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Community-based Advance Care Planning Seminars: Increasing Knowledge in
Decisional Adults

BY

Molly Kuehl

A paper submitted in partial fulfillment of the requirements for the degree

Doctor of Nursing Practice

South Dakota State University

2017

Community-based Advance Care Planning Seminars: Increasing Knowledge in
Decisional Adults

This Doctor of Nursing Practice (DNP) Project is approved as a credible and independent investigation by a candidate for the DNP degree and is acceptable for meeting the project requirements for this degree. Acceptance of this DNP Project does not imply that the conclusions reached by the candidate are necessarily the conclusions of the major department.

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Acknowledgements

I wish to acknowledge the assistance of:

Dr. Mary Minton, Project advisor, South Dakota State University: Department of
Graduate Nursing

Dr. Francine Arneson, Avera Medical Group Palliative Medicine

My Graduate Nursing Committee: Dr. Sheryl Marckstadt, Dr. Mary Isaacson – South
Dakota State University: Department of Graduate Nursing; and Dr. Joseph
Darrington – South Dakota State University: Department of Agriculture and
Biosystems Engineering

Michelle Butler, Support Specialist, Avera Medical Group Palliative Medicine
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Abstract

Healthcare workers care for patients with many comorbidities- many of whom enter the system without a clear understanding of their values and preferences. Private discussions about advance directives (ADs) are effective, but cost-prohibitive. Community-wide education campaigns may result in improved quality of life (QOL) (Blackford & Street, 2012a; Bomba & Orem, 2015; Pecanac, Repenshek, Tennenbaum, & Hammes, 2014; Wilson, Kottke, & Schettle, 2014). The purpose of this project was to determine whether community-based seminars about advance care planning (ACP) increase knowledge in decisional adults 18 and older. This project combined discussion format with an ACP presentation. The presentation was delivered by a Doctor of Nursing Practice (DNP) student for a convenience sample of decisional adults (n = 42) ranging in age from 22-80 years of age. A pre/post ACP/AD Knowledge Survey was utilized to measure change in knowledge, and a demographic survey was administered to gather sample descriptives. A Wilcoxon signed rank test was statistically significant ($p = .0004$) for ACP/AD knowledge increase. These findings support that nurse practitioners are well poised to address ACP in the community setting. Their advanced knowledge of disease processes and patient centered care places them in an ideal position to promote patient understanding of ACP/AD processes. . Delivering ACP education in a community-based setting allows for dissemination to a large group of individuals at little to no cost to organizations and saves time for providers and patients alike – as well as allowing for meaningful discussions.

Keywords: advance care planning, advance directives, nurse practitioner, community-based seminar, end of life, quality of life

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List of Abbreviations

ACP – Advance Care Planning

AD(s) – Advance Directive(s)

APP – Advance Practice Provider

APRN – Advance Practice Registered Nurse

CPR – Cardiopulmonary resuscitation

CDC – Centers for Disease Control and Prevention

CMS – Centers for Medicare and Medicaid Services

CNP – Certified Nurse Practitioner

DNP – Doctor of Nursing Practice

DNR – Do not resuscitate

DPOA – Durable Power of Attorney

DPOA-H – Durable Power of Attorney for Healthcare

EMR – Electronic Medical Record

EMS – Emergency Medical Services

EOL – End of Life

EBP – Evidence Based Practice

ICU – Intensive Care Unit

LW(s) – Living Will(s)

NP – Nurse Practitioner

PSDA – Patient Self Determination Act

RN – Registered Nurse

Definitions

Advance care planning – a process in which a person plans for their future medical care.

This process includes assigning at least one surrogate decision maker (DPOA-H) to make decisions for them in the event they lose decisional capacity. The process may also include filling out a living will (LW). Additionally, a person may choose to lay out a general plan of care based on their values and beliefs. This general plan allows healthcare teams and decision makers to make informed choices in the best interest of the individual (Bomba & Orem, 2015; Brinkman-Stoppelenburg, Rietjens, & Van der Heide, 2014).

This is an ongoing process that includes: an individual thinking about what their preferences may include, talking about these preferences with loved ones and their healthcare team, documenting their preferences or wishes for EOL care, and revisiting these preferences and documents throughout life and after certain life events, e.g., family death, divorce, change in health, change in preferences (McMahan, Knight, Fried, & Sudore, 2013; Sabatino, 2010).

Advance care planning document(s) – comprehensive document(s) that may or may not include legal document(s) that conveys the values, preferences, and overall goals of care an individual would want for themselves at the end of their life. This can be used by the individual, loved ones, decision maker(s) and a healthcare team to guide the care of an individual whether or not decisional capacity is lost.

Advance directive(s) - legal document(s) that conveys a person's end-of-life (EOL) care preferences when capacity is deficient, thus supporting autonomy in healthcare choice making. Usually a combination of a living will and designated durable power of attorney

for healthcare (DPOA-H) form, may include a do not resuscitate (DNR) physician order (Wenger, Asakura, Fink, & Oman, 2012).

Living will(s) – legal document that conveys a person’s preferences for medical treatments, which specifies inclusion or exclusion of life-sustaining treatments such as mechanical or non-invasive ventilation, tube feedings, or intravenous hydration or antibiotics (Kavalieratos, Ernecoff, Keim-Malpass, & Degenholtz, 2015).

Decision Maker – This term will be used for the purpose of this project, to refer to the individual(s) a person has chosen to make medical decisions for them in the event they are no longer able to do so for themselves. In other documents, this may also be referred to as a healthcare agent, proxy, a durable power of attorney for healthcare (DPOA-H), or a surrogate decision maker.

Comfort One – This term is used in the state which the project primarily takes place to refer to an order signed by a physician or nurse practitioner (NP) when a patient does not wish to be resuscitated if Emergency Medical Services (EMS) are called. Patients who possess these documents are encouraged to order the accompanying bracelets that indicate their DNR status to EMS or emergency room personnel. A patient that possesses one of these documents and wears a bracelet wishes to forego cardiopulmonary resuscitation (CPR) and mechanical ventilation in conjunction with this procedure if found unresponsive (Sabatino, 2010).

Decisional capacity – An individual’s ability to clearly discern their preferences and best interests based on their values and beliefs (Samsi & Manthorpe, 2011); may also be referred to as competence. This may be impaired by things such as prescriptive medications, street drugs, conditions causing chronic hypoxia, delirium, dementia, and

many other temporary, permanent, or progressive conditions that may alter a person's ability to make sound decisions in their own best interest.

Community-based seminar – a seminar which is held in a community setting, such as a hospital conference room, place of worship, or a public meeting space. The community-based seminar is free to the public and is open to anyone for attendance.

Interdisciplinary team – a team made up of two or more disciplines including but not limited to: physicians, advance practice registered nurses (APRNs), nursing, social work, and chaplaincy. Within these discipline categories further specializations may exist, such as Palliative care, Hospice Care, Oncology, etc.

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Chapter 1

Introduction

More than 25% of all Americans suffer from more than one chronic condition (Centers for Disease Control and Prevention, 2013). Many of these patients enter the healthcare system without having a clear understanding of their own values, preferences, or options regarding their care. For instance, 90% of people surveyed in a 2013 national poll stated that having a conversation with loved ones about their end-of-life (EOL) wishes was important, but only 27% had done so (The Conversation Project, 2013). Even fewer patients enter the healthcare system having participated in prior advance care planning (ACP) dialogue or having documented advance directives (ADs) (AARP, 2008). In a survey done by the California HealthCare Foundation (2012), 82% of those surveyed stated that having their wishes in writing was important, but only 23% had actually completed ADs. Clear ADs are important to guide the provision of appropriate care for patients in emergency situations, for those with serious chronic illness and in clinical conditions in which patients have lost decision making capacity or are at the EOL.

Previously, primary focus on improving patient outcomes has concentrated on AD documents, specifically living will (LW) and Durable Power of Attorney for Healthcare (DPOA-H), which serve as templates for patients to convey their preferences while offering providers some legalistic protection (Detering, Hancock, Reade, & Silvester, 2010; Sabatino, 2010). This has been known as a legalistic transactional model due to its focus on protecting the rights of individuals and the involvement of the legal system in the development of laws and statutes governing such individualized transactions

(Sabatino, 2010). Traditionally, individuals have sought the assistance of lawyers when completing their ADs in a state of wellness.

Increasing complexity in patient health conditions in recent years has made navigating AD documents more challenging for lawyers who are often unfamiliar with the prognosis and medical intricacies of multiple serious chronic illnesses. Addressing ADs within a healthcare setting has traditionally been a physician responsibility (Sabatino, 2010). Unfortunately, such conversations are often delayed until severe illness or imminent death necessitates they take place. A combination of barriers have made these important conversations difficult for providers to introduce and navigate in a timely and effective manner (Detering et al., 2010). Moreover, many healthcare providers cite discomfort with discussing ADs, and may avoid these conversations during routine visits (Bomba & Orem, 2015; Keating et al., 2010; Sabatino, 2010). This may leave patients or their families feeling poorly educated and rushed to make decisions about EOL care during times of severe illness or rapid decline, detracting from the overall quality of the EOL experience.

More recently, healthcare has shifted its focus from a legalistic transactional model towards a communications approach, known as ACP. This method places more emphasis on an individual's overall values and preferences, ongoing discussions with decision makers and healthcare providers, patient understanding of their state of wellness or illness, and whole-person care at the EOL (Baughman, Ludwick, Palmisano, Hazelett, & Sanders, 2015; Blackford & Street, 2013; Detering et al., 2010; Sabatino, 2010). While ADs are included within the process of ACP, the focus shifts from completion of the legal documents to education of patients and family with the intent to improve the

quality of EOL care (Institute of Medicine, 2015). ACP encourages patients to think about the type of care they would like to receive, discuss their wishes with their decision makers and healthcare providers, document their wishes, and revisit these discussions and documents on a regular basis throughout the course of life (Baughman et al., 2015; Brinkman-Stoppelenburg et al., 2014). While ACP is now a billable service, healthcare providers are poorly reimbursed for this when it is compared to other services rendered in primary care clinics or inpatient facilities (Centers for Medicare and Medicaid Services, 2016a, 2016b). ACP conversations can involve extensive education, clarification, and reinforcement; and are often time consuming (Keating et al., 2010). With limited reimbursement for healthcare providers, potentially uncomfortable subject matter, and their time intensive nature, it becomes clearer why ACP and AD discussions do not happen regularly between primary healthcare providers and patients.

Interprofessional teams involving physicians, social workers, registered nurses (RN) and advance practice registered nurses (APRN) may play an effective role in educating patients about AD (Detering et al., 2010). These interprofessional teams may help patients to understand why ACP is important, what the process entails, the legal documents involved such as ADs, and how ACP can improve EOL care (Howell et al., 2014). Utilizing an evidence-based practice (EBP) community-based seminar format to educate patients about ACP promotes conversations amongst participants and healthcare workers during a time of relative wellness, thereby enhancing learning (Hinderer & Mei Ching, 2014). This simultaneously provides an opportunity for a more cost-effective and time-efficient approach to disseminate information about ACP to larger community-based groups.

Background

Before the 1970s, cases of patients and families fighting for preservation of dignity, quality of life (QOL) while dying, and autonomy in medical decisions were not topics commonly cited in healthcare or legal literature. Advancements in medical technology during that time period allowed patients to live in persistent vegetative states while mechanically ventilated, bringing a new wave of ethical concerns to healthcare. The case of *In re Quinlan* (1979), in which Joseph Quinlan pursued a court order to allow his daughter to be removed from her ventilator, provided a turning point in this type of medical decision. According to Watson (2010), New Jersey ruled:

The individual's rights overcome state interest...the only practical way to prevent destruction of an individual's right to privacy is to permit the guardian of Karen to render their very best judgement...as to whether she would exercise it in these circumstances. (p. 9)

Following this ruling, California passed legislation in 1976 legalizing LWs, with all remaining states following suit closely thereafter (Watson, 2010). Many other court cases have brought patient autonomy into public awareness, such as *Cruzan v. Director, Missouri Department of Health* (1990), in response to which the United States Congress worked to pass the landmark Patient Self Determination Act (PSDA) in 1991 (Watson, 2010).

While the newer healthcare technologies can cure many illnesses and stave off disease states longer, the ethical implications of prolonging life in situations where patients have lost competence are complex. When patients have lost decisional capacity and their QOL is no longer what they would have chosen for themselves, a well-

documented and well-communicated advance care planning document becomes a tool to empower patients and their decision makers. ADs are underutilized legal documents that can help enhance patient autonomy, relieve surrogate decisional burden, and may lead to lower costs associated with EOL care by avoiding unwanted treatment (AARP, 2008; Detering et al., 2010; Institute of Medicine, 2015; Taylor, Osterman, Van Houtven, Tulskey, & Steinhauser, 2007). Many patients cite lack of information or understanding of what ACP entails as reasons they have not completed an AD or engaged in the ACP process (Hinderer & Mei Ching, 2014).

Significance of the Problem

The exact number of persons without ADs is unknown; however a 2007 national poll by AARP® showed that less than one-third of adults 35 years of age and older had formal documents in place, and a more recent survey by the California Healthcare Foundation of California (2012) residents showed that only 23% of adults had put their wishes in writing (AARP, 2008; California HealthCare Foundation, 2012). This leaves a large segment of the population whose EOL wishes have potentially not been discussed with loved ones and their healthcare providers, and remain undocumented. The Centers for Disease Control and Prevention (CDC) estimate that a quarter of all Americans, and two out of three elderly Americans now hold diagnoses of multiple chronic conditions (Centers for Disease Control and Prevention, 2013). Patients are living longer and surviving more serious injuries and illnesses, making it very important for them to reflect on their own wishes for EOL care (Centers for Disease Control and Prevention, 2013). Once patients recognize their own wishes, it is important to discuss these wishes with those who are close to them, document their wishes to provide guidance in directing their

health care, and revisit these documents over time to reevaluate changing values or preferences (National Hospice and Palliative Care Organization, 2016).

Focused attention in literature and research has been given to patients with particular illnesses (cancer, congestive heart failure, chronic kidney disease, etc.), elderly adults, or the perceived barriers that healthcare providers face in discussing ADs with their patients (Detering et al., 2010; Epstein, Shuk, O'Reilly, Gary, & Volandes, 2015; Keating et al., 2010). Few studies, however, have been conducted on generally healthy decisional adults 18 years and older in relation to ADs or the ACP process. There is a great need for discussion of values, care preferences, and ADs no matter the age or health of an individual, as illustrated by the high profile cases of Cruzan and Quinlan. While the risk of acquiring multiple serious chronic illnesses increases with age, accident or sudden illness can render anyone of any age incapacitated. This reinforces the importance of completing a comprehensive advance care planning document to enhance autonomy and ensure compliance with patients' wishes (Centers for Disease Control and Prevention, 2013; National Hospice and Palliative Care Organization, 2016)).

