

INCREASING AWARENESS ABOUT ADVANCE CARE PLANNING AMONG WOMEN IN
CROW WING COUNTY, MINNESOTA

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ABSTRACT

Advance care planning (ACP) includes making decisions about end-of-life care in the form of a health care directive which includes identifying a health agent to make decisions for people when they are unable to make decisions for themselves. A health care directive gives people the opportunity to make end-of-life care wishes known to family members, providers, health care facilities, health agents, and others (National Institute on Aging, 2017).

ACP can result in increased patient satisfaction of care, better provider understanding of the patient's end of life wishes, as well as decreased family, provider or patient anxiety when having to make urgent health care decisions (Dube, McCarron and Nannini, 2015). Despite literature to support the importance of advance care planning, the completion rates of health care directives in the United States range from only 18% to 30%. A lack of awareness about advance care planning is one reason people do not complete an advance directive (Ashcraft & Owen, 2016).

Raising awareness by providing health care directive completion education and information to women attending the *Health is Your Best Accessory* event offered an opportunity to increase the number of women with completed health care directives. Over 900 women attended the health event. Participants completed the survey after the presentation. Sixty-seven percent ($N=49$) of the participants surveyed ($N=73$) reported not having a health care directive (HCD) on file with their primary care provider. Sixty-two participants of the women's health event indicated they were interested in additional information about advance care planning and were invited to a follow-up seminar to participate in a PowerPoint presentation and step-by-step tutorial in completing a health care directive. Two people attended the follow-up seminar. Survey data collected showed the attendees rated the presenter, presentation, and content as

excellent, and both answered yes when asked if they felt they had enough information, after taking part in the presentation, to complete a health care directive.

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CHAPTER ONE. INTRODUCTION

Background and Significance

Advance care planning (ACP) includes making decisions about end-of-life (EOL) care in the form of a health care directive (HCD) or advance directive (AD), which includes identifying a health agent to make decisions for people when they are unable to make decisions for themselves. An HCD gives a person the opportunity to make end-of-life (EOL) care wishes known to family members, providers, health care facilities, health agents, and others. Ideally, an HCD is established when a person is in a state of wellness and can make informed decisions about their health care wishes (National Institute on Aging, 2017). The terms HCD, and AD are often used interchangeably, however, the preferred terminology when discussing EOL decisions is HCD. HCD is the preferred term over AD because HCD specifies the directive is health related and not related to finances or property (Lynn Betzold, personal communication, February 22, 2018). For this project, the preferred terminology of HCD will be used, except for in the literature review in which the terminology used by the author will be maintained.

Persons living in a rural setting pose a unique problem when it comes to ACP. Ashcroft and Owen (2016) use the term “triple jeopardy”, when referring to completion of AD among rural residents. Triple jeopardy refers to elderly persons, living in remote areas, with limited access to health care services and providers. Limited providers or agencies available to devote resources and to prioritize EOL care conversations contributes to the low completion rate of ADs among rural elderly (Ashcraft & Owen, 2016). People living in rural areas tend to have lower income, have less progressive values, and less education. Elderly persons account for a disproportionate number of those residing in rural areas. People residing in rural areas are more likely to have a chronic illness (nearly 33%) and are more likely to be in poor to fair health.

Being uninsured, and delaying treatment contribute to the increased health disparities in rural patients (Artnak, McGraw and Stanley, 2011).

Statement of the Problem

ACP includes making decisions about end-of-life care in the form of a HCD which includes identifying a health agent to make decisions for people when they are unable to make decisions for themselves. A health care directive gives individuals the opportunity to make end-of-life care wishes known to family members, providers, health care facilities, health agents, and others (National Institute on Aging, 2017).

ACP can result in increased patient satisfaction of care, better provider understanding of the patient's end of life wishes, as well as decreased family, provider or patient anxiety when having to make urgent health care decisions (Dube, McCarron and Nannini, 2015). Despite literature to support the importance of advance care planning, the completion rates of health care directives in the United States range from only 18% to 30%. A lack of awareness about advance care planning is one reason people do not complete an advance directive (Ashcraft & Owen, 2016).

Crow Wing is a rural county in Minnesota with a 2010 population of 62,500 people, and of those, just over half (50.2%) of the residents are female (Census.gov, 2016). Currently, there is no community outreach program for HCD completion. A project focused on community outreach within this rural community will help to begin the process of increasing the number of completed ADs in rural Minnesota.

Health is Your Best Accessory is an annual women's health event held in Brainerd, Minnesota. Cuyuna Regional Medical Center (CRMC) sponsors the event in partnership with several area businesses and various partners in health. The event was designed to empower

women to take better care of their health. The February 2017 event had over 700 attendees. According to the CRMC Wellness and Foundation Coordinator, most of the women who attended the event in 2017 were over the age of 45 (Jennifer Holmwig, personal communication, December 15, 2017). The purpose of the event was to raise awareness within the community about common health concerns for women. The event offered wellness screenings, health related presentations and demonstrations as well as more than 77 booths on various health topics of interest to women.

Project Description

The project implemented, was not the co-investigator's original plan for the practice improvement project. The co-investigator originally sought to increase HCD completion rates of Medicare recipients at Riverwood Health Care Center (RHCC) in Aitkin, MN. Through the development and implementation of a resource packet that could be given to patients at an annual Medicare wellness exam, the co-investigator projected that an increase in completed HCDs by Medicare patients would be seen. However, due to unforeseen medical reasons, the co-investigator was unable to continue with the original project.

To use the research and work already completed, the co-investigator decided to take the project in a slightly different direction. Instead of focusing on implementing the packet in a facility, the co-investigator made the decision to take a community-based approach. A lack of awareness about advance care planning is one reason people do not complete an advance directive (Ashcraft & Owen, 2016). Raising awareness by providing HCD completion education and information to women attending the *Health is Your Best Accessory* health event offered an opportunity to increase the number of women with completed HCDs. Women were the target audience since the *Health is Your Best Accessory* event is designed for women in Crow Wing

County. The event allows the co-investigator to reach a large number of people, who happen to be women, with the intent of raising awareness of ACP.

The following objectives guided the project: 1) Develop an informational poster presentation about ACP, as well as a packet of information which can aid participants in beginning the ACP process. 2) Raise awareness about ACP among women attending the *Health is Your Best Accessory* event. 3) Provide an opportunity for participants of the *Health is Your Best Accessory* event to attend a follow-up seminar to receive more detailed information about ACP and help completing an HCD.

CHAPTER TWO. LITERATURE REVIEW

Introduction

According to the National Institute on Aging (2017), ACP involves: 1) Exploring health care decisions made during EOL care. 2) Thinking about preferences on EOL care decisions before they arise. 3) Having discussions with others about personal wishes. End-of-life care wishes are converted to a written, legal document referred to as a health care directive. A health care directive allows patients to express their own wishes, should they become unable to speak due to significant injury or illness, regardless of their age (National Institute on Aging, 2017).

A comprehensive literature review was conducted using the keywords advance care planning, health care directive, quality measures, advance directive, women's health, fiscal impact, and end-of-life care. This chapter includes articles reviewed containing information about ACP as related to legal implications, population dynamics, the aging population, women, HCD completion rates, chronic disease, cancer, health care spending, quality measures, education, rural considerations, and benefits of ACP. The purpose of the project is to raise awareness about ACP among women in Crow Wing county Minnesota.

Advance Care Planning, Legal Implications

The Federal Patient Self Determination act of 1990 is an amendment to titles XVIII (Medicare) and XIX (Medicaid) of the Social Security Act introduced to protect patient's rights and to ensure health care decisions are communicated and protected. The legislation requires health care facilities, home care agencies and health maintenance organizations to:

1. Inform patients of their rights under State law to make decisions concerning their medical care (Congress.gov, 1990).

2. Periodically inquire as to whether a patient executed an advanced directive and document the patient's wishes regarding their medical care (Congress.gov, 1990).
3. Not discriminate against persons who have executed an advance directive (Congress.gov, 1990).
4. Ensure that legally valid advance directives and documented medical care wishes are implemented to the extent permitted by State law (Congress.gov, 1990).
5. Provide educational programs for staff, patients, and the community on ethical issues concerning patient self-determination and advance directives (Congress.gov, 1990).

For an AD to be legal in the state of Minnesota, the health care directive must have the patient's name clearly indicated, signed, and dated by the patient, witnessed by two adults or a Notary Public and state the patient's preferences for care if they are incapacitated or unable to make decisions for themselves. If the patient does not have an AD, a health care agent must be appointed to make healthcare decisions for the patient. A health care agent is a trusted individual that is well known and will follow the patient's wishes about future health care. Although there are several AD forms available, from a variety of sources, a detailed form is preferred because the patient can be specific about their preferences for EOL care. A properly witnessed and completed AD form should be given to the primary care provider, the identified health care agent, as well as a copy kept for the patient's own personal record. Per the National Institute on Aging (2017), an AD should be reviewed every time there is a change in health status and at a minimum with every change in a decade. The goal of ACP is more than just completion of a document; the process is a lifelong, evolving conversation that helps patients be engaged in their own health care decisions.

