalf of the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics—2016 update: a report from the American Heart Association. *Circulation*, 2016, 133:e368-e360.
- O'Sullivan, R., Malik, K., Angeles, R., & Ageneral, G. (2015). Advance directives: survey of primary care patients. *Canadian Family Physician*, 61(4), 353-356.
- Respecting Choices. (n.d.). Retrieved from <https://www.respectingchoices.org/our-work/advance-care-planning/advance-care-planning-101.cfm>
- Scheininger, S., Griebelton, A., & Briggs, L. (2011). Disease specific advance care planning for heart failure patients: implementation in a large health system. *Journal of Palliative Medicine*, 14(11), 1224-1230. <https://doi.org/10.1089/jpm.2011.0106>
- Weathers, E., O'Carroll, R., Curran, N., Fitzgerald, C., Kearns, T., Coffey, A., and O'Sullivan, R. (2016). Advance care planning: A systematic review of randomized controlled trials conducted with older adults. *Maturitas*, 91, 101-109. doi:10.1016/j.maturitas.2016.06.016

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