Impact on Patients

Patients' preferences vary greatly regarding EOL care. A literature review on ADs among older adults performed by Kossman (2014) found that some of the factors influencing EOL preferences include health literacy, educational level, cultural and spiritual background, socioeconomic status, and personal experiences (Kossman, 2014). Overwhelmingly, however, individuals consistently express that they would prefer to die in their own home. Yet, up to 76% of patient deaths occur in hospitals, where more

aggressive medical care is typically provided (California HealthCare Foundation, 2012; National Center for Health Statistics, 2010; Teno et al., 2004).

Participating in ACP while competent or before receiving multiple serious diagnoses can lead to improved healthcare provider and decision maker compliance with patients' wishes, and reduce decisional burden for decision makers (Detering et al., 2010; Hickman & Pinto, 2014). In addition, having an AD and an accompanying advance care plan document in the electronic medical record (EMR) that is well understood by the patient's decision makers and healthcare team has been linked to reduced hospital admissions at the EOL and a greater focus on symptom management and comfort (Detering et al., 2010; Durbin, Fish, Bachman, & Smith, 2010). The process of ACP advocates for consistent communication between patients and their decision makers as illnesses progress or disease states change, allowing for updated documentation as needed. This practice encourages patients to revisit important conversations and documentation as their preferences change (Centers for Disease Control and Prevention, 2015). Thoroughly educating patients, families, and healthcare providers on the importance of treating ACP as an ongoing, lifelong process engages the group to advocate for EOL care that is more consistent with patient preferences (Centers for Disease Control and Prevention, 2015; Hinderer & Mei Ching, 2014; The Conversation Project, 2013).

Impact on Healthcare

In 2015, the Institute of Medicine (IOM) released *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. This report gave five key recommendations for the healthcare system to implement to improve the quality of

EOL care. Three of the recommendations are tangentially related to ADs while the other two recommendations are directly related to this project.

The first recommendation was for the provision of patient and family centered care, and for government and private insurers to cover such care in the presence of advanced illness at the end stages of life (Institute of Medicine, 2015). While hospice services are covered by Medicare, room and board are not, leaving patients and families needing intensive hospice care in a nursing home or inpatient hospice facility setting to pay out of pocket for these room and board costs (Centers for Medicare and Medicaid Services, 2016). Additionally, while ACP discussions are now billable under Medicare, they are not as profitable as procedures or alternate visit codes, leaving providers in a difficult situation.

The second recommendation of the IOM report (2015) encourages payers to link reimbursement to improved standards which are “measurable, actionable, and evidence-based”(Institute of Medicine, 2015, p. 12). This holds providers accountable to standards such as regular ACP discussions, documenting the presence of ADs in the EMR, and whether ACP discussions have taken place with patients with certain diagnoses. The third recommendation calls for healthcare providers to be proficient in providing palliative care which includes communicating with patients and families, collaborating with other disciplines, and managing patient symptoms in EOL scenarios (Institute of Medicine, 2015). Engaging patients and their families in ACP discussions in a state of wellness or early after a diagnosis of a chronic illness can set patients up for a Palliative based mindset further on in their life (Teno, 2007).

Recommendation four calls for government at federal, state, and local levels as well as private insurers and health-care agencies to incorporate funding of social and medical services for quality EOL care consistent with the values and informed preferences of individuals with advanced serious illness (Institute of Medicine, 2015). This becomes especially important when the preferences of individuals include services that are best delivered in a home setting and are less invasive. Funding for medical services that is in line with patient preferences can guide QOL at EOL. The fifth recommendation asked for a wide variety of stakeholders to provide evidence-based information about ACP and advanced illness to the public in an effort to encourage informed decision making (Institute of Medicine, 2015; Unroe, Ersek, & Cagle, 2015). This project hopes to contribute to the evidence base of ACP knowledge in an effort to emphasize the value of educating patients about the topic.

Costs in Healthcare

The Center for Medicare and Medicaid Services (CMS) began reimbursing for voluntary ACP on January 1, 2016 (Centers for Medicare and Medicaid Services, 2016b). Physicians and Advance Practice Providers (APP) can bill for these services which include conversations regarding patient care preferences at the EOL. ACP can be billed for if taking place with patients, families, or decision makers, and can be billed for in a clinic or hospital setting (Centers for Medicare and Medicaid Services, 2016a). If patients are unable to speak for themselves, the clarification, discussion, and completion of ADs can take place with the decision makers and be billed. While this may provide some incentive for healthcare providers to engage in ACP with patients, it is one piece of a complex network of barriers. Implementing strategies to encourage patients to engage

in ACP while still healthy, or early on in their disease course, continues to challenge healthcare organizations.

Many current reimbursement structures provide incentives for aggressive medical treatments and inpatient hospitalizations, which are incongruent with the ultimate goals of many individuals and can contribute to increased and unnecessary expenditures (Unroe et al., 2015). A 2010 study found that the average cost of a hospitalization with an intensive care unit (ICU) stay at the EOL was \$38,000, while an EOL hospitalization without an ICU stay was \$13,000 (Zilberberg & Shorr, 2012). Another study looked at terminal cancer patients who reported high spiritual support and care congruent with their values and beliefs had a lower cost of care by \$2,441 in the last week of life (Balboni et al., 2007).

Population of Interest

The population of interest includes adults 18 and older with decisional capacity seeking to learn more about the process of ACP and AD documents for themselves or others. Because one-on-one discussions regarding ACP and ADs are cited as cost prohibitive and may be restricted by staff availability in both inpatient and outpatient settings, community-based seminars have been evaluated as a more effective way to educate a broader patient base about ADs and the ACP process (Blackford & Street, 2012a, 2012b; Blackford & Street, 2013; Bomba & Orem, 2015; Bravo et al., 2016; Hinderer & Mei Ching, 2014; Matsui, 2010; McLennan, Boddy, Daly, & Chenoweth, 2015; Pecanac et al., 2014; Wilson et al., 2014). This allows organizations to increase community engagement while providing important education to the public regarding EOL care and ACP. Providing community-based education in a group format is a non-

threatening way to broach a sensitive topic with individuals seeking more information. Seminars provide a way to deliver general education regarding ACP, allowing patients to assess their EOL preferences and begin discussions with their decision makers before seeking out appointments with their healthcare providers.

Clinical Question

A PICOT question guided this project where P stands for population, I stands for intervention, C stands for comparison group, O stands for outcome, and T stands for time frame.

P: Decisional adults 18 and older

I: Community-based educational seminar about ACP

C: Knowledge at baseline

O: Increased knowledge of the ACP process

T: Three months

(P) In decisional adults 18 and older, (I) does a community-based educational seminar about ACP led by an interdisciplinary team (O) increase knowledge of the ACP process (C) compared to baseline (T) in a three month period?

Purpose of the Project

The purpose of this project was to determine whether community-based educational seminars about ACP led by an interdisciplinary team increased knowledge of the ACP process. A secondary measurement assessed completion rates of AD documents during the community-based seminars.

The long term goal of this project is to establish a system-wide ACP community-based seminar program. The seminars will initially be brought to smaller rural

communities by the initiating team, and be observed by local providers willing to run the seminars in the future. These physicians, APRNs, RNs, and social workers will then begin holding their own sessions in their rural community based on the model set forth by the pilot team. In addition, a need for implementing ACP seminars in local places of worship has been identified. Planning to incorporate the organization's parish nurses into leading these seminars in public places of worship has been initiated. While the ACP community seminars will be ongoing and continue to grow as a program, the purpose of this project seeks to establish the program in one community and measure initial trends associated with a baseline population.

Chapter 2: Literature Review and Model of Evidence-Based Care

Introduction

This chapter will review the literature related to ACP interventions and education in a community setting. Patient, decision maker, and provider attitudes and beliefs regarding ACP, as well as gaps in the evidence, will be discussed. The Johns Hopkins Nursing Evidence-Based Practice Model (JNHEBPM) (Dearholt & Dang, 2012) and Reed's Theory of Self Transcendence (Reed, 2014), which guided the project, will be described. Kotter's Eight Step Process of Successful Change will be examined as the framework for change (Kotter, 2016).

Review of Literature

A literature search for the PICOT question was conducted using CINAHL, Cochrane Database, Ovid and PubMed, as well as material from AARP, the National Consensus Project for Quality Palliative Care, Centers for Disease Control and Prevention (CDC), United States Preventive Services Task Force (USPSTF), Centers for Medicare and Medicaid Services (CMS), California HealthCare Foundation, National Center for Health Statistics (NCHS), National Hospice and Palliative Care Organization, Hospice and Palliative Care Nurses Association (HPNA) and the American Nurses Association (ANA). Additionally, several hand searches were conducted for specific articles that were cited within retained sources. This resulted in a broad overview of ACP concerning nursing and other allied health professionals.

Initial keywords included *advanc* directiv** and *advanc* care plan** producing between 2,271 and 11,659 results. Additional search terms were then added in combination with these initial keywords using the Boolean operators *AND* and *OR* to link

the terms. New search terms included *community*, *seminar*, and *education*. These terms were added to the initial search approach to answer the PICOT question more efficiently. Database searches were limited to articles published in 2007 or later, had been peer-reviewed, and were written or translated in English. Full text availability was a necessity either online or in print through South Dakota State University or the University of South Dakota. Articles were excluded if the population of interest was too narrow in scope. This included populations in which only a specific disease group or region without generalizable results was studied. Articles were also excluded if the evidence focused on inpatient interventions, or if they focused on EOL, hospice, or palliative care rather than ACP or AD completion in decisional adults.

In total, 552 articles were returned; of the 552 articles, 20 were identified as applicable to the PICOT question and retained for further review. Appendix D offers a complete outline of search terms used and results returned per database once search terms were refined. Supplementary resources were identified through assessment of the reference lists from these articles and these have been incorporated into the literature review.

Quality of Evidence

The literature was appraised using the Johns Hopkins Nursing Evidence-Based Practice Research Evidence Appraisal Tool, and Non-Research Evidence Appraisal Tool, dependent on literature type. The Johns Hopkins tools offer a way to rate literature in two ways, by level of evidence and quality of evidence. The Level of evidence ranges from I to III for research evidence, with Level I being the most rigorous type of experimental study or randomized controlled trial (RCT), and Level III being a non-

experimental or qualitative study. The quality of evidence is based on the assessment of 12-16 domains of each piece of evidence such as sample size, consistent narrative, and whether limitations were addressed. The quality for research evidence is rated high quality, good quality, or low quality. For non-research evidence, level of evidence can be rated a level IV—which would include publications such as clinical practice guidelines or consensus statements—or a Level V, which may include a non-systematic literature review or expert opinion. Non-research evidence is also rated as high quality, good quality, or low quality based upon evaluation of three to seven domains (Dearholt & Dang, 2012). Appendix D offers a detailed appraisal of the literature retained, assessing both level and quality of evidence.

Evidence Findings

Benefits of ACP and AD

Impact of ACP education on patient choices. Having an AD alone without participating in ACP may not significantly reduce hospitalizations toward the EOL, or in-hospital deaths (Silveira, Wiitala, & Piette, 2014). A national study in 2007 found that 70.8% of study participants who passed away had an AD, and those that passed away in a nursing home or at home with hospice were more likely to have an AD and less likely to have used a feeding tube or ventilator in the last month of life (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). A New York state initiative for a community approach to ACP found that when individuals 18 and older engaged in meaningful EOL planning with their decision makers, healthcare teams, and families, AD rates increased from 48% to 55% over 6-8 weeks of workshops (Bomba & Orem, 2015).

Impact on decision makers. Individuals acting as decision makers are at risk to develop post-traumatic stress disorder (PTSD), depression, anxiety, and decisional burden associated with their role (Detering et al., 2010; Hickman & Pinto, 2014). In cases where decision makers were expected to engage in care planning in chronically critically ill patients who had not participated in ACP and did not have ADs, decision makers reported significant role stress and depressive symptoms (Hickman & Pinto, 2014). A national study conducted found that of 1,587 patients, 70.8% had an AD in place. Decision makers of patients with an AD cited fewer concerns with physician communication and higher patient satisfaction (Teno et al., 2007).

Patient Attitudes and Beliefs

While up to 70% of individuals state that their preference is to die at home, almost 76% pass away in a healthcare institution (California HealthCare Foundation, 2012; Gruneir et al., 2007; National Center for Health Statistics, 2010). Patients often cite reasons for not having completed an AD such as their physician did not bring it up or they do not have enough education/information (Cohen & Nirenberg, 2011; Kavalieratos et al., 2015; Litzelman, Cottingham, Griffin, Inui, & Ivy, 2016; McLennan et al., 2015). A study of young adults aged 18-30 found that young adults feel ACP is valuable but lack information regarding the process and thus do not take part (Kavalieratos et al., 2015).

Patients often feel relieved when their healthcare worker brings up the topic and are willing to talk about their wishes for EOL care (Litzelman et al., 2016). Patients feel it is important to have conversations in a state of well-being with their decision maker, loved ones, and health care provider regarding their values and what QOL at the EOL means to them in order to prevent conflict and ease difficult decisions (Durbin et al.,

2010; Houben, Spruit, Groenen, Wouters, & Janssen, 2014; Malcomson & Bisbee, 2009; McMahan et al., 2013).

Community-based Approach

AD completion rates can be improved if participants can identify with educational information and engage in meaningful discussion (Durbin et al., 2010; Hinderer & Mei Ching, 2014). Community-based group seminars regarding ACP may facilitate understanding and improve attitudes, as well as prompt conversations with loved ones and increase completion of advance care planning documents (Hinderer & Mei Ching, 2014). An ongoing initiative in an urban Mid-West collection of communities found that when diverse healthcare organizations have united initiatives to recruit community engagement in ACP, there are higher proportions of with ADs or advance care planning documents on file in EMRs (Wilson et al., 2014).

International Evidence

A study conducted in Australia found that members of a community lacked knowledge of the ACP process, and found forms difficult to access and fill out. Additionally, these adults had misconceptions about who should engage in ACP and were found to avoid taking part in the process due to anxiety (McLennan et al., 2015). Patients who have participated in ACP have been found to utilize more comfort focused measures such as hospice and palliative care services, while decreasing the amount of inpatient hospitalizations towards the EOL (Brinkman-Stoppelenburg et al., 2014). Many older adults prioritize symptom management and comfort treatments at the EOL, and would choose to decline life-sustaining actions (Bravo et al., 2016; Brinkman-Stoppelenburg et al., 2014). In a randomized controlled trial conducted among 86 older adults and their

decision makers, older adults in the intervention group receiving education and information regarding ACP were more likely to choose comfort care only with no life prolonging interventions. Because the intervention group was given education and had time over three months to reflect on their wishes and hold discussions with their decision makers, their decision makers were also more likely to choose care that aligned with what the patient would have chosen for themselves (Bravo et al., 2016). Patients who participate in ACP may be less likely to want cardiopulmonary resuscitation (CPR) or life sustaining treatments offered (Detering et al., 2010), and patients who are educated with video decision aids are less likely to choose CPR (Jain et al., 2015).