Population Dynamics and the Aging Population

The United States Census Bureau issued a report in 2014 entitled *65+ in the United States: 2010* (West, Cole, Goodkind and He, 2014) that reports on individuals 65 years and older living in the US. Information in the report addressed age structure, mortality, health behaviors, income and poverty, work and retirement, living arrangements and special dynamics such as sex imbalances, life expectancy and social characteristics. After age 65, women outnumber men and they often live alone. In the age group 65 to 69, women outnumbered men at a rate of 89 men per 100 women. Among those ages 90 and over, men accounted for only 38 to every 100 women (West, et al., 2014). Additionally, persons 65 and older who live alone tended to have less social support and financial resources, and experienced greater vulnerability and substandard living conditions. Furthermore, a difficult living situation has been associated with poor health and an increased risk of depression, especially in women older than age 85 (West et. al).

Advance Care Planning, Women

Megumi Inoue (2016), who analyzed data from the Health and Retirement Study (HRS) related to ACP found that “women were more likely than men to have engaged in both a discussion and advance directives” (2016, p. 416). Women outlive men, and experiencing the death of a spouse, friend, or family member is an opportunity to contemplate EOL care. Several studies found that women are more likely to have an ACP prior to death (Inoue, 2016).

There is limited research specific to gender and ACP conversations or AD completion. Several studies examined gender in the context of various ethnicities, cultures, level of education, marital status, and income; however, studies focused strictly on gender were scarce or nonexistent. Women are more likely to take on a caregiver role, which could be an influential

reason for why they may, or may not, complete an AD, but further research is needed to prove whether this is a factor in AD completion rates of women.

Advance Care Planning, Completion Rates

Statistics on the rates of AD completion vary from study to study. In one of the larger studies done to date, Katherine Courtright completed a meta-analysis of 150 studies related to AD between the years 2000 and 2015. Of the 796,000 individuals included in the analysis, 36.7% had completed a formal or informal AD of some kind. Twenty-nine percent had a living will, and thirty-three percent had a designated medical power of attorney. About half of the individuals with a completed AD did not have a chronic illness (Crist, 2017).

The Health and Retirement Study (HRS) was a longitudinal project sponsored by the National Institute on Aging. Adults over the age of 50 in the United States completed a survey with questions about health and economic situations, including advance care planning. The study began while the participant was alive; after the study participant's death, an appointed proxy was queried about what they knew about the participant's ACP. In 2016, Inoue analyzed the HRS data and found that of the 1,056 respondents, 19% did not have an AD at the time of their death and only eleven percent had discussed their EOL wishes with someone. Advanced age, and a higher socioeconomic status were strong predictors for AD completion. The authors felt advanced age was a predictable finding because as people age, the incidence of illness increases, subsequently prompting ACP discussions.

HealthStyles is a survey conducted in the United States that collects information and health-related opinions of adults 18 years or older annually. Rao, Anderson, Lin and Laux (2016), examined the HealthStyles survey from 2009 and 2010. Of the 7946 participants surveyed, 26.3% had an AD in place. Further analysis of the results showed that females or

individuals with a chronic disease, a college education, or a designated primary care provider were more likely to have an AD.

ACP completion rates are highest in nursing home residents. Ashcraft & Owen (2016), reported that 60%-70% of nursing residents have an ACP, with higher completion rates in urban versus rural facilities (Ashcraft & Owen, 2016). One type of ACP often found in nursing homes is a Provider Orders for Life-Sustaining Treatment (POLST) form. A POLST is a legal, portable document that outlines a patient's wishes in an emergency. In a cross-sectional telephone survey conducted in 2014, Sebastian, Freitas, and Fischberg (2015) contacted 39 nursing home facilities to assess their POLST implementation paradigm. Of the 23 facilities that responded, 20 had a POLST completion rate of just over 50% (Sebastian, Freitas, and Fischberg, 2015).

Silveira, Wittala, and Piette (2014) conducted a retrospective cohort study that examined trends in AD completion between 2000 and 2010. The authors found that the rate of AD completion had risen by 25% to an all-time high of 72% in 2010. The increased use of durable power of attorney for health care, defined as “any legal arrangements for a specific person or persons to make decisions about the decedent’s care or medical treatment if he or she could not make those decisions him or herself” (Silveira, Wittala, & Piette, 2014, p. 709) was the presumed reason for the increase in the rate of AD completion. Although the increased number of completed AD is reassuring, the authors urged continued advocacy for patient autonomy through the completion of ADs.

The Minnesota Cancer Alliance is a partnership of various health organizations and leaders within Minnesota (Minnesota Cancer Alliance, 2014). The partnership’s goal is to decrease the strain of cancer for those residing in Minnesota. A chief objective of Cancer Plan

Minnesota focuses on ACP and AD completion by cancer patients. The most recent survey in Minnesota reported a 31.6% AD completion rate (Minnesota Cancer Alliance, 2014).

Bravo, Trottier, Arcand and Dubois (2016), compared two ACP interventions, two individual home visits or one group educational session, and the resulting AD completion rates of each intervention. The authors found that the participants in the single group educational session had a slightly higher AD completion rate (82%) as compared to the participants that received two home visits (80%). The results of this study suggest that individualized home visits and group sessions may yield comparable results in AD completion rates.

Advance Care Planning, Chronic Disease and Cancer

Individuals are living longer, consequently the prevalence of chronic diseases is expected to rise. The increased number of individuals living with chronic disease escalates the need for EOL planning. Supiano, McGees, Dassel, and Utz (2017) examined end-of-life preferences in currently healthy adults through a survey aimed at exploring how various terminal diseases, and their expected death trajectories, would influence EOL care choices. Respondents reported that conditions including pancreatic cancer, congestive heart failure, and Alzheimer's disease would influence their EOL wishes. One of the more frequently voiced personal values reported was the idea of being a burden. Patients often defined burden as having a concern for family and friends who assume a caregiving role and the strain it causes while watching a person progress through a disease and die. Additionally, time, finances, and emotional strain were also identified as burdens related at the EOL. A major finding of the study was that the circumstances surrounding a disease influences EOL care decisions (Supiano, McGees, Dassel, and Utz, 2017).

Pautex, Notaridis, Derame, and Zulian (2010) completed a study that examined EOL care preferences for elderly patients with cancer. During the timeframe of the research, 1600

patients were hospitalized with a cancer diagnosis in an advanced stage; only 149 (9%) patients expressed interest in completing an AD. Of the 149 patients, 50 took part in the study. Only 10% ($n=5$) of the patients had an AD. The main reasons patients wished to complete an AD was to increase self-determination, to strengthen communication with caregivers and proxies, to avoid being a burden, to lessen fear of too aggressive treatments, and for reassurance that their EOL care decisions would be honored (Pautex, Notaridis, Derame & Zulian, 2010).

Advance Care Planning, Health Care Spending

There is a paucity of evidence that ACP, in and of itself, decreases health care costs at an individual or systems level. Most studies on the cost-effectiveness of ACP include patients receiving palliative or hospice care services. A lack of research specific to ACP makes the determination of fiscal impact of ACP alone difficult.

Nicholas, Langa, Iwashynam, and Weir (2011), looked at retrospective data of Medicare beneficiaries who died in the years 1998-2007. The levels of Medicare spending for regions with low, medium, and high EOL expenditures were compared. Geographical areas with an abundance of health care resources and services had higher EOL medical costs. Nicholas et al., (2011) found in regions where aggressive EOL care was available, the cost of care would be reduced by \$265 million, if just 6% of those who died in regions with access to an abundance of resources and services would have had an AD that limited life-sustaining treatment like those in low spending regions. The assumption is that end-of-life care spending is only reduced when the person chooses to have services that are different from the geographical norm (Nicholas et al., 2011).

Contrary to what other authors have concluded, Fonk, Davidoff, Lutzow, Chelsey, and Mathiowetz (2012), did not find cost savings at the EOL for persons with an AD. The authors of this study examined data ($N=858$) about patients enrolled in the Independent Care Health Plan

(iCare) patients who died between January 1, 2005 and August 2010. EOL costs were measured in the last month of life only. Results from the study revealed that patients who are sicker were more likely to have an AD, and higher EOL health care costs. The data suggests that ADs themselves do not decrease EOL care costs. The study was limited to a single health care organization. A larger, more wide-spread study is needed to determine the actual cost effectiveness of AD. A lack of robust information, and the existence of contradictory studies call upon the need for further research on the impact of ACP interventions on the cost of health care at the EOL.

Advance Care Planning, Quality Measures

The Centers for Medicare and Medicaid Services (CMS) have in place many quality measures that require eligible professionals to meet a set threshold, to requisition reimbursement of covered services. CMS monitors the completion of AD by hospital patients. Providers must document if the patient has an AD and if so, whether the facility has a copy of the AD in the electronic health record (EHR). If the patient does not have an AD on file in the EHR, providers must document discussion about AD and the reason for not having an AD, for example, the patient requested more information on ADs, or the patient declined additional information. Additional quality measures pertaining to AD are currently under development at CMS (Centers for Medicare and Medicaid Services, 2017).

In October 2017, the Minnesota Department of appropriated \$250,000 from the state fund for fiscal year 2018 and 2019 to one or more ACP resource organizations. The intent of the grant is to increase ACP awareness in MN, encourage ACP conversations, increase the availability of ACP resources, and to develop a quantifiable and practical evaluation for ACP (MN Department of Health, 2017).