Impact of ACP on compliance with patient wishes and QOL at EOL. ACP is thought to improve QOL at the EOL, and to improve decision maker and healthcare compliance with patient wishes. A systematic review found that patients who had a documented DNR order had increased utilization of hospice services, decreased use of CPR support measures, and decreased hospitalizations. Additionally, this review found that do-not-hospitalize orders were related to fewer hospitalizations and increased utilization of hospice services, and having ADs was related to higher use of out-of-hospital care that focused on comfort rather than life-sustaining measures (Brinkman-Stoppelenburg et al., 2014). Patients who engaged in comprehensive ACP, rather than focused only on completing ADs, had higher satisfaction with their care at the EOL (Detering et al., 2010). Their decision makers cited greater compliance with the patients' wishes and fewer concerns with communication (Brinkman-Stoppelenburg et al., 2014; Detering et al., 2010; Teno et al., 2007).

Healthy working relationships among colleagues within an organization are essential to guide ACP in practice to ensure a cohesive environment where providers have the patient's best interest in mind (Colville & Kennedy, 2012). A 16-month multi-site study conducted in Victoria, Australia examined whether implementing an ACP model into existing community palliative care structures would be practical. This study found that participation of patients' decision makers served as a more significant outcome measure than completion rates of ADs. By improving education and communication among sites and with patients, the scope of the model was made broader and it was incorporated into routine palliative care in the community (Blackford & Street, 2012a). In a systematic review and meta-analysis conducted in the Netherlands on the efficacy of various ACP interventions, it was found that interventions which focused on ADs and communication about EOL care resulted in increased AD completion and improved communication between patients and healthcare providers (Houben, 2014).

A randomized controlled trial was conducted in Melbourne, Australia in which a control group received usual care and an intervention group received ACP. Rates of anxiety, stress, and depression were significantly less in surviving family members of the intervention group (Detering et al., 2010). When coupled with conversations surrounding values and preferences, a randomized controlled trial of living patients and their decision makers found that decision makers are better at predicting overall goals of care than specific treatments a patient may want (Bravo et al., 2016).

Evidence Summary (Recommendations for Practice)

Nurses are well poised to provide patient education on ACP and ADs, either alone or as part of an interdisciplinary team. While one-on-one discussions about ADs are

effective, they are also cost-prohibitive and can take extensive amounts of time during inpatient and outpatient settings. As a result, community-based educational seminars on ADs and the process of ACP have been proposed as a cost-effective way to provide education to competent adults (American Nurses Association, 2014; Cohen & Nirenberg, 2011; Litzelman et al., 2016). Combined written and verbal interventions have been shown to be more effective than written interventions alone when looking at AD completion, therefore a seminar format may improve participant understanding of the ACP process and facilitate completion of ADs (Durbin et al., 2010). Features of a healthcare system are critical to applying ACP best practice, and a complete organizational approach is required to effect change (Baughman et al., 2015; Blackford & Street, 2012a). Community-wide education campaigns may result in increased engagement in ACP and AD completion, and improved QOL at EOL as evidenced by several efforts across the globe (Blackford & Street, 2012a; Bomba & Orem, 2015; Pecanac et al., 2014; Wilson et al., 2014)

Gaps in the Evidence

Most studies conducted include specific illness categories or patient populations such as HIV, oncology, or geriatric patients. Few studies have been conducted on a broad and diverse patient population base. Additionally, most studies have included largely Caucasian or African American patients, and all patients in United States studies were English speaking. It is well known that patients with diverse ethnic and cultural backgrounds may benefit from discussions regarding EOL care preferences. However, patients who are non-English speaking are often excluded from studies in the United

States, or patient populations are not always diverse enough to provide representative sample of a population to assess for clinical implications in practice.

Nurse-led education on ACP and ADs is associated with improved patient attitudes about ACP and ADs and a higher likelihood of patients' completion of an AD (Hinderer & Mei Ching, 2014). More evidence is needed to show whether community-based education on ACP impacts the number of ADs completed, improves patient knowledge of the ACP process, and if having an advance care plan document impacts patient perceived QOL and quality of the dying experience.

Evidence-Based Practice Model

The Johns Hopkins Nursing Evidence Based Practice Model (JHNEBP) was used to apply this research to nursing practice. The basis of this model includes three key elements; practice, research, and education, as well as a three phase process which includes developing a practice question, gathering evidence, and translating the findings (Dearholt & Dang, 2012). This project employed these three key elements, as ADs and ACP are directly applicable to practice. Initiatives are already in place to improve the quality of care at EOL, and empower patients and their decision makers to make informed choices. Literature has shown that many providers are uncomfortable discussing EOL decisions (Aziz, Miller, & Curtis, 2012; Keating et al., 2010). Research must be furthered to understand how the ACP process contributes to improved patient QOL at the EOL, how ACP and ADs may contribute to decreased decision maker and healthcare worker distress, and how interventions can be generalized to the public. Education is needed for both patients and healthcare workers to drive further knowledge regarding this subject. While several studies have shown success in improving patient

attitudes through community ACP programs, no single intervention exists that has been widely studied (Blackford & Street, 2012a, 2012b; Bomba & Orem, 2015; Pecanac et al., 2014; Wilson et al., 2014). This project is based on educating decisional adults 18 and older about ACP to improve knowledge.

The model is driven at the center by evidence-based research which serves to enlighten the three key elements previously mentioned. This model applies the development of a practice question (PICOT question in this project); exploration, assessment, and synthesis of the best available evidence; and finally the model applies the translation of this evidence into a plan for action or practice change (Dearholt & Dang, 2012).

Phase One: Practice Question

The first phase of the JHNEBP process consisted of gathering a team and framing a practice question (Dearholt & Dang, 2012). An interdisciplinary team was recruited through contact with the Palliative Care (PC) department at the organization in which the project took place. The PC team consists of a physician, two certified nurse practitioner(s) (CNP(s)), a registered nurse (RN) who formerly served as a chaplain, a social worker (SW), and a support specialist who also serves as a notary. The interdisciplinary team was then queried to discern what information would be most valuable to gather regarding the seminars and participants. This allowed for an EBP question directed at a measurable outcome that was both of interest to the group and of value to the organization. The scope of the EBP question was then examined, and it was decided that decisional adults 18 years and older would be included. Key stakeholders were then identified.

Many studies have assessed interventions for inpatients and outpatients and have looked at community-based interventions for specific demographics (for instance, adults 65 years and older). The stakeholders felt that it would be of value to educate and gather information on all decisional adults 18 and older at this time, to gain a broader understanding of the impact of the seminars. The stakeholders include the PC team, participants, and physician groups referring their patients to the seminars. The project manager was designated as the DNP student, with the primary organizational contact and collaborator being the PC physician.

Phase Two: Evidence

The second phase of the JHNEBP process involved performing a literature review based on the EBP question to gather, evaluate, and synthesize the best available evidence in order to make recommendations for practice change (Dearholt & Dang, 2012). A literature search was conducted utilizing several databases, and professional resources. The overall strength and quality of evidence was then compiled and interpreted for review in an effort to guide the recommended practice change (Dearholt & Dang, 2012).

Phase Three: Translation

The third and final phase of the JHNEBP process focused on translating the evidence into practice, if reasonable and appropriate (Dearholt & Dang, 2012). Due to successful community-based seminars on ACP being implemented in other areas of the country, it was decided that implementing a community-based seminar on ACP would be a realistic practice change. The team, in conjunction with organizational leaders, determined that starting with two seminars per month was a cost-effective way to implement the practice change, thus finding a good fit for the organization. An action

plan was then created and resources were secured so the plan could move forward. The PC physician and organization determined that the seminars would begin in January of 2017, with pilot sessions beginning in August of 2016. The DNP student developed the educational program for the start date. The program content and process were revised based on team and participant feedback following the pilot sessions. Evaluation took place once the proposal was approved and content and process were established. A facility to hold the seminars was secured, and the seminars were added to the organization's community calendar. Outcomes were evaluated post-intervention as information gathered from the project surveys and demographic tools was recorded and synthesized in an effort to understand what effects, if any, resulted from the seminars (Dearholt & Dang, 2012).

Reporting the outcomes to the stakeholders took place after the project was completed. In the synthesis of the outcomes, the next steps for ACP seminars were identified and recommendations for furthering practice based on outcomes were made. The findings will be disseminated through the organization's research conference, and applications for publication and presentation will be made to journals as well as state and national conferences (Dearholt & Dang, 2012). This comprehensive process ensures the best possible utilization of evidence to move practice forward, and disseminate the findings to colleagues.

Theoretical Approach

This project utilized a nursing theory to allow for a more comprehensive understanding of the many variables which needed to be considered. Participant demographics, attitudes and understanding about the topic, as well as organizational

influences such as space availability, resources devoted to the seminars, and openness to ACP as a topic were important to consider. By framing the project around a nursing theory, the DNP student was able to better anticipate potential barriers and organize the project. A change theory was used to assist with a framework for implementing and sustaining the project. This allowed for continuous reassessment of progress throughout the data collection period.

Nursing Theory

Reed's Theory of Self-Transcendence guided the approach to this intervention. The theory emphasizes patients' abilities to rise above trials yet persist in a state of well-being and sense of wholeness (Reed, 2014). The theory emphasizes that development continues past young adulthood, and postulates that those that can find meaning through the processes of aging and failing health are more likely to achieve self-transcendence and an enriched state of well-being. With personal development comes an acceptance of aging and eventual death, but not all individuals accept their mortality (Reed, 2014). Those that can cope well with the concept of their own death may be more likely to engage in ACP and complete an ACP document and ADs to dictate the direction of their EOL care. The self-transcendence theory focuses on three relationships; intrapersonal, interpersonal, and transpersonal. These relationships are important in ACP as one makes decisions and communicates wishes, values and plans to family members and healthcare providers. Self-transcendence is affected by one's well-being, vulnerability, personal and contextual factors, and these three relationships (Reed, 2014).

In order for someone to reach a level of self-transcendence in which they are willing to accept their mortality and complete an advance care planning document, they

must have a healthy intrapersonal relationship (Reed, 2014). Knowing their own values, beliefs, and desires help guide the decisions they will express in these personal documents. An individual who does not have a deep understanding of their own belief system may find themselves vulnerable in the wake of a new diagnosis, finding it difficult to cultivate a true sense of well-being in the context of their current state of health. This individual may not be able to cope with formulating an advanced care planning document until they have had education about their diagnosis and had time to grieve the loss of their former state of well-being.

Someone completing an advance care planning document will need to designate a decision maker to make decisions for them in the event they lose decisional capacity. Due to the emotional implications surrounding EOL circumstances, interpersonal communication is important. Fostering interpersonal relationships during the ACP phase can help to improve QOL during EOL circumstances, and ease tensions between family members and loved ones, thereby improving the overall dying process (Reed, 2014).

Transpersonal communication refers to relationships with beings outside of oneself - such as a higher being. Having the ability to relate to a higher power can facilitate decision making and provide comfort during a time of introspective turmoil (Reed, 2014). Finding meaning and well-being during times of vulnerability may prove difficult for individuals with poor transpersonal communication, thereby making it challenging to achieve self-transcendence during times of trial. Individuals with a strong sense of transpersonal communication are more readily able to maintain well-being despite shifting contextual factors including sudden illnesses or financial changes. These individuals may find that they are ready earlier on in their lives to participate in ACP due

to a sense of wholeness and lack of uncertainty about death. They may also more achieve and maintain self-transcendence more readily (Reed, 2014).

Change Theory

Kotter's Eight Step Process of Successful Change is the change theory that guided this project (2016). This theory's first step is to create a sense of urgency regarding the issue at hand. For this project, the IOM's report (2015) *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, and the National Consensus Project for Quality Palliative Care report (2013) *Clinical Practice Guidelines, 3rd Edition*, created a sense of urgency surrounding ACP and ADs. These reports both call healthcare professionals to action in accepting responsibility for discussing EOL care with their patients.

Step two includes building a coalition, which was done in conjunction with the interdisciplinary PC team. Step three is to form a strategic vision and initiatives, which was done with the PICOT question and purpose statement. Step four includes enlisting facilitators, which was accomplished through recruiting stakeholders and a comprehensive team of experienced and supportive individuals to contribute knowledge to the project. Removing barriers and taking action, and then generating short term wins are steps five and six respectively. These were done through identifying barriers and working to minimize them. Through utilizing pilot sessions and implementing feedback from participants and team members, barriers were minimized prior to data collection. Looking through the demographic data and holding discussion with participants after each session helped to identify areas for improvement for future seminars, thereby improving the overall effectiveness of the project. Step seven includes sustainability

while step eight cites instituting long term change into practice if indicated (Kotter, 2016).

Chapter 3: Methods and Procedures

Introduction

Community-based ACP seminars have been proposed as an effective alternative to one-on-one interactions to provide education and promote discussion in adult patients regarding EOL wishes (Bravo et al., 2016; Hinderer & Mei Ching, 2014). While there is no solitary intervention or educational program that evidence finds singularly effective, there is promising research on community ACP seminars overall (Bomba & Orem, 2015; Bravo et al., 2016; Hinderer & Mei Ching, 2014). The seminar approach provides a non-confrontational environment for patients to receive education, ask questions, and in the case of this project fill out AD documents, if desired. This addresses the PICOT question by educating decisional adults 18 years and older about ACP, assessing whether participant knowledge increases post-intervention, and observing how many participants choose to complete ADs.

Methods

Design

This quality improvement project aimed to improve communication about the importance of ACP between one healthcare organization and decisional adults 18 and older. A pre/post intervention was used to measure change in knowledge about ACP. This project was deemed quality improvement because the purpose of the project was limited to implementing an intervention which sought to improve the quality of participant care (Office of Human Research Protections, 2016). It combined an educational presentation with discussion format, and gathered information from participants using two surveys to trend demographics and measure knowledge of ADs

and the ACP process. Several pilot sessions were utilized to refine the educational presentation prior to data collection (Appendix J). Input was sought from the healthcare team and community members (stakeholders) to further develop the community-based intervention.

Setting

The community in which the seminars were held is an urban Midwest City (population 171,544) in a rural state. The seminars were held on the campus of a hospital in an urban Midwest town. This hospital is one of three major medical facilities in the community, and it was anticipated that participants were primarily patients of the institution at which the seminars took place. An outpatient building housed several small conference rooms and classrooms, appropriate audiovisual equipment, and desks for participants to utilize. Beverages were provided. Sessions took place in the afternoon on the second and fourth Thursdays of each month.

Sample

Decisional adults 18 and older comprised the convenience sample for this project. The population from which the sample was derived was largely Caucasian (86.6%), with minority groups including African American (4.2%), American Indian (2.7%) and others (United States Census Bureau, 2010). It was anticipated that the participants would be male and female. Because the sample was recruited through advertising, overhead facility announcements, and healthcare provider referrals, it was difficult to anticipate specific age trends or disease states prior to gathering participant information.

The sample size needed to determine statistical significance was approximately 60 participants for the signed rank test for comparison of the pre- and post-intervention data.

The anticipated number of sessions was two per month indefinitely, per facility planning, with an exception for January of 2017 for which three sessions were scheduled. Sessions accommodated a maximum of 30 participants. Data collection was set for three months, or eight sessions. Anyone in attendance under the age of 18 years old would be excluded from the sample. Non-English speaking adults would be encouraged to participate in the sessions via use of translation boards, but would be excluded from the sample due to ethical considerations with consent.

Marketing and recruitment. Decisional adults 18 and older were recruited through marketing, overhead facility announcements, and healthcare provider referral to attend the monthly seminars. Team members reached out to primary and specialty healthcare providers within the organization. The PC team and DNP student rounded to clinics and discussed the seminars with healthcare providers and employees with the goal of recruiting patients, employees and other potential participants (parents of employees, adult children of patients, etc.). Fliers were distributed to regional clinics, and the event was added to the organization's online community calendar.

Intervention

The education and PowerPoint presentation were developed by the DNP student based on evidence-based literature and current practice guidelines. Information from the National Consensus Project for Quality Palliative Care (2013), National Center for Healthcare Statistics (NCHS) (2010), National Institutes for Healthcare Improvement (IHI) (2016), National Hospice and Palliative Care Organization (NHPCO) (2016), and the IOM (2015) guided the development of the intervention. Input from the PC physician was taken into consideration when developing the content. It consisted of a 30 minute

presentation that addressed the process of ACP, why ACP is important for all individuals 18 and older, the content and meaning of AD documents, defining QOL (identifying a personal meaning in the context of EOL care), cardiopulmonary resuscitation (CPR) (what it entails, success rates, what to consider when making a decision regarding CPR), and services that can be helpful as one nears the end of their life.

Educational Format

The education was developed using four themes that recur in the literature. Individuals were encouraged to think about their values and preferences, and how these would guide their care at the EOL. During this phase, the education emphasized the importance of reflecting on who to choose as a decision maker in the event that decisional capacity is lost. Additionally, patients were encouraged to educate themselves regarding different treatment options that may be available and explore how these may fit into their personal value sets (Institute for Healthcare Improvement, 2016; Institute of Medicine, 2015; National Consensus Project for Quality Palliative Care, 2013; National Hospice and Palliative Care Organization, 2016).

Once individuals had reflected on their values and preferences, the next recommendation was to talk about it. This included engaging in conversations with loved ones, those selected as decision makers, and the healthcare team (Institute for Healthcare Improvement, 2016; Institute of Medicine, 2015; National Hospice and Palliative Care Organization, 2016). After discussions had taken place, individuals were encouraged to document their wishes. Legal forms such as LWs and DPOA-H make up traditional ADs, while newer advance care planning documents outlining goals of care and preferences are also useful (Institute for Healthcare Improvement, 2016; Institute of Medicine, 2015;

National Consensus Project for Quality Palliative Care, 2013; National Hospice and Palliative Care Organization, 2016). ACP is an ongoing process, so this educational intervention emphasized the importance of reevaluating personal values and preferences, selected decision makers, and documentation throughout the lifespan. The intervention provided suggested circumstances and intervals at which to reevaluate based on current recommendations (Institute for Healthcare Improvement, 2016; National Hospice and Palliative Care Organization, 2016).

Participants were educated about what ACP means, what the process entailed, and how to begin. The presentation opened with an overview of ACP. In the intervention, the following definitions were used to answer the question-What is ACP?

- Clarification of values and goals (Institute for Healthcare Improvement, 2016)
- Embodiment of preferences through written documents and medical orders
- Discussion of medical preferences in the context of serious illness (Institute of Medicine, 2015)
- Ideally includes discussion with their primary clinician and decision maker or DPOA-H (Institute for Healthcare Improvement, 2016; National Hospice and Palliative Care Organization, 2016)
- May start at any time in a person's life and be revisited periodically (Bomba & Orem, 2015; National Hospice and Palliative Care Organization, 2016)
- Allows for flexible decision making in the context of the person's current medical status (Institute of Medicine, 2015)

It was emphasized that ACP is an ongoing conversation about what an individual would or would not want in terms of a medical plan of care if they were facing something serious or life threatening (Brinkman-Stoppelenburg et al., 2014).

Think about it. Reflecting and clarifying personal values and goals was a recurring theme in the literature (Institute for Healthcare Improvement, 2016; Institute of Medicine, 2015; National Consensus Project for Quality Palliative Care, 2013; National Hospice and Palliative Care Organization, 2016). The importance of understanding one's own wishes before engaging in conversation with others was highlighted in the presentation. Participants were encouraged to identify what an acceptable QOL may look like to them. This included reflecting on progressive or sudden changes in cognition and/or functional status, as well as how they may define QOL in the context of a terminal illness or coma (Institute of Medicine, 2015; National Hospice and Palliative Care Organization, 2016). The presentation emphasized that an acceptable QOL may be different for everyone, and that personal, environmental, social, cultural, and spiritual factors influence these insights (Brinkman-Stoppelenburg et al., 2014; Institute of Medicine, 2015).

Participants were also given information on how to choose a decision maker, or DPOA-H, and encouraged to reflect on who may or may not be a reasonable option to fill this role. The person selected to be a decision maker must meet legal criteria (be at least 18 years or older and competent) (Institute of Medicine, 2015). Additionally, it is typically best if the person selected knows the individual well, is willing and able to speak on behalf of the individual should they become unable, should be able to separate their own feelings from the individual's wishes, should be able to handle potential

conflict between loved ones, should be reasonably available in the event of emergency, and should be willing to discuss the individual's preferences and goals of care now (Institute for Healthcare Improvement, 2016; Institute of Medicine, 2015). Many individuals reconsidered their first instinct after reflecting upon these measures, understanding that some loved ones may not be able to discuss sensitive EOL wishes now, or separate their own feelings from the individual's in the context of an EOL circumstance.

Finally, patients were given information regarding different medical interventions and services available at the EOL. This education was given so that patients had the opportunity to ask questions, seek clarification, and further understand and reflect upon available treatment options and services they may or may not be interested in. The procedure of CPR was reviewed, and a discussion about who may or may not be a good candidate, survival rates, and secondary outcomes and sequelae followed (Ahmad, Mudasser, Khan, & Abdoun, 2016; Chan et al., 2013; Your Health Choice, 2012). Interventions such as intravenous therapies (nutrition, hydration, antibiotics), oxygen, non-invasive and invasive ventilation including tracheostomy, tube feeding (nasogastric, percutaneous), and time defined trials were all briefly defined, discussed, and clarified for participants (Institute for Healthcare Improvement, 2016; Institute of Medicine, 2015). Participants were encouraged to stay after the seminar for additional clarification, or take specific questions about interventions in the context of their own illnesses to their healthcare providers.

Palliative care and hospice services were outlined, defined, discussed, and clarified. These were included in the presentation to educate participants early on in the

ACP process about the availability and philosophies of these services so patients were able to incorporate symptom management or comfort focused measures into their ACP conversations if desired (American Nurses Association, 2014; National Consensus Project for Quality Palliative Care, 2013; National Hospice and Palliative Care Organization, 2016).

Talk about it. Once patients had reflected on the values that will guide their care, what care options they may or may not be interested in, and who they think would make a suitable decision maker, it was time to begin conversations. Ideally, conversations started early, before the onset of serious illness or injury, and involve loved ones including the anticipated decision maker(s). Participants were encouraged to discuss what values and beliefs they hold that should guide their care, what QOL means to them personally, and what treatment options they would or would not be interested in should they lose decisional capacity (Institute for Healthcare Improvement, 2016; Institute of Medicine, 2015; National Hospice and Palliative Care Organization, 2016). Having these conversations provides an opportunity for individuals to clarify any preferences that may be misunderstood. They may also want to sit down together with some loved ones who may be inclined to disagree, and may benefit from engaging in these discussions at the same time (Institute for Healthcare Improvement, 2016).

Individuals were also encouraged to discuss their values and preferences with their providers. Participants were encouraged to ensure they have a solid understanding of any illness or diagnosis they have, the natural course of the illness with or without treatment, common symptoms of their illness and how they can be managed, and their prognosis with or without treatment (Centers for Disease Control and Prevention, 2013;

Institute for Healthcare Improvement, 2016; National Consensus Project for Quality Palliative Care, 2013). Participants were encouraged to ask questions and seek recommendations as appropriate during visits with their healthcare provider.

Document it. Information was reviewed on how individuals are able to document their preferences and chosen decision maker. Traditionally, legal documents, or ADs, consist of a LW and DPOA-H. It is important to document who the chosen decision maker(s) is/are, and make sure they understand their responsibility. Participants were encouraged to fill out additional documentation that focuses on their values and overall preferences, rather than specific treatments and scenarios that may occur. These advance care planning documents encourage open and honest communication with the healthcare team, decision maker, and other loved ones. Participants were educated about the option for a travelling DNR order. In the state where the project took place, this is referred to as a Comfort One document. Surrounding states have similar documents known as a Physician Order for Life Sustaining Treatment (POLST) (Minnesota Network of Hospice and Palliative Care, 2016; South Dakota Department of Health, 2016).

Reevaluate. Individuals' values and preferences tend to change over the lifespan as their experiences mold them. Factors such as wellness or illness, injury of self or a loved one, personal loss, socioeconomic status, cultural and spiritual influences, and aging may alter one's views over time. Due to these influences, it was recommended that individuals reevaluate their advance care planning document and ADs periodically and continue to treat ACP as a fluid process (Institute for Healthcare Improvement, 2016; Institute of Medicine, 2015; National Hospice and Palliative Care Organization, 2016). Any major life changes, such as the diagnosis of a new illness, a death in the family, a

divorce, a sudden decline or deterioration in health, or reaching a new decade in life, should prompt individuals to revisit their advance care planning document and ADs and reflect on whether they may note any changes in their values and preferences for EOL care (Institute for Healthcare Improvement, 2016; Institute of Medicine, 2015).

Pilot Sessions

Several pilot sessions were utilized to refine the education and flow of the seminars. The education was provided by the PC physician at the first pilot session with observation and critique by the rest of the team, with the DNP student leading subsequent seminars (Appendix J). Participants at pilot sessions ranged in age from mid-20s to mid-80s and were mixed male and female. One non-English speaking individual did attend one session and was accommodated via video interpreter board. An unanticipated finding in pilot sessions was that participants drove from outlying communities, some as far as 90 miles, to attend the seminars.

Verbal feedback from the pilot session participants was overwhelmingly positive regarding the seminars. Participants stated that the seminars were informative, that they were satisfied with how their questions were answered, that it was not what they expected, and that they would recommend the seminar to others. Many participants throughout the pilot sessions requested hand-outs of the presentation with additional information, or supplementary resources. Additionally, it was noted that the presentation was written with the assumption that participants would have a working background knowledge of the medical field. While definitions and clarifications were verbalized throughout the presentation, it was felt that the slide show should be modified to accommodate participants whose health literacy levels may be lower (Centers for Disease

Control and Prevention, 2013). Appropriate edits were made to modify the slide show while ensuring the integrity of the content was maintained.

Feedback was mixed as to whether participants were seeking information on ACP for themselves or loved ones. One younger participant and spouse were present due to a recent diagnosis of a serious progressive illness, and were seeking more information regarding the ACP process. Employees from the healthcare system, including physicians and nurses attended pilot sessions. Some employees were seeking information for their practice, while others sought to understand ACP for themselves, or wanted information on how to approach the topic with their loved ones.

Instruments

The demographic survey (Appendix E) obtained with permission from Hinderer & Lee (2014) was used to assist with retrospective sample trending. Originally a 14-item survey, it was adapted into a 10-item survey that addresses concepts such as presence of chronic disease, education level, age, and ethnicity (Hinderer & Lee, 2014). The original survey included identifying information such as name, address, telephone number, and email address that were removed for the purposes of this project.

The ACP/AD Knowledge Survey (Appendix F) adapted from Murphy, Sweeney, and Chiriboga's (2000) survey guided understanding of participant knowledge of the ACP process and ADs pre- and post-education (Murphy, Sweeney, & Chiriboga, 2000). The ACP/AD Knowledge Survey is a 10 item, true/false survey. Participants were given two blank copies of this survey, one to complete prior to beginning the seminar, and one to complete after the seminar concluded.

Project Procedure

Documentation and Data Collection

Upon arrival, each participant was asked by the PC support specialist to sign in with their name, age, and primary healthcare provider's name. These sign in sheets were retained by the support specialist and not used for data collection purposes. Participants were given a cover letter, two copies of the ACP/AD Knowledge Survey marked pre and post, and one copy of the demographic survey, as well as an advance care planning document and AD documents on the table in front of them upon arrival. Each set of surveys were assigned a matching identification number to aid with tracking responses. Surveys were stapled together to ensure accuracy of the groupings. The cover letter was separated so participants could refer back to this as needed.

The support specialist was introduced at the beginning of each seminar. Participants were informed that if they chose to fill out legal documents, such as their ADs that day, that the support specialist served as a notary. She would notarize the documents, make copies for the participants to give to their decision maker and other loved ones, and keep a copy to fax to their primary healthcare provider or scan into the EMR if the participant consented.

Pre-seminar surveys were administered prior to beginning each session. Participants were asked to complete post-seminar surveys before leaving the seminar. The demographic survey could be completed at any time throughout the seminar. At the conclusion of the seminar, any participants that needed help filling out ADs, needed documents notarized, or needed copies made were encouraged to stay after.

All surveys were collected at the conclusion of the seminar once participants had left. Data from participant surveys was entered into Microsoft Excel spreadsheets. The data was separated into overall scores of ACP/AD Knowledge Survey, ACP/AD knowledge survey individual questions, demographic survey results, and AD documents completed at each seminar. All data was entered into its own spreadsheet, but saved into one document.

Dissemination of Data

Reporting the outcomes to the stakeholders will take place after the project has been completed with final edits. In the synthesis of the outcomes, the next steps for ACP seminars were identified, and recommendations for furthering practice based on outcomes were made. These findings will be disseminated through the organization's research conference in October of 2017, and applications for publication and presentation will be made to journals as well as state and national conferences. This comprehensive process ensures the best possible utilization of evidence to move practice forward and disseminate the findings to colleagues. These steps follow the JHNEBP model for dissemination of findings (Dearholt & Dang, 2012).

Ethical Considerations

Institutional Review Board

South Dakota State University and the organization at which the project took place approved the project through their IRBs (Appendix A, Appendix B). This project was given a rating of 2 by the Alberta Research Ethics Community Consensus Initiative (ARECCI) tool (Alberta Research Ethics Community Consensus Initiative (ARECCI)

Network, 2010). No data was collected before IRB approval was obtained from both institutions.

Protection of Human Subjects

Consent to participate. Participants were given a cover letter (Appendix H) explaining the purpose of the project and outlining what was expected of them if they chose to participate. A verbal explanation and introduction were given by the DNP student before each seminar to explain the purpose of the study: to provide education regarding ACP in a community-based setting to decisional adults 18 and older, and measure whether this resulted in a knowledge increase (Office of Human Research Protections, 2016). The DNP student allowed time for questions and clarification. Participation in survey completion was voluntary and not required to participate in the seminars.

Personally identifiable information. Participants' personally identifiable information was not used for information synthesis. Personally identifiable information was removed from end data analysis. Participants were able to withdraw at any time without jeopardizing relationships with either the health care organization or the academic institution.