Advance Care Planning, Increasing Awareness

The California Health Foundation (CHCF) is an organization committed to making improvements to the way people of California receive care. To address continued concern for ACP needs of those living in California, coalitions were formed in the late 1990's and early 2000s. Coalitions included "hospitals, skilled nursing facilities, emergency medical service providers, hospices, nursing homes, senior centers, and consumer groups" (Rabkin, 2014, p. 3). To gain a better understanding of successful strategies for community implementation of ACP, Rabkin interviewed ten members of the coalition. The interview process revealed several recommendations pertaining to implementation of ACP initiatives within communities, including the emphasis on utilizing community advocates who were passionate about ACP. The following strategies were suggested:

1. Target both providers and consumers to raise awareness within the health care system and the community at large;
2. Hold meetings and distribute meetings at community centers and other locations where community members congregate;
3. Engage faith-based and other community leaders outside the health care system to address broader emotional and spiritual issues raised at the end of life;
4. Develop and use a mailing list to reach consumers with information about workshops, events, and other advance care planning resources (Rabkin, 2014, p. 12).

Interestingly, Rabkin (2014) found that patients who receive ACP education within the community often share their experiences with others. Positive word-of-mouth has helped to spread information about the benefits of ACP without costing the coalitions any money.

Implementing ACP within the community is not without its challenges. Coalitions often face

funding issues and are unable to hire enough staff to expand programs to meet the needs of the communities they serve. Although the coalitions are leading the nation in ACP, ongoing enhancement of community-based ACP is required. Rabkin suggested that a need exists for continued research on all aspects of ACP to determine appropriate benchmarks and establishment of goals for improvement (Rabkin, 2014).

Hinderer and Lee (2014) led community-based ACP seminars in Maryland and Delaware, with 103 attendees. Over half of the attendees were college educated, Caucasian females ranging in age from 20-80. Forty-five percent of the 103 attendees had a chronic illness. The seminar curriculum centered around the Five Wishes Guide, which is an international step-by-step guide for individuals and families to examine personal attitudes about HCD, start conversations about last wishes, and to complete an AD or Living Will. At the conclusion, attendees completed a post-test. Of the 86 completed post-tests, the authors found that 83% of attendees felt that the seminar was useful, and 98% reported that they were likely to complete an AD and begin a conversation about EOL decisions with family or friends. Prior to the seminar, only a third of participants, the majority being older females, had completed an AD (Hinderer and Lee, 2014). After conducting a community-based ACP seminar, Hinder and Lee (2014) concluded that community-based education is an effective method to improve AD completion.

In 2007, a group of critical care nurses in Idaho participated in a Heart and Health Fair sponsored by their local medical center (Later and King, 2010). The goal for the health fair was to raise awareness of ACP through conversations with health fair participants. The nurses felt the health fair provided an environment that was nonthreatening and affable to participants. Attendees were invited to stop by the booth, discuss ACP, and receive assistance in filling out an AD. The nurses report that their booth was successful in that “a majority of the approximately

900 health fair attendees stopped by the booth” (Later and King, 2010, p. 33). The success of the booth resulted in the critical care nurses being invited back to take part in the event the following year. As a follow-up to the initial health fair, a one-hour informational symposium was orchestrated for the local community. The follow-up symposium was highly marketed and resulted in over 100 attendees. Sixty-five percent in attendance reported they had little or no knowledge of ADs. Only 22% reported having an AD completed. A question and answer session facilitated by a critical care nurse, allowed participants to ask specific questions and get guidance in completing an AD. Impressively, 98% of attendees reported they intended to pursue completing an AD after receiving information at the symposium. Due to the overwhelming success of the health fair and follow-up symposium, the co-investigator chose to replicate the Eastern Idaho critical care nurses’ model.

Advance Care Planning, Rural Considerations

Persons living in a rural setting pose a unique problem when it comes to ACP. Ashcroft and Owen (2016) use the term “triple jeopardy”, when referring to completion of AD among rural residents. Triple jeopardy refers to elderly persons, living in remote area, with limited access to health care services and providers. Limited providers or agencies available to devote resources and to prioritize EOL care conversations contributes to the low completion rate of ADs among rural elderly (Ashcraft & Owen, 2016). People living in rural areas tend to have lower income, have less progressive values, and less education. Additionally, the elderly account for a disproportionate number of those residing in rural areas. People residing in rural areas are more likely to have at least one chronic illness (nearly 33%) and are more likely to be in poor to fair health. Furthermore, rural inhabitants are often uninsured, and delay seeking medical treatment,

further compounding the health disparities encountered by rural Americans (Artnak, McGraw and Stanley, 2011).

Advance Care Planning, Barriers

Many barriers influence a person's willingness to complete an HCD. According to a survey conducted in 2009 and 2010 by Porter Novelli, 7946 adult participants most often responded (24%) that the top reason for not completing an AD was a lack of awareness (Rao, Anderson, Lin, and Laux, 2014).

Later and King (2007) also explored barriers to ACP. The identified barriers included a delay in seeking ACP until a health crisis had occurred, cultural and ethnic considerations, a lack of education about EOL care, and the inability to access information about ACP. Later and King suggested interactive, educational sessions as a successful way to increase AD completion rates.

Hamilton (2016), suggested that individuals are unwilling to discuss EOL because doing so would involve thinking about their health and the potential for deterioration, even death. Additionally, Hamilton implied that practitioners may also be uncomfortable with having ACP conversations for fear that patients could potentially endure undue anguish.

Advance Care Planning, Benefit

According to Dube, McCarron and Nannini (2015), ACP can result in increased patient satisfaction of care, better provider understanding of the patient's EOL wishes, as well as decreased family, provider or patient anxiety when having to make urgent health care decisions. Caregivers forced with having to make EOL care decisions for their loved ones often struggle with decisional conflict. In a study conducted by Chiarchiaro, Buddadhumaruk, Arnold, and White (2015), 251 critically-ill patients, and 471 proxy decision makers completed a questionnaire for assessing whether a relationship existed between a completed AD and

decisional conflict. Decisional conflict is a sense of uncertainty that comes from having to make a decision that may challenge one's personal beliefs. Of the 471 proxy decision makers surveyed, 267 reported that ACP took place prior to the patient dying. The authors found that almost half of the proxy decision makers reported moderate or elevated levels of conflict when making decisions to forgo life-sustaining treatment. Prior ACP conversations about EOL care resulted in lower decisional conflict (Chiarchiaro, Buddadhumaruk, Arnold, & White, 2015).

One purpose of ACP is to ensure that patients' wishes for EOL care are known and honored. A study conducted by Mack, Weeks, Wright, Block, and Prigerson (2010), examined the EOL care preferences of 325 patients with advanced cancer. The authors purpose was to compare the EOL care patients received and the care preferred by the patients. The initial interview was with the patient, and then two weeks following the patient's death, a questionnaire was given to a predetermined caregiver. Results from the study showed that patients who received EOL care consistent with their wishes, had had conversations with their physician prior to death, about their EOL care preferences. Unfortunately, 13% of patients surveyed did not receive EOL care consistent with their wishes. Patients reported experiencing increased distress and a decreased quality of life when they received life-sustaining treatments despite their desire not to (Mack et al., 2010).

Theoretical Framework

A theoretical framework should guide a practice improvement project. Kurt Lewin, a social psychologist, was a pioneer in the study of organizational development and group dynamics (Shirley, 2013). Among his work was the development of force field analysis and The Change Theory. Force field analysis defines forces as either driving (helping) or restraining (hindering) movements toward a desired result. Driving forces are the forces that influence and

push for change to happen. Restraining forces oppose driving forces and attempt to hinder change. Essentially, driving forces are the factors for change, while restraining forces are the factors against change. For change to happen, the driving forces must outweigh the hindering forces. Equilibrium exists when the driving forces equal the restraining forces (Shirley, 2013).

Change Theory

Lewin's Change Theory involves three stages (Shirley, 2013). In the first stage, unfreezing, the need for a change is identified and a change agent examines the circumstances that influence a situation. Lewin's concept of force field analysis occurs in this step. The change agent identifies the forces driving a behavior either for, or against change. In the unfreezing stage, the co-investigator recognized the need for a change to increase awareness about ACP with the hopes of increasing completion rates of HCD among women in Crow Wing County. As a part of the unfreezing stage, a literature review was conducted, and factors influencing successful completion of an HCD were explored, while also examining barriers to completing an HCD. Although there was no research specific to influential factors for women in completing an HCD, the co-investigator kept in mind which sort of influences would be most effective from a women's perspective. A person's perspective may vary based on gender, ethnicity, social status, and education. The co-investigator applied the factors found in the literature, while keeping in mind perspective to reach a state in which the driving forces outweighed the restraining forces. Restraining forces as identified in the literature review, included a lack of awareness about ACP, denial or lack of awareness about current health status, and a lack of access to information about ACP.

The second stage, moving or transitioning, involves the change agent creating a detailed plan to encourage people to attempt the change (Shirley, 2013). Encouraging people to attempt

change is not without difficulty. Change is often accompanied by fear of the unknown, which requires the change agent to communicate clearly and coach individuals to overcome fears. To counteract the restraining forces the co-investigator developed and presented a poster at the women's health fair. A resource packet was developed and distributed at the women's health event as well. Both interventions were an attempt to increase awareness about ACP. To offer an additional educational opportunity, the co-investigator developed a follow-up ACP and HCD seminar. In phase two, the co-investigator attempted to increase participant knowledge and likelihood of completing an HCD, using a PowerPoint presentation and step-by-step tutorial in completing an HCD. The most influential driving force for the practice improvement project was the co-investigators passion about ACP.

In the final stage, refreezing, the change becomes the new norm and beliefs about the change stabilize. Driving forces facilitate change and prevent restraining forces from hindering the change (Shirley, 2013). Reaching equilibrium extends far beyond the works of the co-investigator. Continued efforts to increase awareness and knowledge about ACP are essential for a cultural change to happen and for ACP to become the norm. Implications for further research is discussed in chapter six.

CHAPTER THREE. PROJECT DESIGN

The following objectives guided the project: 1) Develop an informational poster presentation about ACP, as well as a packet of information which can assist participants in beginning the ACP process. 2) Raise awareness about ACP among women attending the *Health is Your Best Accessory* event. 3) Provide an opportunity for participants of the *Health is Your Best Accessory* to attend a follow-up seminar to receive more detailed information about ACP and help completing an HCD. The project focused on what ACP is, who ACP is for and why it is important to complete an HCD. A logic model directed the planning and implementation phases of the project.

Logic Model

A logic model (figure 1) is a systematic approach used to visualize the relationship between resources available, planned activities, and the intended results of the project. A logic model consists of inputs, activities, outputs, outcomes, and impact (W.K. Kellogg Foundation, 2004). In this chapter, inputs and activities of both phases of the project are discussed. Outputs, outcomes, and impact will be discussed in chapter four.

Inputs and Activities

Inputs are the resources used for planning and implementation. Activities are implemented by using the identified resources to produce an intended result (W.K. Kellogg Foundation, 2004). For this project, resources included the co-investigator, team members, venues, time, and materials. Team members consisted of the co-investigator, the CRMC Wellness Coordinator, Honoring Choices MN representative, and the CRMC Senior Services Coordinator. All team members were involved in the planning phase of the project. Activities included the development and distribution of a resource packet, development and presentation of

a poster board, development and presentation of an ACP PowerPoint, as well as the development and implementation of two different surveys, one for each phase.

Phase one of the project took place on February 1st, 2018 from 3:00 pm to 7:30 pm at the Northern Pacific Space in Brainerd, Minnesota. The Northern Pacific Space is a large, historical, mixed-use complex that hosts numerous events annually. The venue was set-up with 77, eight-foot tables draped in a black table cloth. Refreshments, including hot appetizers, desserts, and beverages were provided by Heartwood Senior Living Facility. The population targeted was women in attendance at the *Health is Your Best Accessory* event. Indirectly, friends, family-members, and co-workers of women attending the health event were also targeted. Although not measured, the hope was that women went home after having been invited to the follow-up event and shared the invite with others.

The greatest resource for the practice improvement project was the time spent developing the poster presentation (Appendix A) and gathering information for the resource packet. Material for the resource packet was adapted from the Honoring Choices Minnesota information sheets available online to the public, free of charge. Included in the packet was information sheets from Honoring choices MN which included an eight-page detailed health care directive form, a step-by-step guide detailing completion of an HCD and choosing a health care agent, as well as information sheets detailing key terms necessary for completion of an HCD (Honoring Choices Minnesota, 2017). Materials from Honoring Choices Minnesota were included in the informational resource packet rather than creating original documents, because similar information packets using Honoring Choices Minnesota material were successfully implemented in two local hospitals.

Activities for phase one of the project included taking the materials developed and distributing a resource packet during the event, and the development and presentation of a poster board on advance care planning. The intent of the resource packet was to aid participants in completing an HCD.

Phase two of the project took place on February 22nd, 2018 from 2:30 pm to 4:00 pm at the Brainerd Public Library in Brainerd, Minnesota and was a follow-up seminar from the *Health is Your Best Accessory* event. The Brainerd Public Library was chosen as the site for the follow-up seminar because it was free to use, easy to reserve online, centrally located in the community, and a well-known location to people of Crow Wing county. The co-investigator chose to refrain from hosting the follow-up seminar at a place of worship, or any one specific hospital system to be inclusive to all. The room was set-up with tables and chairs. There was a projector available for use to present the PowerPoint on a large screen for easier viewing. HCD forms and information packets were available to participants. The co-investigator provided bottled water and cookies for participants.

The PowerPoint presentation (Appendix B) for phase two of the project was developed by the co-investigator and was adapted from information found in the Honoring Choices Minnesota step-by-step guide in completing an HCD form. The PowerPoint defined ACP, who may benefit from ACP, why ACP matters, as well as how to choose a health care agent. The intent of the presentation was to assist attendees in completing an individualized HCD. Initially, a representative from Honoring Choices Minnesota was supposed to attend the follow-up seminar in order to offer an added level of expertise to the seminar, however, due to scheduling conflicts, the representative was unable to attend. The co-investigator's PowerPoint presentation was reviewed by the Honoring Choices Minnesota representative prior to the presentation.

Included in the PowerPoint presentation was a page-by-page tutorial for completing an HCD. Participants were allowed to interrupt and ask questions during the tutorial.

CRMC provided paper and color printing services for completion of the information packet, and poster presentation for phase one, as well as the surveys for phase one and two. The booth fee for the *Health is Your Best Accessory* event of \$50 was waived because there was no charge for student presenters. The room reservation fee at the Brainerd Public Library for the follow-up seminar was waived because there was no charge for a student to use the large meeting room.

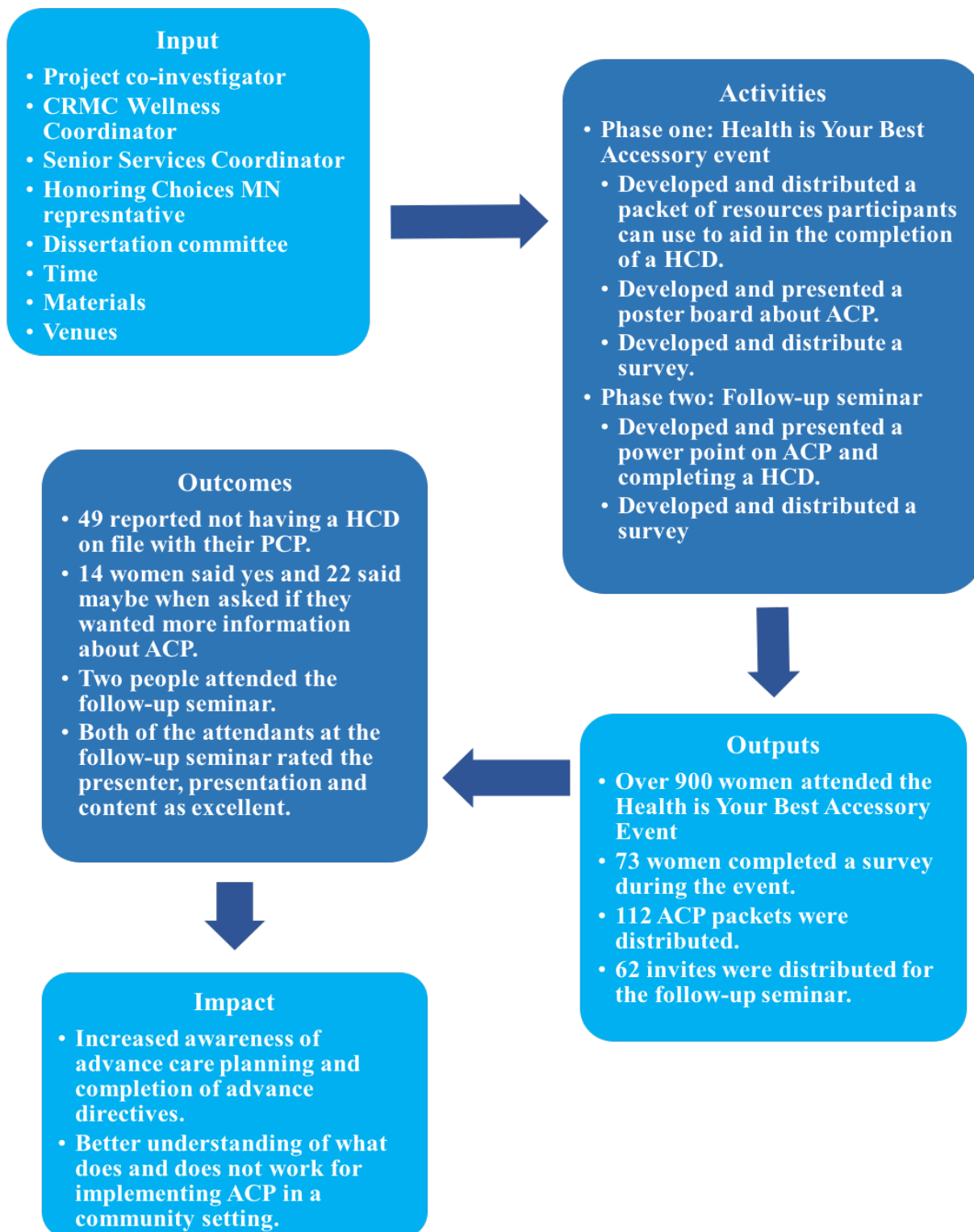


Figure 1. Logic model

Institutional Review Board Approval

The first phase of the practice improvement project was certified as exempt by the NDSU Institutional Review Board on January 30, 2018 (Appendix C). The second phase of the practice improvement project was certified as exempt on February 21, 2018 (Appendix D). Both phases of the project qualified under Exemption Category 2b: research involving the use of survey procedures or interview procedures or observation of public behavior for which subjects cannot be identified, or release of the information would not be harmful to the subject. Data collection did include information which could have directly or indirectly identified the participants, however, no potential harm would have come to participants if confidentiality had been breached. Minors were not involved in the poster presentation and there was no recruiting of special populations (pregnant women, fetuses, prisoners, cognitively impaired individuals, economically or educationally disadvantaged individuals). There was minimal risk to attendees and participation was voluntary. Consent was obtained by attaching a cover letter to the survey, handed out during both phases of the project, informing participants why they are being asked to take the survey as well as the option to opt out should they not have wanted to participate (Appendix E).