Protection of data. Data was entered into Microsoft Excel and was stored on a flash drive to which the DNP student has access. The document was password protected. Copies of the file were made on two compact discs that are being stored in a fire resistant locked cabinet in the PC office for three years after the completion of the project, along with the thumb drive. This was per facility Institutional Review Board (IRB) protocol. All paper copies of the surveys were scanned and saved as .pdf files on the thumb drive

and compact discs. The paper copies were then destroyed. A copy of the data will also be provided to the academic institution per department protocol.

Analysis

A Wilcoxon signed ranks test for scalable data was used to evaluate whether the educational seminars had a positive effect, negative effect, or no effect at all on participants' knowledge of ACP. This nonparametric test was used due to the non-normality of the data. The p value for significance was set at <0.05 . Descriptive statistics were used to analyze data collected from the demographic surveys. This allowed the information to be organized and summarized for use in future practice improvement.

Environmental and Organizational Context

Many factors contributed to the support for ACP at this organization. Staff burnout related to EOL care, the desire to provide high quality EOL care, and advocating for holistic care that is goal-focused all provided impetus for this project (American Nurses Association, 2014). Additionally, the cost of healthcare continues to rise for patients and healthcare systems alike (Centers for Disease Control and Prevention, 2013; National Center for Health Statistics, 2010). ACP is a responsible way to approach guiding EOL care through patient preferences and may lead to fewer medical interventions and hospitalizations as patients age and die (Institute of Medicine, 2015). The organization provided an avenue for this project to move forward at a rapid pace, and implementation of the project fell in line with the mission, vision and values of the healthcare system which focus on a holistic and mission-based approach to guiding patients through health and illness. The ability to give patients and families a more

meaningful EOL experience by educating them early about ACP directly correlates with the holistic care vision of the organization.

Stakeholder and Facilitators

Stakeholders include the PC team and the participants. Additional stakeholders include social workers, case managers, and healthcare providers organization-wide.

Facilitators include the PC support specialist, committee members of the organizational Nursing Research Council, members of organizational Nursing Practice and Integration department, and members of the organizational Ethics board and legal counsel.

Barriers

Before the project began, potential barriers were identified. The two greatest concerns identified by the team were under-marketing of the seminars and severe weather during the winter months which could affect attendance. Additional barriers were identified throughout the implementation and completion of the project time frame.

Impact

Organization

The goal was to implement this ACP educational seminar, and then expand to additional community avenues and outlying communities within the organization's network. An identified prospective place of great impact for the seminars is local places of worship, in which parish nurses and social workers could lead the discussion. This location has the potential to make a large organizational impact on the number of patients within the healthcare network who have documented ACPs within the EMR readily accessible a mouse-click away. A notary would be present at these seminars as well, and would make copies of any ADs or advance care planning documents completed. They

would then follow the same procedure used for the on campus seminars, and fax a copy to the primary care provider of the patient, information that would be collected at sign in. The primary care provider is responsible for uploading the documents into the EMR. This would improve overall communication between facilities and providers regarding patient wishes, values, and long-term goals of care. It additionally could result in lowered costs for patients, organizations, and insurers. The long term effects of the seminars could be far reaching and long lasting, however many confounding variables exist and effects could be difficult to measure long term.

Finances

This project did not measure effects on patient or organizational finances. Patients who have a firm advance care planning document in place and have had open and honest discussions with their family and healthcare team may avoid unwanted and costly hospitalizations towards the EOL (National Center for Health Statistics, 2010; Taylor et al., 2007). In addition, expensive hospital stays, frequent readmissions, and transfers can be avoided for individuals, saving them, their insurers, and healthcare systems dollars. Decreased transfers from outlying facilities for patients who wish to stay close to home at the EOL additionally results in lowered costs for patients, organizations, and insurers (National Center for Health Statistics, 2010; National Consensus Project for Quality Palliative Care, 2013).

The project costs to consider in long term implementation include room rental, provision of beverages, provision of paper documents and pens, and time of staff involved. At this time, the room on the organization's campus was provided at no cost to the DNP student or PC team, as the project is being implemented into the long term

structure of the monthly scheduled educational opportunities. The beverages, which include coffee, tea, water, and fountain soda, fell under the umbrella of facility costs. The cost of these items were not separated out or billed to the department, and were considered a part of the overall operating costs of the organization. The PC team provided the advance care planning documents and advance directive documents for each session. The estimated cost for these items for the eight seminars during the data collection period was \$13.00. The cover letter and surveys were printed at the project DNP student's, and the cost for these items was estimated at \$17.00. Because the seminars took place during the work day and were built into the support specialist and PC physician's schedules in advance, there were no additional paid hours devoted to the seminars on behalf of the organization. In the future, if seminars would move outside of normal salaried hours, a new cost analysis would be needed, or a rotating schedule of volunteer seminar leaders was proposed. The sustainability of the seminars could depend heavily on finding individuals who are passionate about ACP to act as seminar facilitators if it is determined that volunteers are needed.

Policy Decisions

The organization at which these seminars took place has many outlying facilities that span several states, each of which have their own legislation regarding ADs. Long term, if the seminars become outreach events, firm plans must be in place prior to expanding into each state regarding legality of the documents used at the seminars, and the APP's scope of practice in that state. If a uniform document is desired across the healthcare system for use in the EMR, state legislation and the overall organizational

policy should be reviewed prior to implementation to ensure a streamlined approach for ease of future use.

Quality of Health Care

Having an ACP in place serves as a helpful way for healthcare teams and decision makers to assist in EOL decision making that aligns with the values of the patient. This can mean an improved perceived QOL even through the dying experience (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013). When able to focus on comfort and sidestep unwanted invasive treatments, patients preserve their autonomy and dignity. When educated about ACP, patients often choose less invasive measures and a comfort approach towards the EOL (Baughman et al., 2015)

Rural or underserved populations

Patients within driving distance of the community in which the seminars were offered were able to benefit from these seminars during the project phase. Future expansion of the program may include multilingual sessions at the multicultural center in the town in which the program is initially being offered. Future plans include expansion of the program to rural communities, centers of worship, potential utilization of telehealth and extension office services.

Summary

ACP is becoming more important as patients present with more chronic illnesses, decreased states of competence, and healthcare costs continue to climb (Centers for Disease Control and Prevention, 2013). One-on-one ACP can be time restrictive and cost prohibitive in both inpatient and outpatient settings. Community-based seminars have been proposed as an effective way to disseminate education regarding ACP (Bomba &

Orem, 2015; Hinderer & Mei Ching, 2014; Pecanac et al., 2014). By collecting information regarding patient knowledge of ACP before and after an educational intervention, this project sought to further the current evidence base associated with community-based ACP seminars as an intervention to increase ACP knowledge.

Chapter 4

Findings

Introduction

The project time period began in January 2017 and ended in early April, 2017. One session in February resulted in zero participants due to severe weather, thus the project period was extended by one session. The total number of seminar attendees equaled 56. There were 45 seminar attendees who participated in the project. Three sets of these surveys were incomplete – either having only a pre- or post-knowledge survey completed, or the participant took a survey home with them – so they were unable to be utilized in the data set. This resulted in an *n* of 42. One participant filled out a pre/post survey, but did not fill out a demographic survey, this data was retained for analysis.

Demographics

Participants' demographics represented variation in age, educational level, presence of chronic illnesses, experience in acting as a DPOA-H, and making EOL decisions for someone else. The demographics were largely homogenous in ethnicity, with only one participant being of Asian ethnicity and all others being Caucasian. There were eight study participants aged 20 to 40, nine participants aged 41 to 60, and 24 participants aged 61 to 80 years of age. One Participants' demographics were unknown. None of the participants had ever experienced being on life support, and many had existing ADs in place. Table I shows demographics including age and education level of participants, the mean of the difference in sums of their pre/post ACP/AD Knowledge Survey Scores, and the standard deviation of each group. This chart shows that participants with a college level education comprised 78% of the sample, while 22% had

a high school level education. Due to the limitations of the survey, it is unknown if any participants had less than a high school level of education. According to the most recent census, only 27% of South Dakota (SD) residents have a college level education (United States Census Bureau, 2010). This indicates that the sample is not representative of SD's population as a whole. Additionally, many of the participants were healthcare workers or providers – which is not reflected in the survey. Future data collection may benefit from separating out healthcare workers from non-healthcare workers to further analyze trends associated with knowledge increase of ACP.

Table I

Descriptive Statistics by Gender and Educational Level

Educational Level	Gender	Difference of Sums		
		N	Mean	Standard Deviation
High School	F	7	1.14	0.9
	M	2	0.05	0.71
	All	9	1.00	0.87
College	F	15	0.13	0.83
	M	5	0.80	1.92
	All	20	0.30	1.17
Graduate School	F	8	0.88	1.46
	M	4	1.25	1.26
	All	12	1.00	1.35
All	F	30	0.57	1.10
	M	11	0.91	1.45
	All	41	0.66	1.20

The Wilcoxon Two-Sample Test found that there was not a significant difference between the score improvement of male and female participants. The Kruskal-Wallis test determined that there was not a significant difference in score improvement based on educational level, however there was a trend towards those with a high school education improving their scores the most. This could be due to graduate school and college graduates scoring higher on the pretest, leaving a smaller window for improvement.

The Means Procedure revealed that it was not clear whether a dependence between ACP/AD Knowledge Survey score improvement and age existed. The mean age of participants was 57.2 years, the median age of participants was 63 years, and the mode was 64 years. The range was 22 years to 80 years old. Table 2 shows a brief synopsis of participant responses to the remainder of the demographic survey, which can be found in Appendix E. These results were not compared to pre/post ACP/AD Knowledge Survey scores, but were informational only.

Table 2

Participant Experiences

	Do you have one or more Chronic Illnesses?	Do you have Insurance?	Have you ever been on Life Support?	Have you ever acted as DPOA-H for someone else?	Have you ever helped someone else make EOL decisions?	Do you have an AD/LW?
Y	16	40	0	13	10	18
N	25	1	41	28	31	23

Results

The knowledge surveys were scored using a percentage converted to a decimal in the spreadsheet. Each question was worth one point – if a participant answered one question incorrectly, the score reflected on the spreadsheet as a 0.9. The scores for

participants' pre- and post-knowledge surveys were recorded in an Excel spreadsheet and compared using the Wilcoxin signed ranks test. This non-parametric test was selected in place of a paired t-test due to the non-normality of the data. A paired t-test could have been used if a test for normality is satisfied, however when the Shapiro-Wilk test for normality was applied to the data, it was determined that normality was violated. Because there were two sets of data from one group, the variances were not independent. The p value for significance was set at ≤ 0.05 , meaning there would be a less than five percent likelihood that the result would have occurred by chance. A significant difference existed between pretest and posttest scores ($p = .0004$).

Clinical significance. This project showed marked clinical significance. Participants were engaged in the seminars through questions, story sharing, and seeking to understand, they took part in meaningful discussion with the DNP student, the PC physician and CNPs, and other participants. Eight participants completed ADs throughout the course of the project period. Three participants emailed asking for further information and resources. Two sessions were set up outside of the proposed project format in a church and a senior living center to accommodate special requests.

Because many of the participants were healthcare staff, it was frequently expressed that these sessions served a dual purpose for these attendees. They felt they were able to utilize the information for themselves and loved ones, but many expressed that they felt better equipped to talk to patients and their families about ACP. Additionally, many participants expressed that they came to the seminars to get information for their elderly parents or loved ones, but found the information very valuable for themselves.

Statistical significance. The *p* value of 0.0004 was statistically significant, and indicates that it is unlikely that the knowledge increase in participants occurred by chance. Table 3 shows the statistical analysis of pretest and posttest ACP/AD Knowledge Survey scores. It also displays the difference of the sums of the pre and posttest scores.

Table 3

Statistical Significance of Pretest/Posttest ACP/AD Knowledge Survey Results

N = 42			
	PreTest	PostTest	Difference of Sums
Mean	0.848	0.91	0.643
Median	0.9	0.95	
Mode	0.9	1	
Standard Deviation	0.129	0.103	1.19
Range	0.5	0.3	
Midrange	0.75	0.85	
Alpha	0.05		
Skewness			0.932
P value	0.0004		

McNemar’s test for Paired Samples. McNemar’s test for Paired Samples was used to conclude if differences existed between the dichotomous dependent variable between the two related groups. This test additionally examined the direction and degree of change in individual answers from pretest to posttest on the ACP/AD Knowledge Survey, as well as correlation with demographics. A different score was calculated for each pair of data. The greater the amount of change the more weight the pair was given.

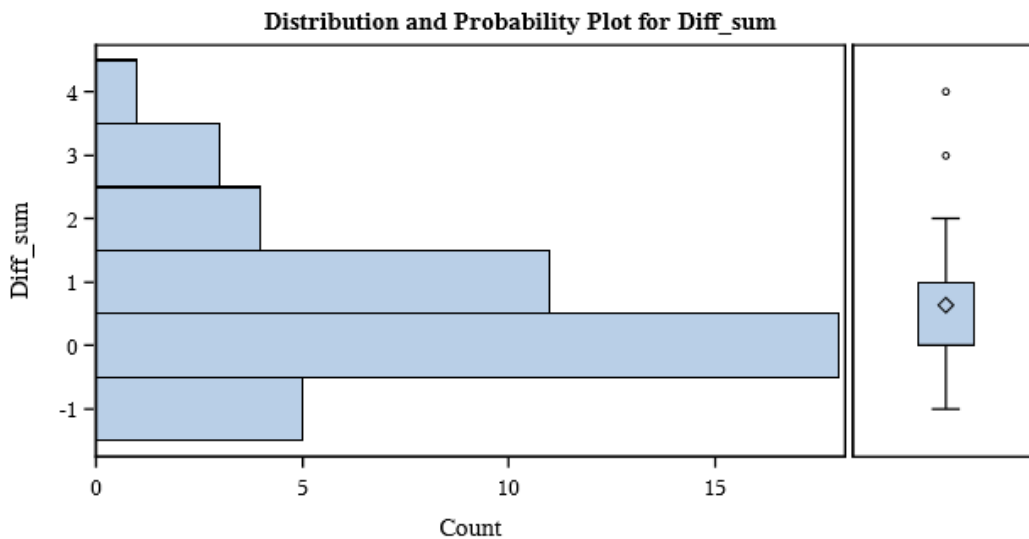
The question answered incorrectly most frequently in the pretest was question five, which read: *You should avoid second guessing your advance care plan treatment preferences.* Twenty people answered this incorrectly in the pretest, and 10 people

answered incorrectly in the posttest. This showed a 24 percent increase in correct answers from pre- to post-test. The second most incorrectly answered question was question number four which read: *Place your advance care plan or advance directives in a safe deposit box to ensure notification of directives and access when needed.*

Seventeen participants answered this incorrectly in the pretest, with only five participants answering incorrectly in the posttest, for a 31 percent increase in correct answers from pre- to post-test. An increase in correct answers in the questions answered incorrectly most often, questions four and five, was observed from pretest to posttest. Figure 1 shows a distribution and probability plot for the Difference in Sums of the pretest and posttest ACP/AD Knowledge Survey answers 1-10. This is skewed in a positive direction, meaning that the sum of posttest scores is greater than the sum of pretest scores, which suggests the scores improved.