Data Collection

Data was collected during both phases of the practice improvement project. On February 1, 2018, during the women's health event, data was collected about age, race, presence of chronic diseases, whether a participant already had an HCD on file with their PCP, and lastly if after attending the presentation they would like more information about ACP (Appendix F). Age, race, and the presence of chronic diseases were asked in order to attempt to find trends in completion rates of ACP. The survey included a list of chronic conditions along with the option

to write in any conditions not listed. The co-investigator kept a tally of the number ACP resource packets distributed and the number of invitations given to the follow-up seminar.

During the second phase of the project, participants were asked to take a Likert scale survey (Appendix G) about the quality of the presenter, presentation, content, and whether the participant had enough information to complete an HCD after the seminar. The co-investigator kept a tally of the number of participants who attended the follow-up seminar.

CHAPTER FOUR. EVALUATION

Evaluation Methods

Evaluation involved determining whether the project objectives were met. Evaluation of phase one, phase two involved asking participants to complete a survey after the completion of each phase. Data from the surveys is discussed in chapter five.

Objective One

The first objective was to develop an informational poster presentation about ACP, as well as a packet of information which can assist participants in beginning the ACP process. A Logic Model guided the planning and evaluation of objective one as defined in Chapter 3.

Objective Two

The second objective was to raise awareness about ACP among women attending the *Health is Your Best Accessory* event. A poster presentation was displayed during the event. The co-investigator was available to discuss ACP and completing an HCD. Resource packets were available to participants who were interested in more information about ACP. Evaluation of objective two included analyzing the survey, and by keeping a tally of the number of people who were interested in the resource packet.

Objective Three

Objective three was to provide an opportunity for participants of the *Health is Your Best Accessory* to attend a follow-up event to receive more detailed information about ACP and completing an HCD. Evaluation of objective three involved analyzing the survey completed by participants of the follow-up seminar.

Logic Model

Activities result in outputs (W.K. Kellogg Foundation, 2004). Outputs of the practice improvement project included over 900 women attending the *Health is Your Best Accessory* event. Seventy-three women completed a survey during the event, and 112 resource packets were distributed to participants interested in more information about ACP. Sixty-two invitations to the follow-up seminar were handed out to those who showed interest in learning more about completing an HCD. Invitations were printed on a half-sheet of paper and printed on bright green paper to make them more noticeable. Participants received an invitation if they indicated on the survey they were interested in more information about ACP. Additionally, people who expressed an interest in the follow-up seminar during conversations held with the co-investigator were also invited.

Outcomes are an effect of the outputs, and result in change (W.K. Kellogg Foundation, 2004). Outcomes of phase one included 49, of the 73 participants surveyed reporting not having an HCD on file with their primary care provider. Thirty-six participants marked *yes* or *maybe* when asked if they wanted additional information about ACP and completing an HCD. In phase two, of the 62 invitations distributed at the women's health event, only two participants attended. Both attendees at the follow-up seminar rated the presenter, presentation, and content as excellent.

Expected changes are the impact made as a result from the activities implemented (W.K. Kellogg Foundation, 2004). The goal of the practice improvement project was to increase awareness about ACP among women in Crow Wing county, Minnesota. Through increasing awareness and offering an opportunity to increase knowledge about ACP, the expectation was that an increase in completed HCDs among women in Crow Wing county would also result.

CHAPTER FIVE. RESULTS

Phase One

Data was collected from the *Your Health is Your Best Accessory* event held on the evening of February 1, 2018. Over 900 women attended the event. Seventy-three surveys were completed, with 100% of the participants being Caucasian females. Ages of the participants included 20-39 ($n=15$), 40-59 ($n=30$), 60-79 ($n=25$) and 80+ ($n=3$) (figure 2).

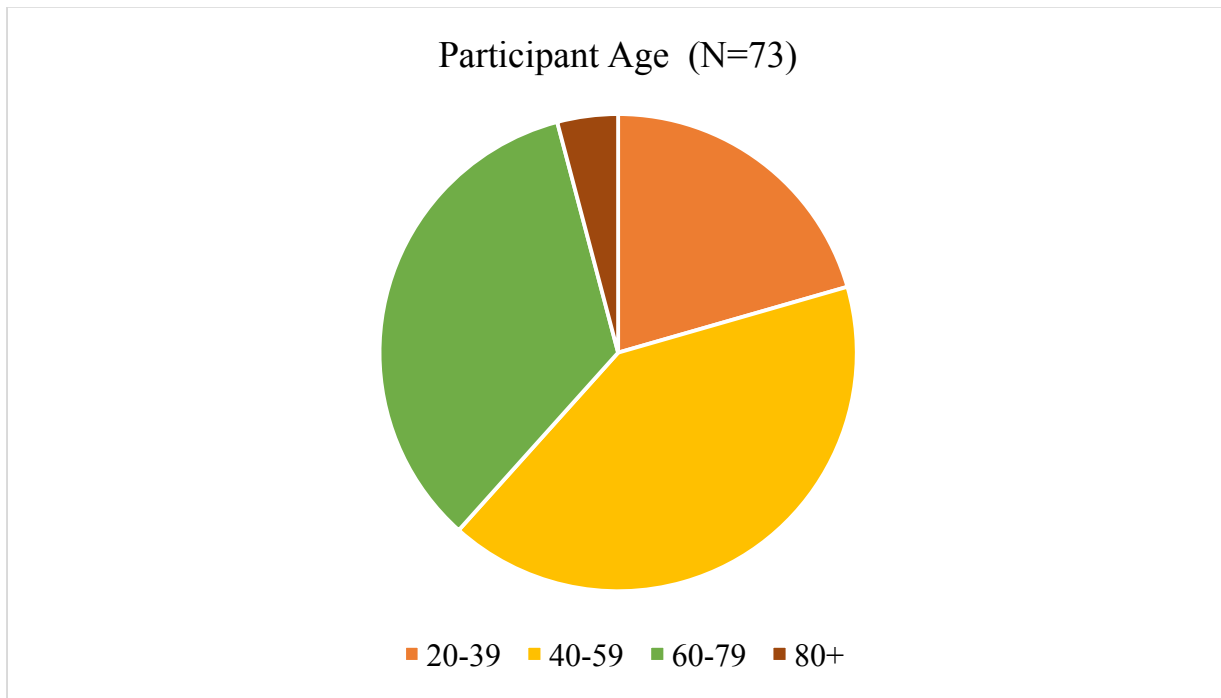


Figure 2. Participant age

The participant reported chronic diseases can be found in figure 3. The top three diseases reported were high blood pressure ($N=17$), arthritis ($N=11$), and other chronic diseases ($N=8$). Other chronic diseases reported consisted of depression, mitral valve prolapse, post-polio syndrome, high cholesterol, and osteoporosis. Twenty-four participants surveyed reported having an HCD on file with their PCP, and 49 reported not having an HCD on file with their

PCP (figure 4). The final question of the survey asked whether the participant was interested in more information about ACP. Results can be found in figure 5.

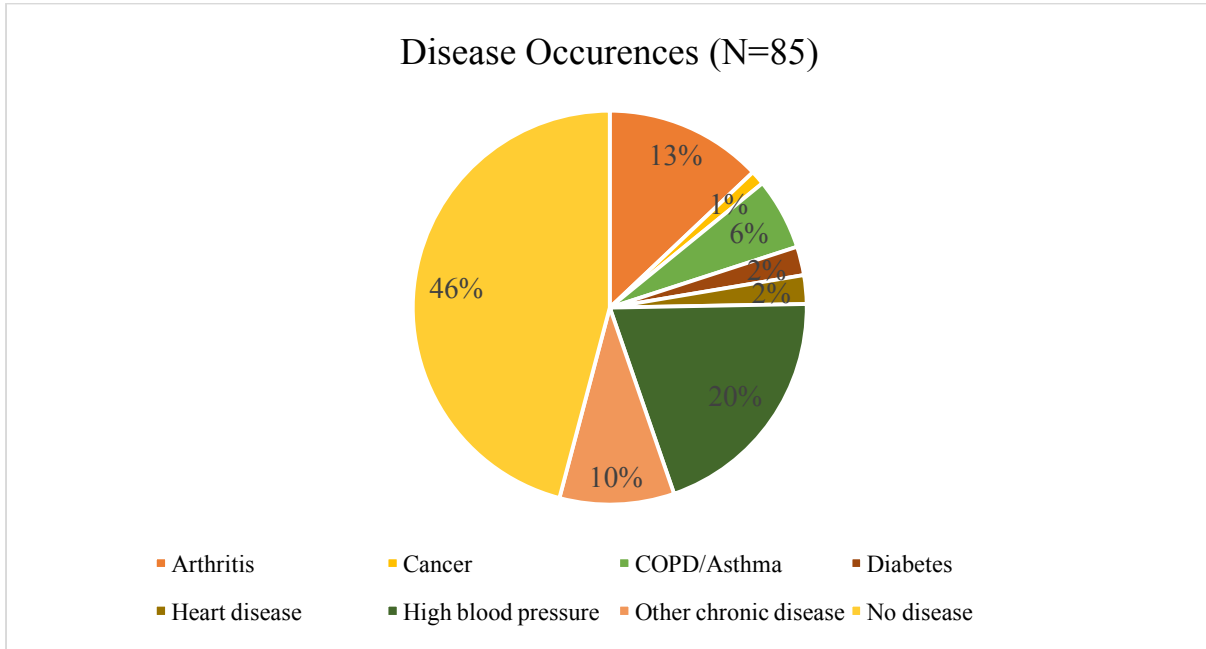


Figure 3. Disease occurrence

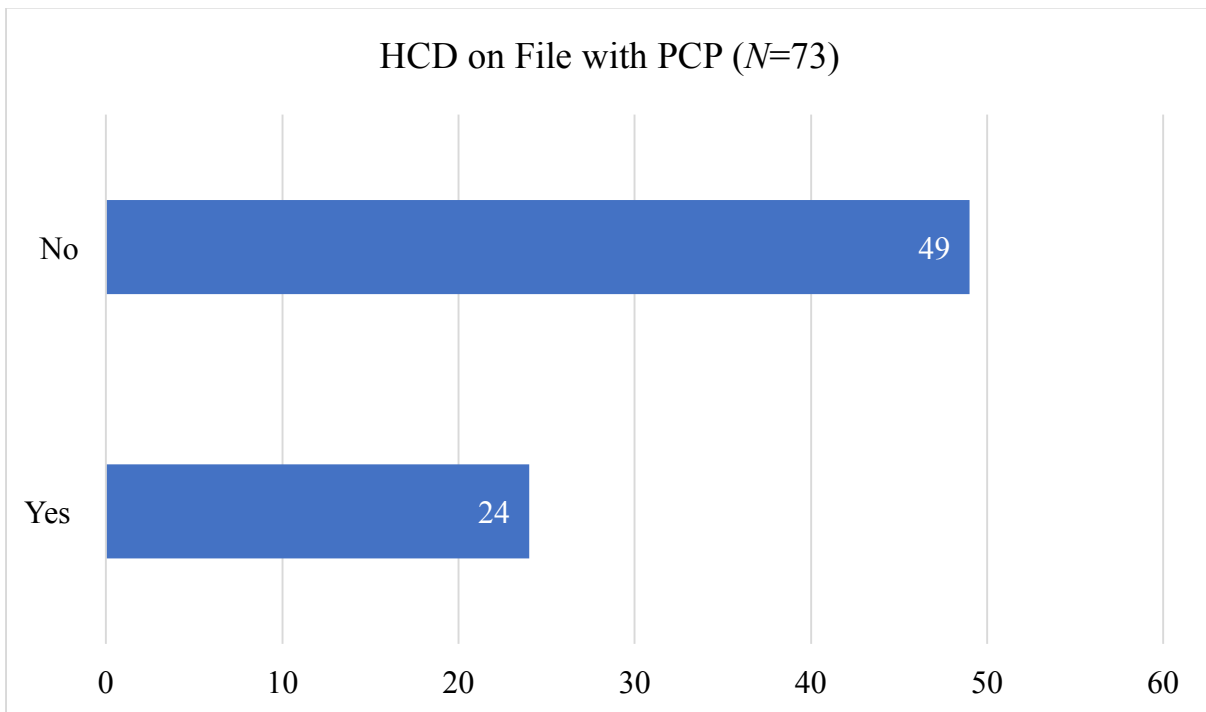


Figure 4. HCD on file with PCP

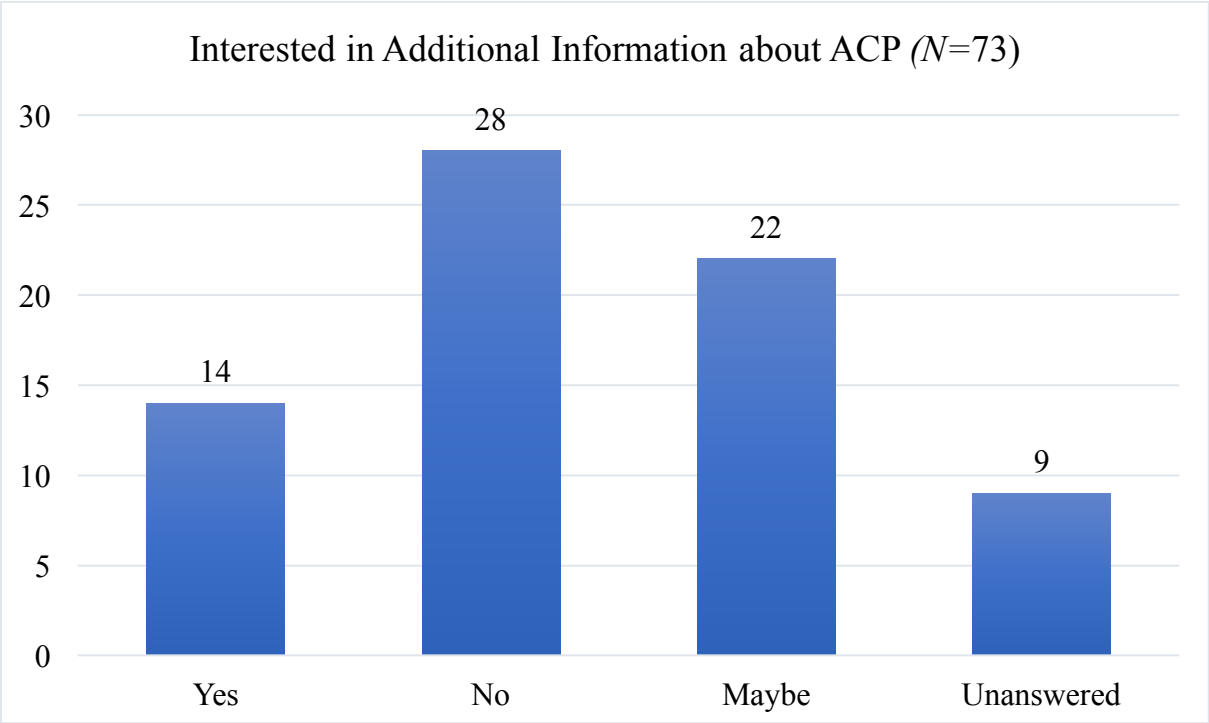


Figure 5. Interested in additional information about ACP

One hundred twelve ACP resource packets were distributed. Invitations to the February 22 follow-up event were given out to participants that answered *yes* or *maybe* to the survey question of whether they would like additional information about ACP. Additional invitations were handed out to individuals who expressed interest in ACP but did not want to fill out a survey. A total of 62 invitations were distributed.

Phase Two

Data was collected from the follow-up event held at the Brainerd Public Library on February 22, 2018. Two people, a husband and wife, attended the follow-up event. According to the survey data collected, both participants rated the presenter, presentation, and content as excellent, and both answered yes when asked if they felt they had enough information, after taking part in the presentation, to complete an HCD. Both participants were actively engaged in the presentation and interacted with the co-investigator during the step-by-step HCD tutorial.

CHAPTER SIX. DISCUSSION AND RECOMMENDATIONS

Interpretation of Results

The objectives of this project were to 1) Develop an informational poster presentation about ACP, as well as a packet of information which can assist participants in beginning the ACP process. 2) Raise awareness about ACP among women attending the *Health is Your Best Accessory* event. 3) Provide an opportunity for participants of the *Health is Your Best Accessory* to attend a follow-up seminar to receive more detailed information about ACP and completing an HCD. Included in this chapter is an interpretation of results for phase one and two, limitations of the project, and recommendations. Also included are implications for practice and further research as well as application to the NP role.

Objective One

Objective evaluation was guided by a logic model and included outputs, outcomes, and impacts. Over 900 women attended the *Health is Your Best Accessory* event. Over 67% of the (N=73) participants surveyed reported not having an HCD on file with their primary care provider. The results of the women's health event survey are in line with the US average of HCD completion in which 70-82% do not have an HCD completed.

Objective Two

The overall impact of the poster presentation and resource packet implemented at the *Health is Your Best Accessory* event remains unknown. The intended goal was to increase the number of completed HCDs among women in Crow Wing county, Minnesota. Although only 36 survey participants reported *yes* or *maybe* to wanting additional information about ACP, 62 invitations to the follow-up seminar were distributed. Many people did not want to fill out a survey, however, in conversations held with the co-investigator, the attendees expressed an

interest in attending the follow-up seminar, therefore invitations were given at that time as well. Resource packets were distributed during the event ($n=112$). The expectation was that many of the women who attended the health event would be gathering information for themselves, however, during the conversations held, the co-investigator noted that many participants stated they planned to take home information for someone else. The hope is that some of the participants who received a resource packet complete an HCD in the future.

Trends in HCD Completion Rates

During the women's health event, data was collected about age, race, presence of chronic diseases, whether a participant already had an HCD on file with their PCP and lastly if after attending the presentation they would like more information about ACP (Appendix F). Age, race, and the presence of chronic diseases were asked in order to attempt to find trends in completion rates of ACP. Age appears to be a factor in the number of chronic diseases present with participants, which makes sense because younger people are less likely to have chronic illnesses. The absence of disease may influence the person's perception on the need for an HCD, however, even if a disease is present, the person needs to be able to recognize they do have a chronic illness.