Figure 1

McNemar’s test for Paired Samples: The UNIVARIATE Procedure, Difference of Sums



Barriers

Because participants were drawn from a convenience sample, the sample size depended on the quality of marketing and the buy-in from physicians and employees. Effective marketing was the largest barrier identified by the team in recruiting participants to attend. This was not well executed and is an aspect that would need to be re-worked for future seminars. Another large barrier identified by many prospective participants was the time of day. The seminars were held at 1:30pm, and lasted about one hour. This timing provided a challenge for those working 8am-5pm, Monday through Friday jobs.

Some participants attended the seminar but were not prepared to fill out ADs at the seminar. In the winter months, weather was a potential barrier for participants wanting to attend. Some participants felt they were very well educated on ACP and ADs, and were unwilling to fill out the surveys. Some participants did not fully understand what the surveys were asking. A few participants did not understand the pre/post design, and only filled one out, or filled both out but took one with them rendering their data unusable. Many participants arrived late for the sessions, and thus were unable to participate in the surveys as the scores may have been skewed.

In sessions that had a larger number of participants, there was overall less time for each participant to ask questions. In smaller sessions with fewer attendees, participants may have felt more vulnerable and less willing to ask questions. Overall, the session size did not seem to affect whether or not participants engaged in meaningful discussion with team members and each other – whether during or after the seminars.

Chapter 5:

Conclusions

Discussion of Outcomes

The project achieved the goal of implementing a community-based seminar and increasing ACP knowledge in decisional adults 18 and older. Not only did the project show clinical significance by prompting meaningful discussion amongst participants, answering questions, and providing clarifications about the ACP process and EOL circumstances, but the project also showed statistical significance for improving ACP knowledge ($p = .0004$). It was also determined that a correlation between education level and score improvement may exist, although this was not statistically significant.

Furthermore, the two questions which were answered incorrectly most often on the pretest, questions four and five, showed 31 percent and 24 percent increases in correct answers on the posttest, respectively. This is clinically significant as well, as these questions involve information regarding storage of ADs and reevaluation of a person's advance care planning document and ADs over time. Some participants verbalized that prior to this seminar, they did not understand that the ACP process involves reevaluating their values and preferences over time, and revisiting the documents as life circumstances change. One participant stated "I thought once I had filled out the documents I never needed to look at them again, they are even locked in my safety deposit box, which I learned today is also wrong!" While the content in this seminar directly addressed what to do with one's ADs and advance care planning documents, and suggested evidence based times at which to reevaluate one's ACP through the "Document It" and "Reevaluate" sections, this suggests a knowledge gap in the general public. This

information can be used to tailor future seminars and reinforce this important information.

Participants represented a large age range, which was unexpected. This indicates that further research in all decisional adults 18 and older regarding ACP may be beneficial, as individuals under the age of 65 may be seeking information on ACP. Many attendees already had ADs in place, which was another unexpected finding. The assumption prior to conducting the project was that primarily patients without ADs in place would be attending the seminars.

Limitations

The quality improvement project had several limitations. These included an ethnically homogenous population, and a small sample size ($n = 42$). While the sample was ethnically homogeneous, consisting of 41 white individuals and one Asian individual, this is largely representative of the local and regional population of the community and tristate area in which the seminars took place. The sample was likely ethnically representative of the community, but this could have limitations with reproducibility in more ethnically diverse populations. Additionally, the education level of the sample was higher than the general population. Advertising on a larger scale as well as in places such as churches, clinics, grocery stores, and other public points of access may help to recruit individuals of all socioeconomic statuses and education levels.

Participants requested on several occasions that a handout be available at the seminars. Because of facility restrictions on distributed materials, however, an approved handout was unable to be formulated for this project. Participants were provided pens and scratch paper to take notes, and were encouraged to email the DNP student with

further questions, for a pdf copy of the slideshow, or for further references. Three participants did take advantage of emailing the project manager for further information – however a handout may have provided an efficient way to distribute a “go to” document which participants could have kept in their cupboard, on their refrigerator, or in their file cabinet for reference at home.

A limitation of the study identified by the DNP student was that the ACP/AD Knowledge Survey contained statements or questions which some participants felt were worded in a manner that was difficult to understand. Additionally, all ten correct answers on the survey were false, making some participants second guess whether or not they had answered the questions correctly. A more comprehensive survey with easier to understand statements or questions, and a more diverse answer key would be indicated for future projects.

Clinical Implications

Participants attended the seminars during the work day on week days. For those retired, they left their homes during winter months to learn about ACP. While the sample size is small ($n = 42$), this does not encompass all seminar attendees in the data collection period (56), and does not take into account the pilot sessions which were well attended. Feedback was positive at each seminar, and participants consistently expressed thankfulness for the opportunity to learn about ACP. Several participants throughout the data collection period came to the seminars to learn more about the process before initiating conversations with loved ones and their physicians – which is what the seminars were meant for. Overall, this project helps further the notion that adults have a

desire to discuss this topic, but may be lacking information and skills in initiating the process.

The project helped demonstrate that having ADs and a notary available on location may help prompt participants who are ready to complete documents to do so. One participant shared “There was an advantage in being able to complete the advance directive and have it scanned to my doctor. Otherwise the form would die on my desk”. This specific metric may be measured in the future for statistical significance, however it is important to continue to focus on ACP as a whole and not solely on the legal documents. In addition, the potential to alleviate anxiety with EOL decisions for patients, families, and caregivers through education and discussion is a real possibility. The sessions also prompted important EOL discussions with loved ones and healthcare providers, although this was not a measured outcome and is based on participant feedback only.

Impact

Organizational Impact

The seminars have been added to the organization’s community calendar for twice monthly sessions through the end of August, 2017. The PC team is currently working with the marketing department to increase marketing efforts. Additionally, the project manager and other PC team members are holding seminars at churches, small groups, senior centers, and community centers through the summer and fall. The DNP student is working with the extension office liaison from the University through which the project was conducted to set up webinars for the fall.

Financial Impact

The project was not set up to measure financial gains or losses associated with the ACP seminars. While some studies have suggested that knowledge of ACP may decrease invasive interventions at the EOL, thereby decreasing overall costs, this project did not measure such outcomes (Institute of Medicine, 2015). Long term there may be travel costs associated with implementing the seminars in outlying communities, and an evaluation of these costs will take place at that time. While the seminars could have long term financial advantages, these metrics could be difficult to capture and would need to be set up in a separate study and measured over months if not years to evaluate whether the ACP seminars impacted healthcare spending.

Impact on Policy

This project suggests that community-based ACP seminars are an effective way to increase knowledge in decisional adults 18 and older. While the project outcomes currently have not impacted organization, community, state, or federal policies, the data contribute to the growing evidence base in this important area. Improving the educational methods and techniques at an organizational level is the first step to enacting change on a larger scale. The potential to improve organizational policies regarding ACP discussions and education lies in the ability of the program to remain free and available to all participants.

Impact on Quality of Health Care

While the immediate impact on quality of healthcare was not measured, increasing knowledge of ACP in decisional adults 18 and older is important. Increasing knowledge in one individual may have clinical significance if that individual has

meaningful conversations surrounding their EOL wishes, and establishes ADs and advance care planning documents. The impact on each individual's quality of health care received should be considered, even if it is not measured in this project. This includes potential anxiety reduction, alignment of providers' actions with patient beliefs, and improved perceived QOL at EOL.

Impact on Rural or Underserved Populations

Even though addresses were not recorded, many participants verbalized that they had driven from out of town to attend the sessions. This is important to note because if participants are willing to drive long distances, greater than 90 miles in one case, to learn about ACP, it provides a case for the organization to continue holding the seminars. The community in which the seminars were held during the project period has several ethnicities represented. It would be feasible to implement seminars with a scheduled interpreter for the minorities which represent the largest language base in the community. This would impact the financial outreach of the seminars but could be a valuable service to minority adults 18 and older whose primary language is not English.

Due to the portable nature of this educational format, the seminars have great potential to impact rural and populations as well. Implementing the seminars in rural communities through the organization's many clinics, centers of worship, and community centers is one way to bring the education to outlying facilities. Nurses or social workers in smaller communities could be trained as facilitators and hold seminars biannually to ensure the topic stays at the forefront of peoples' minds and that individuals are reevaluating their values and preferences on a regular basis. Another proposed method of disseminating the education is through free webinars for University faculty,

organizational staff, and community members. Communities with the technological capabilities to host a webinar could connect with the DNP Student or a trained facilitator in the hub community.

New Evidence Generated for Practice

This project confirmed that community-based educational seminars are a viable method to increase knowledge about ACP in adults. Because this project included all decisional adults 18 and older, it added to the evidence base which largely consists of special populations with specific diagnoses or age categories. Additionally, it was discovered that individuals with ADs already in place seek out learning opportunities regarding ACP and are also able to increase their knowledge on the topic. Having legal documents and a notary present at the seminar did result in eight participants completing ADs during the project period. This may be an important observation for future projects and future practice.

The greatest knowledge deficits and subsequent knowledge increases related to reevaluating one's ACP after completion, and where to keep the completed documents. Participants engaged in a significant amount of discussion during the seminars regarding how to choose a DPOA-H, when to reevaluate one's ACP, questions about CPR and other interventions available at the EOL, and how to initiate conversations with loved ones. Ten participants total stayed after the seminars had completed to discuss specific health concerns or circumstances with the project manager or other PC team members present. These participants each expressed gratitude for the additional time and information.

Recommendations for Future Projects

Future studies in the field of ACP can focus further on how to measure and impact patient attitudes and beliefs regarding ACP and patient readiness to engage in ACP. It may also be beneficial to expand the evidence-base on ways in which to improve patient follow up with ACP after attending a community-based seminar. Comparing a control group and intervention group in which a notary is present with legal documents on hand, and how this impacts completion of ADs may be another important area to expand on from this project.

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Appendix A: SDSU IRB Approval Form



Office of Research Assurance
and Sponsored Programs

Box 2201, SAD 200
SDSU
Brookings, SD 57007-1998
Phone: 605-688-5051
FAX: 605-688-5530

Dianne.Nagy@sdstate.edu

To: Molly Kuehl, College of Nursing

Date: January 12, 2017

Project Title: Community Based Advance Care Planning Seminars: Increasing Advance Directive Completion in Community Dwelling Adults

Approval #: IRB-1701005-EXM

Thank you for bringing your project to the Human Subjects Committee. Your project is approved as exempt from the Common Rule. The basis for your exempt status (from 45 CFR 46.101 (b)) is:

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:
(i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

If there are any unanticipated problems involving risks to subjects or others or changes in procedures during the study, please contact the SDSU Research Compliance Coordinator. At the end of the project please inform the committee that your project is complete.

If I can be of any assistance, don't hesitate to let me know.

Sincerely,

Dianne Nagy
Acting IRB Coordinator



3000 W. Avera Drive
Sioux Falls, SD 57108-5721
605-322-4755
Fax: 605-322-4780

Avera.org

Appendix B: Facility IRB Form

August 25, 2016

Molly Kuehl,
South Dakota State
Universtiy 3812 S.
Outfield Ave.
Sioux Falls SD 57110

Dear Ms. Kuehl:
Concerning the following Study:

Our Study # 2016.055

Protocol Title: Community Based Advance Care Planning Seminars: Increasing Advance Directive Completion in Community Dwelling Adults

The Avera Institutional Review Board reviewed the above listed protocol and accompanying study information. Your application has been examined and the research project does fall into one of the common rule exempt categories. *A Study granted exempt status is not subject to annual renewal requirements.*

The determination of Exemption was based on the following common rule citation; "45 CFR 46.101(2)"

2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior

NOTE: *Once your exempt study has been completed please provide the IRB with a **Final Report** and any findings to allow for closure of the study.*

Please understand that any changes to this research study must be submitted to the Department of Human Subjects Protection, prior to implementation, in order to determine if the study still qualifies for exempt status. Please feel free to contact the Avera Dept. of Human Subjects Protection directly at 605-322-4706 if you have questions about this decision or if you need any other assistance in the future.

Respectfully yours,

Sandra G. Ellenbolt, CIM, JD
Director, Department of Human Subjects Protection/IRB Chair

Appendix C: Facility Approval Letter

DNP Project Site Agreement

Date: 8/9/2016

This letter is in support of Molly Kuehl's DNP Project, Community Based Advance Care Planning Seminars: Increasing Advance Directive Completion in Community Dwelling Adults at Avera McKennan Hospital and University Health Center. This project will explore demographics, as well as attitudes and beliefs associated with Advance Care Planning. The project will also seek to increase completion rates of advance directives through the implementation of Advance Care Planning Seminars.

We look forward to the results of the project.

(Signature of Manager or Director)

(Typed Name of Manager or Director)

Dr. Francine Arneson, M.D.

Appendix D: Stakeholder Agreement

DNP Project Stakeholder Agreement

I agree to serve as the DNP Project Stakeholder to the DNP student named in this agreement.