As seen in table 1, age group 20-39 had the lowest percentage of participants with at least one chronic disease. Age group 60-79 had the highest number of participants with at least one disease but only 48% reported having an HCD on file with their PCP, which is slightly higher than the national average. Age group 80+ had the lowest HCD completion rate, however, the age group also had the lowest participation. Further data collection is needed to strengthen the correlation between age, presence of at least one disease and HCD completion rates.

Table 1

Health is Your Best Accessory *event data*

A	B	C	D	E
Age group (years)	Participants with at least one disease	Participants having HCD with PCP	Percentage of age group with at least one disease (B/A)	Percentage of age group having HCD with PCP (C/A)
20-39 (N=15)	2	3	13.33%	20.00%
40-59 (N=30)	13	9	43.33%	30.00%
60-79 (N=25)	17	12	68.00%	48.00%
80+ (N=3)	2	0	66.66%	0.00%

Objective Three

Of the 62 invitations distributed during the women's health event, only two participants attended the follow-up seminar. Limitations are discussed in the next section of this chapter. Although attendance was low, the two participants rated the presenter, presentation, and content as excellent, however, due to the low number of participants, the result needed to be interpreted cautiously. The PowerPoint presentation and step-by step tutorial in completing an HCD was implemented successfully. Evaluation of the overall impact of the PowerPoint presentation and the step-by-step tutorial were not measured in this study, however both answered *yes* when asked if they felt they had enough information, after taking part in the presentation. The hope is that both participants when on to complete an HCD.

Limitations

The project has several limitations and barriers that affected the design and implementation phases of the practice improvement project. The first limitation was the venue set-up during phase one of the project. The venue was large; however, the booths were setup quite close to each other, which meant there was not a lot of space for participants to see or read the poster. In addition, with over 900 attendees, the venue was overcrowded. Overcrowding

resulted in people passing over the booth because there were participants already engaged in discussion with the co-investigator. Many people were overheard complaining about the crowded nature of the venue. Additionally, people were encouraged to visit specific booths to have a card stamped, which when completed, would result in placement of their name in a prize drawing. The co-investigator's presentation was not one of the booths included in the prize drawing, however, it was situated between two of the booths included. Close proximity to the booths included in the prize drawing resulted in participants passing over the co-investigator's presentation in order to get their card stamped. Many of the other booths had free items, prize drawings or giveaways for participants, however, due to lack of funding, the co-investigator had none. A lack of giveaway items may have made the ACP booth less desirable, meaning less people participated.

The demographics of the women that attended the *Health is Your Best Accessory* event presents another limitation. One-hundred percent of the survey participants were Caucasian women. A lack of diversity means the results of the project cannot be applicable to a wide range of other communities. A few men attended the *Health is Your Best Accessory* event, however, none participated in the poster presentation or the survey. Very few participants over the age of 80 completed surveys. Decreased participation by elderly persons was attributed to difficulty in completing surveys due to physical limitations such as use of a walker, inability to hold a pen, or inability to see the works on the survey.

Another limitation of phase one affected the outcome of the survey results. In the survey, participants were asked to list the presence of any chronic diseases. A list of common chronic illnesses was supplied, however, the survey relied on the participant being able to identify and recognize the presence of a chronic illness. Participants may not have qualified an

illness or disease they have as chronic or may not have recognized the presence of an illness at all.

Phase two also presented limitations. The first limitation of phase two was the timing of the follow-up seminar. Phase two occurred three weeks after the initial event. Personal information was not collected which meant that participants invited to the follow-up seminar could not be reminded to attend. Ultimately, only two people showed up for the follow-up seminar. The seminar took place during the afternoon from 2:30pm to 4:00pm which meant that people who were working during that time would not be able to attend. Alternatively, because it was winter, the co-investigator chose not to have the follow-up seminar in the evening, for fear that older individuals would not want to drive in the dark to attend the seminar.

Recommendations

The *Health is Your Best Accessory* event provided an excellent opportunity to reach many women in the Crow Wing county community. Future opportunities to increase ACP awareness during the *Health is Your Best Accessory* event exist. Taking into considerations, the limitations identified during the project, improvements could be made. During the February 1st event, guest speakers presented various women's health topics in twenty-minute time slots. In the future, ACP could be a topic during the twenty-minute presentations. A dedicated presentation given to a captivated audience would offer an opportunity to have a larger number of people partake in a presentation about ACP. If a dedicated presentation during the twenty-minute time slot was successful, other opportunities could be sought out, and the presentation could be implemented in other settings. An additional recommendation would be to present the information at an event that was more inclusive to all genders and more cultures.

As discussed in the theoretical framework section, perspective is an important aspect to keep in mind when attempting to make a change. A lack of research about perceived barriers to ACP based on gender indicates the need for further research. A project could be implemented that explores different genders, age groups, and ethnicities to identify perceived barriers.

Due to the poor attendance of the follow-up seminar, the co-investigator would recommend the follow-up event be held much sooner after the initial event. Furthermore, a form of contact such as an email should be gathered at the initial event, which would allow for a reminder to be sent out prior to the follow-up date. Alternatively, marketing the follow-up event may offer the opportunity for more people to be reach and result in a higher attendance rate. Local hospitals could be asked to advertise the event.

Implications for Practice

The research explored in the literature review, and the results of the practice improvement project support the need for continued work in raising ACP awareness in order to increase HCD completion rates. Efforts to decrease restraining forces and increase driving forces should be the focus of future efforts. ACP has been shown to decrease patient and family stress and increase satisfaction at EOL.

Dissemination

Dissemination of project research provides an opportunity to improve practice and is an important to the project. The project was presented at the NDSU College of Health Professions Poster Presentation in April 2016. Results of the data collected during the practice improvement project were shared with the project team. Recommendations for future opportunities to raise awareness about ACP in Crow Wing county, Minnesota were made. Overall, team members

were pleased with the results and look forward to the continued focus of ACP on the community. An executive summary of the project can be found in Appendix H.

Implications for Future Research

Further research projects on ACP could include education of providers in having conversations about EOL care and patient's wishes. As stated in the literature review, practitioners may be uncomfortable with having conversations about prognosis for fear patients will endure undue anguish. Providers educated on having ACP conversations, are more likely to feel comfortable having EOL discussions, which in return, could affect the experiences of the patient (Hamilton, 2016).

Additionally, research projects on ACP could focus on rural communities as an area for improvement in HCD completion rates. Ashcroft and Owen (2016) used the term "triple jeopardy", when referring to completion of ADs among rural residents. Triple jeopardy refers to elderly persons, living in remote area, with limited access to health care services and providers. Limited providers or agencies available to devote resources and to prioritize EOL care conversations contributes to the low completion rate of ADs among rural elderly (Ashcraft & Owen, 2016). Community-based ACP has been shown to be an effective way of educating individuals about ACP. Rabkin (2014) found that patients who receive ACP education within the community often share their experiences with others. Positive word-of-mouth has helped to spread information about the benefits of ACP without any money.

Since the outcome of the follow-up seminar was not measured, future research could include the outcome of a PowerPoint presentation and step-by-step tutorial for completing an HCD. Direct correlation between the education implemented and the number of completed

HCDs would strengthen the recommendation of community-based ACP implementation.

Additionally, future research could focus on all genders in a more culturally diverse community.

Successful planning and implementation of the project was guided by Kurt Lewin's Force Field Analysis and Change Theory. Implementation of successful, community-based ACP education involves identifying driving and restraining forces for ACP and developing interventions needed to change the current ACP culture. Changing the current ACP culture would result in equilibrium (Shirley, 2013). Use of Lewin's theory could be used to guide further research.

Application to DNP Role

In following the Doctor of Nursing program essentials, nurse practitioners should strive for implementing evidence-based interventions in to their practice to improve the health of individuals, families, and populations. ACP should be a part of annual wellness visits for adults and has been shown to result in increased satisfaction of patient care, a better understanding of the patient's EOL wishes for the provider, as well as decreased family, provider or patient anxiety when having to make urgent health care decisions (Dube, McCarron, Nannini, 2015).

Doctorate prepared nurse practitioners are encouraged to take on a leadership role within the community. Implementation of community-based ACP education provides an opportunity for nurse practitioners to step up and take on a leadership role. The co-investigator has a great passion for ACP awareness and plans to continue efforts, once out in practice, to increase HCD completion rates.


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APPENDIX A. HEALTH IS YOUR BEST ACCESSORY POSTER PRESENTATION




ADVANCE CARE PLANNING

Kati Holmvig, BSN, DNP-Student: North Dakota State University
Dissertation Committee Chair: Dr. Tina Lundeen, DNP, FNP-BC, NDSU School of Nursing

Getting Started

- ❖ Start with exploring what is most important to you.
- ❖ Talk with loved ones to share your thoughts.
- ❖ Even your closest friends or family may not know your wishes.



Choosing an Agent

- ❖ Your health care agent is the person who will speak for you if you are unable to make decisions for yourself.
- ❖ Choose someone:
 - ❖ Who is trustworthy.
 - ❖ Will honor your wishes.
 - ❖ Who can make important decisions under stressful situations.
- ❖ Stand up for your wishes even if other people disagree.
- ❖ Available in case of an emergency.