Name of Stakeholder:

Dr. Francine Arneson, M.D. Palliative Medicine

Signature of Stakeholder:

Name of DNP student:

Molly A. Kuehl, RN BSN PCCN

Signature of DNP student:

Date: 8/9/2016

Appendix E: Literature Search Table

Database	Search terms	Filters applied	Number of results returned	Number of results retained
CINAHL	Advanc* care plan* AND community AND seminar OR education	*2010 to present	36	8
	Advanc* directiv* AND community AND seminar OR education	*Peer reviewed *Available in English	25	3 (4 duplicate)
PubMed	(advanc* care plan*) AND (community) AND (seminar OR education)	*2010 to present	78	5
	(Advanc* directiv*) AND (community) AND (seminar OR education)	*Peer reviewed *Available in English	53	0 (7 duplicate)
	(advanc* directiv*) AND (community)		194	8 (8 duplicate)
Cochrane Database	Advanc* care plan*	*2010 to present	6	0
	Advanc* directiv*	*Peer reviewed	27	0
	Advanc* care directiv*	*Available in English	2	0
Ovid	(advanc* care plan*) AND (community) AND (seminar OR education)	*2010 to present *Peer reviewed *Available in English	150	1

Appendix F: Evidence Table

Citation	Level of Evidence	Sample/Setting	Participants (n)	Study Design/Purpose	Intervention	Results	Comments; strengths and limitations
(Baughman et al., 2015)	III B	Midwestern state with 9 of 12 possible agencies and 433 of 476 possible care managers	N=433	Descriptive cross-sectional study to examine how attitudes, experiences, and characteristics of care managers and their organizations influence ACP practice	Structured telephone interview and questionnaires	ACP not consistent across agencies or care managers, characteristics of an organization are critical to implementing ACP best practices	Could only determine correlations rather than causal relationships between variables. Did not measure ACP knowledge and skills
(Blackford & Street, 2012a)	III B	Three Victorian-based community palliative services, two metropolitan, and one regional site (Australia)	N=1257	Multi-site action research approach which included planning; intervention and data collection; data analysis; and reflection.	Respecting Patient Choices program using a multi-site action approach	Most important aspect of ACP services is discussion with patient and family, all RNs and allied health professionals should be able to facilitate ACP conversations	Homogenous sample, services were self-selected. Large, multi-cycle study involving multiple sites of different service areas.
(Bravo et al., 2016)	I B	Sherbrooke, Canada. Community dwelling adults and their proxy decision makers	N=235	Stratified randomized controlled trial	Dyads formed involving proxy and participant. Three educational encounters for	The intervention group saw a statistical increase in the participants ability to	Homogenous sample of elderly adults only, involved one-on-one education/interven

					control group versus health education program sought to help older adults clarify and communicate end of life preferences in the case of lost capacity	express their wishes, but did not see an improvement in the proxy's ability to predict their wishes	tion
(Brinkman-Stoppelenburg et al., 2014)	III A	Extensive systematic search of databases performed	N=113 (n is number of studies included)	Systematic review to assess effects of ACP on EOL	Studies included: effects had to pertain to treatment in EOL, compliance with EOL wishes, place of care and death, patients and family satisfaction with care, prevalence and severity of symptoms	DNR and AD have been most often studied, while ACP has been found to decrease life-sustaining treatment, increase use of hospice and palliative care, and prevent hospitalization	Comprehensive search yielding many results, well organized and clear observations made on complex topics
(Colville & Kennedy, 2012)	III C	6 nurses in Scotland (3 in community settings and 3 in acute care settings)	N=6	Descriptive qualitative study	Educational package delivered to nurses, then nurses interviewed one-	Training increased participants awareness of ACP, validated knowledge and	Very small sample size, descriptive qualitative study, well performed and did see an impact

					on-one 10-12 months after ACP education to analyze using comparative approach	skills, positive impact on clinical practice	
(Detering et al., 2010)	IA	Single center university hospital in Melbourne, Australia	N=309	Randomized controlled trial	Randomized to receive usual care or usual care along with facilitated ACP	Patients who passed away in the intervention group were much more likely to have EOL wishes known and followed compared to control group. Family members of intervention group reported significantly less stress, anxiety and depression and higher satisfaction than family of control group members	Intervention was successful in patient population representative of that in most hospitals in developed nations. Non-English speakers and non-competent patients were excluded and may be more likely to be underserved by routine care
(Durbin et al., 2010)	III A	Twelve randomized studies and four nonrandomized	N=16 (n is number of studies)	Systematic Review	Randomized studies were primary focus to draw conclusions	Three randomized studies consistently	While overall no single intervention proves superior in improving AD

		studies met inclusion criteria			about nature of evidence on effectiveness of types of educational interventions in facilitating AD completion	showed that combined written and verbal interventions were significantly (p <.05) more effective than single written interventions in increasing percent of newly completed AD	completion rates, three randomized studies showed combined written and verbal interventions are more effective than written alone. This is not compared to other interventions within the same study.
(Gruneir et al., 2007)	III B	United States	N=29 (articles)	Systematic literature review with multilevel analysis	Linked death certificates with county and state data to assess trends associated with site of death	Opportunities for home death are disproportionately available to certain groups of Americans such as whites, those who die of cancer, and those with increased social support	Unable to use data of any decedent who died in a county with fewer than 50 deaths due to NCHS restrictions. This resulted in a very large number of decedents when summed across all small counties, unable to generalize findings to residents of less populated counties

							due to this.
(Hickman & Pinto, 2014)	III A	Northeast Ohio, US	N=489	Secondary data analysis of cross-sectional data, descriptive statistics, t-tests, chi-square and path analyses were performed to capture surrogate decision maker's decisional burden	Data collected using demographic forms and questionnaires. Single-item measure of role stress and Center for Epidemiological Studies Depression scale used	SDMs who were non-white with low socioeconomic status and low education level were less likely to have AD documentation for their chronically critically ill patient, the presence of AD lessens decisional burden by directly reducing role stress and indirectly lessening severity of depressive symptoms	Clinically useful for patient education on influence of ACP and ADs. Patients who understand how now having ADs in place may negatively affect their SDMs may be more likely to engage in ACP and complete ADs
(Hinderer & Mei Ching, 2014)	II B	Convenience sample, participants attended a seminar on AD,	N=86 Post survey n= 21 (not a large	Quasi-experimental pilot study to measure how effective a nurse-	Educational seminar presenting content on the <i>Five Wishes</i> ,	Positive attitudes regarding AD, found the seminar helpful,	Lack of knowledge is often mentioned as a barrier to AD completion by

		a survey was conducted immediately after and 1 month after if participants agreed to the follow up survey.	enough sample to draw statistically significant results from f/u survey)	led seminar on AD would be regarding attitudes on AD, completion of AD's and involvement in ACP discussion	through 1.5 hr of lecture, video, and overview with time for participant questions. Surveys were used immediately after seminar and if participants agreed one month follow up surveys were sent (only 21 participants mailed back f/u)	many participants had chronic conditions. After the seminar 97.7% (n=84) reported were likely to complete an AD On post f/u survey 33.3% (n=7 out of 21) had completed an AD)	patients, education seems to improve attitudes and completion rates. Strengths: reliable tools used, encouraging results regarding nurse-led seminar Limitations: no baseline data collected about attitudes, knowledge, or existing AD before seminar. Convenience sample, no control group. Poor follow up completion resulting in unusable data for f/u survey
(Houben et al., 2014)	I A	Randomized Controlled trials conducted 1966 to 2013 written	N=55 (studies)	Systematic review and meta-analysis of randomized	Predefined data abstraction form used to record study details.	Interventions focusing on ADs as well as those that include	More than half of the trials included were classified as "low quality

		in English		controlled trials that describe original data on efficacy of ACP interventions in adult populations and were written in English	Methodological quality was assessed using the PEDro scale by 2 independent reviewers. Meta-analytic techniques were conducted using a random effects model. Analyses were stratified for type of intervention: ADs and communication	communication about EOL care increase completion of ADs and occurrence of EOL care discussions between patients and healthcare professionals	trials”. Meta-analysis wasn’t possible for outcomes including the quality of the communication, knowledge of ACP, or EOL preferences
(Jain et al., 2015)	I B	Randomized controlled trials conducted 1980 to 2014 written in English	N=10 (10 trials with 2220 patients)	Systematic review and meta-analysis of randomized controlled trials of adult patients that compared a video decision aid to a non-video-based intervention to assist with choices about use of life-sustaining	Reviewers worked independently and in pairs to screen eligible articles and extract data regarding risk of bias, population, intervention, comparator, and outcomes. Reviewers assessed evidence for	10 trials were included, low quality evidence suggests that patients who use a video decision aid are less likely to indicate a preference for CPR. Moderate-quality evidence suggests that video decision aids result in greater	Only one of 10 studies included a process through which patients could engage in deliberation or discussion with their usual healthcare provider after watching the video, none of the studies evaluated the impact of a video decision aid

				treatments and reported at least one ACP-related outcome	each outcome using the Grading of Recommendations, Assessment, Development, and Evaluation Framework	knowledge related to ACP.	when integrated into clinical care
(Kavalieratos et al., 2015)	III B	Pittsburgh, USA	N=56	Focus groups with subsequent qualitative thematic approach to analyze transcripts	6 focus groups of young adults aged 18-30 to explore baseline knowledge of ACP, ACP preferences, characteristics of preferred surrogates, and barriers and facilitators to completing ACP specific to age	Participants desired more information regarding ACP, expressed positive attitudes, the belief that prior exposure to illness plays a role in prompting ACP, an appreciation that it is flexible process throughout the life-course	Small sample size, descriptive statistics used to analyze transcripts rather than specific instruments used Common themes emerged over the 6 focus groups
(Keating et al., 2010)	III A	United States	N=4074	Logistic regression used to identify physician and practice characteristics	National survey conducted of physicians caring for cancer patients about timing of	65% would discuss prognosis “now”, fewer would discuss DNR status,	Most physicians report would not discuss EOL options with terminally ill patients who are

				associated with earlier discussions around ACP after results of a national survey were received	discussions regarding prognosis, DNR, hospice, and preferred site of death with their terminally ill patients	hospice, or preferred site of death immediately with most physicians waiting for symptoms or until no more treatments to offer	feeling well, more research needed to understand physicians' reasons for timing of discussions and how their propensity to aggressively treat influences timing
(Litzelman et al., 2016)	III B	Indiana, heterogeneous sample of community members and healthcare providers	N=4866	Education initiative to engage community members and healthcare providers, qualitative	Education and training engaged participants to improve comfort discussing EOL issues, improve knowledge of healthcare choices including hospice and PC, and prepare to explore and document personal values, life goals, and priorities as well as goals of care	Participants rated quality and perceived usefulness of educational events from 4-5 on 5 point Likert scale with 5 being most effective. Participant comments were favorable.	Qualitative, not a specific study design utilized. Large sample size and positive results reported, detailed report of methods used.
(Malcomson & Bisbee,	III B	Community Senior Center	N=20	Qualitative study exploring	Four focus groups and	ACP is strongly influenced by	Perspectives taken from a

2009)		and two assisted living facilities in Salem, MA		perspectives of healthy elders on ACP through focus groups	demographic questionnaire were administered to 20 healthy men and women aged 60-94 years old	concern for others; assume that preferences are known to those close to them even in absence of discussions; value healthcare system that supports provider continuity; being known to a provider is important in believing that ACP wishes will be respected; elders want to discuss ACP	homogenous demographic and small sample size. Further research on factors related to informal communication between elders and family members/providers is needed
(McLennan et al., 2015)	III A	Phone interviews conducted throughout the community in Australia	N=26	Qualitative methodology utilizing audiorecording and data transcription which then underwent an inductive thematic coding	26 in-depth phone interviews with community members mean age of 66 years were conducted to gain understanding of motivations for engaging in	Of 26 participants, 15 had appointed a DPOA. Findings do suggest that community members lack ACP knowledge, forms are	Small sample size however rigorous coding process for transcription analysis of thematic content.

				process, then subsequent waves of coding to ensure validity and rigor...peer checking was utilized	ACP, barriers that prevent people from engaging in ACP, and suggestions for promoting ACP	complex and inaccessible, avoid ACP due to fear, misperceptions regarding relevance of ACP based on age and health	
(McMahan et al., 2013)	III B	Mixed race/ethnicity English/Spanish speaking groups at hospitals including VA hospitals in San Francisco	N=69	Focus groups, qualitative, semi-structured discussion guides to elicit themes about what is important for ACP completion and proxies	Surrogates and participants recommend that a patient identifies values and defines what quality of life is to them, choose a proxy wisely and verify that they understand their role, decide whether to grant leeway in proxy decision making, and inform other family/friends of their wishes to prevent conflict	Beyond basic AD, patients and proxies recommend additional steps to ensure solid communication and smoother transition to EOL care	Qualitative, focus groups, good sample size with recurring themes in varied ethnic communities.
(Pecanac et al., 2014)	III A	Columbia St. Mary's-Milwaukee,	N=732	Retrospective chart review	Retrospective chart review of decedents from	Prevalence of ADs increased significantly for	A previously established community ACP

		Wisconsin			2005 to 2010 in a 300 bed Midwestern metropolitan hospital to determine whether the Respecting choices program would improve AD prevalence and utilization in racially diverse population	racial and ethnic minorities after the implementation of Respecting Choices from 25.8% to 38.4% (p=.069).	program was generalized to a more racially and ethnically diverse population
(Silveira et al., 2014)	III B	Health and Retirement Study 2000 to 2010	N=2,122	Retrospective cohort study assessing trends over time in rates of AD completion, hospitalization before death, and death in hospitals	The association between trends in AD completion and hospital death assessed by comparing nested, multivariable logistic regression models predicting the odds of hospital death over time with and without adjusting for AD	Proportion of decedents with an AD increased from 47% in 2000 to 72% in 2010. Proportion of decedents with at least one hospitalization in last 2 years of life increased from 52% to 71% and proportion dying in hospital decreased from 4% to 35%	Significant increase in rates of AD completion from 2000 to 2010 but had little effect upon hospitalization and hospital death, suggesting more than just AD completion is needed to improve quality of EOL care

					status and sociodemographic characteristics. The complex sampling design was accounted for in all analyses		
(Teno et al., 2007)	III A	Telephone interviews of bereaved family members of those who died in nursing homes, hospitals, or at home in 8 states	N=1,587	Qualitative study	Telephone interviews conducted of surviving next of kin, chi-square tests used to examine associations between decedent's AD status and reported concerns with quality of care. T-test used to determine whether overall ratings of satisfaction differed between groups, multivariable logistic	Of 1,587 decedents, 70.8% had an AD. Persons who died at home with hospice or in an NH were more likely to have an AD and less likely to have a feeding tube or use a ventilator in last month of life	Large study, rigorous statistical analysis No control group

					regression model was developed to examine the association between each domain and AD completion		
(Wilson et al., 2014)	III B	Minneapolis/St. Paul metro area healthcare systems	N=8 healthcare systems, over 700 community partners recruited	Descriptive analysis of ongoing initiation of community ACP model	Recruit healthcare systems to endorse one ACP model and increase proportion of individuals with healthcare directive in medical record	Increased amount of health care directives on file for systems involved	Ongoing research, outside company hired to analyze data, specific design not implemented from beginning to guide course of study

Appendix G: Demographic Survey

Please answer the following questions and check or circle the appropriate answers.

1.Age	
2.Gender	Male Female
3. Ethnic origin (or Race): Please specify your ethnicity.	White Hispanic or Latino Black or African American Native American or American Indian Asian / Pacific Islander (please indicate specific origin, i.e. Chinese, etc.) Other (please specify)
4.Level of education	Less than High School Completed High School Completed College Completed Graduate School
5. Do you have any chronic illnesses such as diabetes, high blood pressure, chronic lung disease, chronic heart disease, etc.?	Yes No
6. Do you have health insurance?	Yes No
7. Have you ever been on life support such as a breathing machine or ventilator?	Yes No
8. Have you ever acted as a surrogate decision maker for someone else?	Yes No
9. Have you ever made End-of-Life decisions for someone else?	Yes No
10. Do you have an advance directive or living will?	Yes No

Study ID #:

Date of enrollment:

Appendix H: ACP/AD Survey Pre/Post

Please answer the following questions to the best of your ability

An advance care plan is drawn up once you have become ill to ensure accuracy	True	False
An advance care plan is only used to refuse treatment	True	False
Only people with terminal or fatal illnesses need an advance directive or advance care plan	True	False
Place your advance care plan or advance directives in a safe deposit box to ensure notification of directives and access when needed	True	False
You should avoid second guessing your advance care plan treatment preferences	True	False
After appointment of a decision maker, it is not necessary to discuss specific preferences with that person	True	False
A decision maker must be a legally recognized relative	True	False
A living will indicates how a person wishes to divide their personal possessions	True	False
An advance care plan is only for certain instances because it does not cover all medical situations	True	False
An advance care plan or advance directives cannot be changed after they have been signed	True	False

Study ID #:

Date of enrollment:

Pre/Post:

Appendix I: Correspondence with Dr. K. Hinderer

Email correspondence with Dr. K. Hinderer and Dr. M.C. Lee requesting permission to utilize demographic survey and AD/ACP survey:

Molly,

You have our permission to use the instrument with appropriate citation. Good luck on your project, it sounds exciting.

Katie

Katie Hinderer PhD, RN, CCRN-K, CNE
Associate Professor, Department of Nursing
Salisbury University
DH 206
410-543-6417
410-548-3313 (fax)

From: outlook_738C443573AD04EA@outlook.com
[mailto:outlook_738C443573AD04EA@outlook.com] **On Behalf Of**
outlook_738C443573AD04EA@outlook.com
Sent: Wednesday, June 29, 2016 1:08 PM
To: Katherine Hinderer <KAHINDERER@salisbury.edu>; lee@son.umaryland.edu
Subject: DNP Project, Advance Care Planning Community Seminar: AD/ACP survey

Dr. Hinderer and Dr. Lee,

Greetings! My name is Molly Kuehl, I am entering my final year of a Family Practice DNP program at South Dakota State University, and am in the process of composing my project proposal. In the process of my Literature Review, I found your article

Hinderer, K. A., & Mei Ching, L. (2014). Assessing a Nurse-Led Advance Directive and Advance Care Planning Seminar. *Applied Nursing Research*, 27(1), 84-86 83p. doi:10.1016/j.apnr.2013.10.004

very insightful, well written, and similar in design to what I am proposing to implement. I am writing to you because you mention development of a demographic instrument that included 9 multiple-choice and 3 open-ended questions related to AD completion, ACP conversations, and seminar effectiveness. My project chair and I agree that this survey has the potential to help us collect valuable data from our sample. I am wondering if you will grant me permission to use this survey in my project. I would, of course, provide citation and full credit to you both in entirety, and forward my project or any resultant publications to you once completed.

A small bit about my project to give you some insight: a multidisciplinary Palliative Care team will lead a community-based seminary about ACP. We will provide ACP

documents and time at the seminar for participants to stay and complete if they wish, with the team available to answer questions and make clarifications. We will also have a notary available, and a representative from our organization's EMR software team to upload participants' new ACP documents directly to their EMR-if they happen to follow with a provider from our organization. We will also have availability to make copies of the documents for them on site to give to family or their healthcare provider (if not part of our organization).

I look forward to hearing back from you, and anxiously await your response. Thank you for your consideration in this important and exciting matter!

Kind Regards,
Molly Kuehl, RN BSN PCCN
Chief Development Officer, JY6 Foundation
1E Cardiopulmonary, Hospitalist, Avera McKennan Hospital & University Health Center
4th Year Family Practice DNP Student, South Dakota State University

Appendix J: Participant Cover Letter

Date: (Subject to date of attendance)

Dear Seminar Attendee,

You are invited to participate in a research study. The purpose of the study is to understand whether attendance of an Advance Care Planning Seminar increases completion of Advance Care Planning documents. The study also seeks to understand trends associated with demographics, attitudes, and understanding of Advance Care Planning.

We are inviting you to be in this study because you are a community dwelling adult 18 years or older

If you agree to participate, we would like you to **fill out these two brief surveys before you leave today, and place in the box by the registration table.** The surveys include questions regarding your demographics (age, ethnicity, education level, etc.), and understanding/attitudes regarding advance directives. The surveys should not take more than 5-10 minutes to complete. Please DO NOT add your name or any contact information to the surveys.

Survey or Questionnaire

- **If you do not wish to participate, we ask you to please return the blank survey to the box by the registration table as you leave today.**
- **If you wish to leave a question blank or unanswered, you may do so.**

We will keep the information you provide confidential, however federal regulatory agencies and the Avera Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. Your survey has been labelled with an ID code. If we write a report about this study we will do so in such a way that you cannot be identified.

There are no known risks from being in this study, and you will not benefit personally. However, we hope that others may benefit in the future from what we learn as a result of this study.

Your participation in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you will not be penalized or lose any benefits for which you are otherwise entitled.

If you have any questions, concerns or complaints now or later, you may contact us at the number below. If you have any questions about your rights as a human subject, complaints, concerns or wish to talk to someone who is independent of the research, contact the Department for Human Subjects Protections at 605/322/4755. Thank you for your time.

Molly A. Kuehl RN BSN PCCN
SDSU DNP-FNP Student

Molly.kuehl@avera.org

Avera Medical Group Palliative Medicine
911 E. 20th Street
Suite 509
Sioux Falls, SD 57105

Appendix K: Power Point Slides



What is Advance Care Planning?

A process of:

- Discussion of medical preferences
- Clarification of values and goals
- Embodiment of preferences through written documents and medical orders
 - May start at any time in a person's life
 - Allows for *flexible decision making* in the setting of the person's *current medical status*

75% of Americans do not have an Advance Directive such as a living will.



(Bomba & Orem, 2013; Brickman-Stoppeleburg et al., 2014; Institute of Medicine, 2014; National Center for Healthcare Statistics, 2010; National Consensus Project for Quality Palliative Care, 2013; National Hospice and Palliative Care Organization, 2016; National Institutes for Healthcare Improvement, 2016)

How to Start

Think About It

Talk About It

Document It

Re-evaluate

Think About It

Quality of Life

What is acceptable to you?

- Different for each individual
- Discussions with family and healthcare team can shape understanding

- Cognitive Status (mental capability)
- Functional Status (physical capability)
- Terminal Illness
- Coma



Think About It

How to Choose a Medical Power of Attorney

The person you select:

- Must meet legal criteria
- Should know you well
- Be willing and able to speak on your behalf and act on your wishes
- Be able to separate his/her feelings from your own
- Be willing to talk with you NOW about sensitive wishes
- Be willing to listen
- Be able to handle potential conflict between family and/or close friends
- Be reasonably available

(Institute for Healthcare Improvement, 2010; Institute of Medicine, 2014)

Think About It

Interventions Available in Serious Illness or at End of Life

- Cardiopulmonary Resuscitation (CPR)
- Intubation/Ventilation
- Oxygen
- Tube Feeding
- Intravenous Therapies
 - ▶ Hydration
 - ▶ Nutrition
 - ▶ Antibiotics
 - ▶ Medications

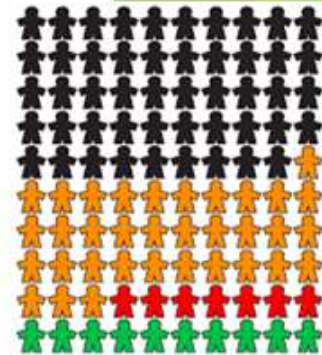


Think About It

CPR Data

- Study in 2015 showed that when CPR is performed on TV, immediate survival rate is 70%
 - Real life immediate survival rate is closer to 37%
- ~5% survival at one year for out of hospital cardiac arrest
- In-hospital cardiac arrest:
 - Survival to discharge of all is ~15%
 - Frail elders <5%
 - Advanced chronic illness <1%
- Outcomes?

(American Heart Association, 2013; Chan et al., 2013; Ahmad et al, 2015; University of Southern California, 2015)



Among "elderly patients who undergo resuscitation after in-hospital cardiac arrest", at one year:

- 49 died during resuscitation²
- 34 died before hospital discharge³
- 7 died after hospital discharge¹
- 10 are alive¹

Think About It

Time Defined Trials

- Good when prognosis is uncertain
- Patient/family needs more time to consider options
- Can help determine course of further treatment

(Institute for Healthcare Improvement, 2016)

Talk About It

How to Prepare Your Medical Power of Attorney

- Start discussions early, ideally before serious illness begins
- Discuss with them:
 - What values and beliefs should guide your care
 - What quality of life means to you
 - What treatment options you are interested in having offered or withheld if you are unable to speak for yourself



(Institute for Healthcare Improvement, 2016; Institute of medicine, 2014; National Hospice and Palliative Care Organization, 2016)

Talk About It

- Discuss your values and preferences with your primary provider
- Ask questions
 - Make sure you have a good understanding of:
 - Your illnesses
 - The natural course with and without treatment options
 - Prognosis with and without different treatment options
 - Common symptoms and how they will be managed
 - Ask for their recommendations

93% of people have not had an end-of-life discussion with their physician.



(Centers for Disease Control and Prevention, 2013; Centers for Medicare and Medicaid Services, 2016a, 2016b; Institute for Healthcare Improvement, 2016; National Consensus Project for Quality Palliative Care, 2015)

Document It

Advance Care Planning

- Focus on values, preferences, and goals
- Not as helpful to document specific treatments or scenarios
- Encourages open and honest communication
- Ensure the documents are easily accessible by your Medical Power of Attorney
- Bring a copy to your Primary Care Provider for your health record

(California HealthCare Foundation, 2012; Institute of Medicine, 2014; Minnesota network of Hospice and Palliative Care, 2016; South Dakota Department of Health, 2016)



"I have a healthcare directive not because I have a serious illness, but because I have a family."

-Dr. Ira Byock

Re-evaluate

1. **Decade** - On your birthday in each new decade
2. **Death** - After the death of a loved one
3. **Diagnosis** - After diagnosis of a serious medical condition
4. **Divorce** - When experiencing a divorce or other major life change
5. **Decline/Deterioration** - When experiencing a decline in health

(Institute for Healthcare Improvement, 2016; Institute of Medicine, 2014; National Hospice and Palliative Care Organization, 2014)



South Dakota: What Happens If You become Sick and Cannot Make Your Own Decisions?

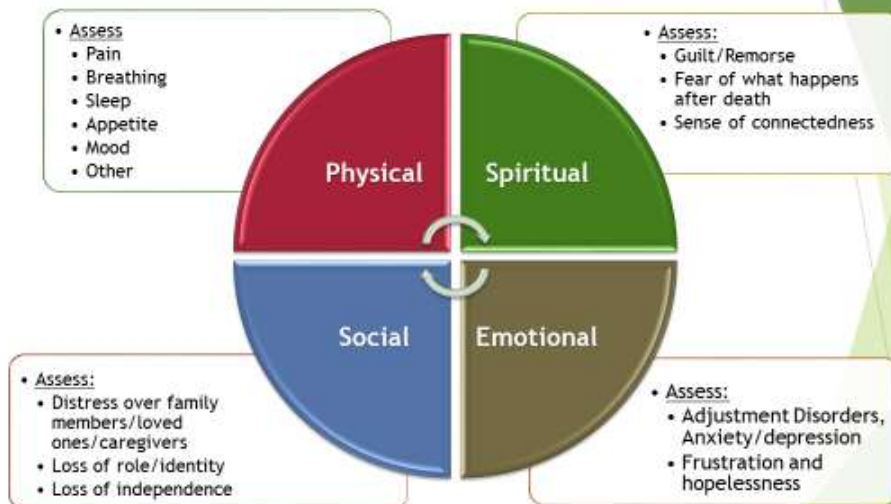
If you **DO** have ADs in place?

- DPOA can use your living will and ACP to work with your provider to guide treatment
- Comfort One

If you **DO NOT** have ADs in place?

- Defaults to a legal hierarchy
 - Spouse
 - Adult Child
 - Parent
 - Sibling
 - Etc

Palliative Care- Whole Person Care



What is hospice?

- Patient, family, and many healthcare providers' ***perception*** is that hospice a *place* where people go to die
- ***Reality:***
 - Not a place:
 - **A Philosophy of Care:** Live as well as we can for the time that we have
 - **A Medical Team:** Doctors, nurses, SW's, chaplains, aides, volunteers
 - **A Benefit:** Medicare or private insurance, Prognosis of <6 months
 - Goal is to neither not prolong nor hasten the end of life
 - Can be provided in different settings and different levels of care

(American Nurses Association, Hospice and Palliative Nurses Association, 2014; National Consensus Project for Quality Palliative Care, 2013; National Hospice and Palliative Care Organization, 2016)

Questions?

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Appendix L: Pilot Work

Two pilot sessions were utilized to refine the education and flow of sessions. The education was provided by the Palliative Care physician at both of the pilot sessions. The project manager took detailed notes during these first two sessions in order to make adjustments to the education. Future sessions were led by the project manager during the data collection period. All sessions had at least one provider (physician or nurse practitioner (NP)) present, and the notary present.

The first pilot session was held at 1pm on a Thursday afternoon in August 2016 in a classroom on the main campus of the healthcare system hosting the project. The session was set at “full” with 30 participants. Thirty six participants attended the session due to couples only signing oneself up and not a spouse, and two participants who arrived without having pre-registered. Participants signed in as they arrived with their name, and the name of their primary care provider. Each seat had a living will (LW) and durable power of attorney – healthcare (DPOA-H) document for the state in which the sessions took place, a facility approved addendum ACP document, and a pen. Team members in attendance included the project leader, the PC physician, two PC NPs, a PC RN, a PC SW, a PC support specialist who also served as notary, and the manager of Internal Medicine and PC to oversee the session. Participants ranged in age from mid-20s to late 70s and were mixed male and female. Many participants expressed that they were from small towns. There were several participants seeking AD documents for surrounding states as they had travelled for the event that day. The various team members were able to locate copies of these documents online, download and print them for use immediately. Four LW, Four DPOA, and one Comfort One document were filled out at this first

session. Surveys were not administered. The power point education took approximately 30 minutes, and group questions and discussion went on for approximately one hour post-education. Participants were free to stay and fill out documents and have them notarized if they wished. Additionally, they were asked to please allow the team to make a copy of the ADs and fax to their primary care provider. Verbal feedback from participants was overwhelmingly positive. Feedback was mixed as to whether participants were seeking information on ACP for themselves or loved ones. One younger participant and spouse were present due to a recent diagnosis of a serious progressive illness, and were seeking more information regarding the ACP process.

The second pilot session took place on a Friday at 1pm in September 2016 in a meeting room with desks on the main campus of the healthcare system hosting the project. The session was set at “full” at 30 participants. This session had seven participants present. Once again they were asked to sign in with their name and primary physician. The participants included three employees of the hosting healthcare system aged mid-20s to mid-30s, three community dwelling older adults aged 70s-80s, and a primary care physician from a rural community. Once again, some participants were seeking information on ACP for themselves and some were seeking information on how to help loved ones. The physician was seeking information not only for their practice but also for understanding how to approach the topic with their parents. From the first session, the slides had been simplified and re-ordered to improve continuity and flow. While a larger session had certain advantages, this smaller session allowed for more intimate conversation amongst the participants and may have led to a deeper understanding for each individual about the importance of ACP. One young employee

had recently been diagnosed with a serious condition that could render them incapacitated at a moment's notice. This participant was incredibly engaged in the information being presented and had many questions on how to choose a surrogate decision maker and initiate conversations with loved ones regarding such sensitive topics. Once again, surveys were not administered at the second pilot session. No LW, DPOA, or Comfort One documents were filled out at the second pilot session. Three participants took Comfort One forms. The same three participants expressed they already had LW and DPOA on file and sought reassurance that these were still legally valid. Three different participants took LW and DPOA forms and had positive feedback about filling these out. They expressed wanting to have discussions with their DPOA prior to filling out the documents, which is emphasized in the education.

Four more pilot sessions were held in September, October, and November of 2016. Feedback from participants and team members attending these sessions was used to refine the intervention and content, as well as drive discussion in future seminars. One set of AD documents, excluding a Comfort One form, was filled out at these remaining four sessions.