What Is Advance Care Planning?


Advance care planning is the process of planning for a time when you may not be able to communicate your own health care decisions. This involves conversations about your values, beliefs, and goals for your future health care.

Who Is Advance Care Planning For?

All adults age 18 and older

Why Complete A Health Care Directive?

A health care directive helps everyone prepare for the unseen and limits confusion. The best time to complete a health care directive is when you are well and able to make your own decisions.



Honoring Choices[®]
MINNESOTA
An initiative of the Twin Cities Medical Society.


- ❖ Speakers are available to give free presentations to groups on advance care planning.
- ❖ Advance care planning facilitators are available to provide free one-on-one sessions to help with advance care planning.
- ❖ Health care directive forms are available online in multiple languages.

Completing a Health Care Directive

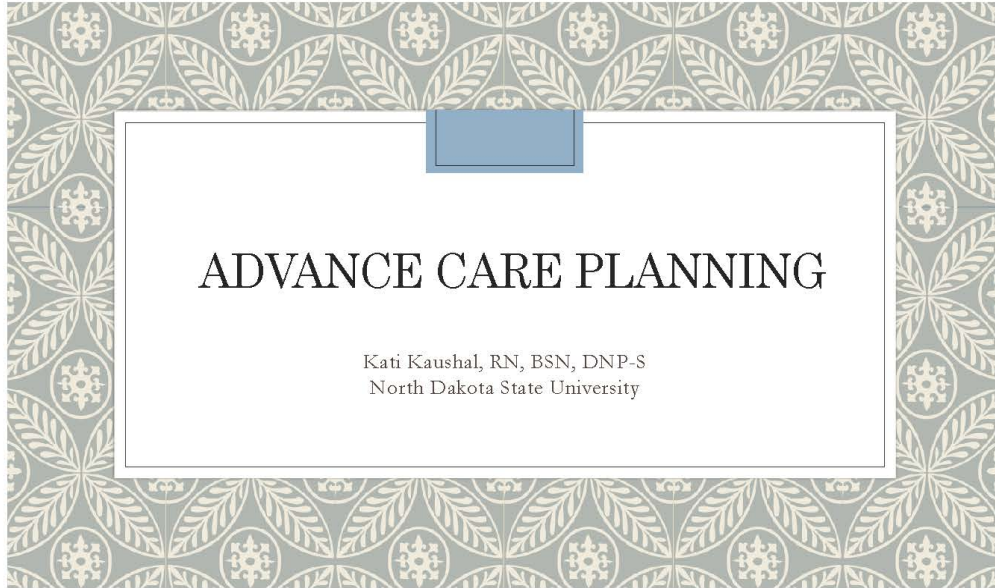
- ❖ Your directive must
 - ❖ Name a health care agent. AND/OR
 - ❖ List your health care or treatment instructions.
- ❖ Legal requirements
 - ❖ You must be at least 18 years old.
 - ❖ Able to understand and communicate your wishes.
 - ❖ Must be in writing, state your full name, and be signed and dated by you.
 - ❖ Witnessed by two adults or a notary public.

Where can I get a Health Care Directive form?

- ❖ Ask your primary care provider
- ❖ Visit HonoringChoices.org
- ❖ From me today!



APPENDIX B. PHASE TWO POWERPOINT PRESENTATION



What is Advance Care Planning?

- Advance care planning is not just a document. It is a process that includes conversations about your health care wishes for the future.
- At its core, advance care planning is three questions:
 - Who would you want to make decisions for you if you couldn't make them yourself?
 - What would be the goals of treatment if you lost the ability to know who you were, who you were with, or where you were?
 - What spiritual, personal, and cultural values would you like your loved ones and your health care team to know about?



Who is Advance Care Planning For?

- All adults age 18 and over. You are never too young or old to make your wishes known!



Why Does it Matter?

- All of us in this room could find ourselves in a situation that leaves us without the ability to speak for ourselves or make our own decisions about health care.
- Friends, family, and our health care providers do not know what we want unless we share our wishes with them.



How to Begin?

- Being here today is a great way to start!
- We will go through the process of choosing an agent and completing a health care directive here today.



Getting Started

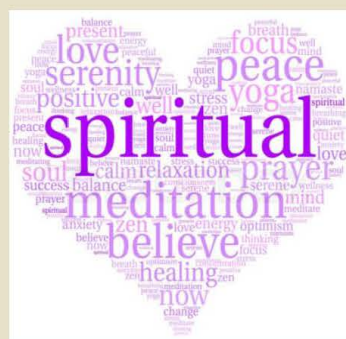
- Explore your own preferences, values, fears and goals for end of life care.
 - What gives meaning, or quality to your life right now?
 - What fears, or worries do you have about your health and aging?
 - What helps you get through tough times or stressful situations?
 - What type of care would you want at the end of your life?
 - Where would you prefer to receive end of life care?
 - How important is quality versus quantity of life for you?



Remember, there are no wrong answers here. Your wishes are your wishes, not matter what they are!

Other Considerations

Personal



Choosing an Agent

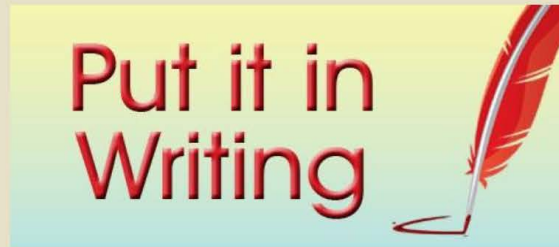
- Your health care agent is the person who will speak for you if you are unable to make decisions for yourself.
- Choose someone:
 - Who is trustworthy.
 - Will honor your wishes.
 - Who can make important decisions under stressful situations.
 - Stand up for your wishes even if other people disagree.
 - Available in the event of an emergency.



Completing a Health Care Directive


- Your directive must:
 - Name a health care agent AND/OR
 - List your health care or treatment instructions.
- Legal requirements:
 - You must be at least 18 years old.
 - Able to understand and communicate your wishes.
 - Must be in writing, state your full name, and be signed and dated by you.
 - Witnessed by two adults or a notary public.

Completing a Health Care Directive



- Page 1:
 - Personal identifying information
 - Choosing a health care agent and an alternate agent if you wish to have one.

On the bottom of every page, we encourage you to write your name and date in case the pages get mixed up

 **Honoring Choices[®]**
MINNESOTA
Health Care Directive
English

Introduction
I have completed this Health Care Directive with much thought. This document gives my treatment choices and preferences, and/or appoints a Health Care Agent to speak for me if I cannot communicate or make my own health care decisions. My Health Care Agent, if named, is able to make medical decisions for me, including the decision to refuse treatments that I do not want.

NOTE: This document does not apply to intrusive mental health treatments, defined as electroconvulsive therapy or neuroleptic medications.

Any advance directive document created before this is no longer legal or valid.

My name: _____
My date of birth: _____
My address: _____
My telephone numbers: (home) _____ (cell) _____
 My initials here indicate a professional medical interpreter helped me complete this document.

Part 1: My Health Care Agent
If I cannot communicate my wishes and health care decisions due to illness or injury, or if my health care team determines that I cannot make my own health care decisions, I choose the following person to communicate my wishes and make my health care decisions. My Health Care Agent must:

- Follow my health care instructions in this document.
- Follow any other health care instructions I have given to him or her.
- Make decisions in my best interest.

My Primary (Main) Health Care Agent is:

Name: _____ Relationship: _____
Telephone numbers: (H) _____ (C) _____ (W) _____
Full address: _____
If I cancel my primary agent's authority, or if my primary agent is not willing, able, or reasonably available to make health care decisions for me, I choose an alternate Health Care Agent.

My Alternate Health Care Agent is:

Name: _____ Relationship: _____
Telephone numbers: (H) _____ (C) _____ (W) _____
Full address: _____

This is the directive of (name): _____ Date Completed: _____

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- Page 2
- On this page, you can specify what your agent can and cannot decide for you.
- There is blank space available for you to write in specific wishes.

I understand my Health Care Agent (primary or alternate) cannot be a health care provider or employee of a health care provider giving me direct care to me unless I:

- Am related to that person by blood or marriage, registered domestic partnership, or adoption
- Provide a clear reason why I want that person to serve as my agent:

Powers of my Health Care Agent:
My Health Care Agent automatically has all the following powers when I am unable to communicate for myself:

- Agree to, refuse, or cancel decisions about my health care. This includes tests, medications, surgery, taking out or not putting in tube feedings, and other decisions related to treatments. If treatment has already begun, my agent can continue it or stop it based on my instructions.
- Interpret any instruction in this document based on his or her understanding of my wishes, values and beliefs.
- Review and release my medical records and personal files as needed for my health care, as stated in the Health Insurance Portability and Accountability Act of 1996 (HIPAA), and the Minnesota Health Records Act.
- Arrange for my health care and treatment in Minnesota or other state or location he or she thinks is appropriate.
- Decide which health care providers and organizations provide my health care.
- Make decisions about organ and tissue donation and autopsy according to my instructions in Part 2 of this document.

Comments or limits on the above:

Additional powers of my Health Care Agent:
My initials below indicate I also authorize my Health Care Agent to:

Make decisions about the care of my body after death.

Continue as my Health Care Agent even if our marriage or domestic partnership is legally ending or has been ended.

Make health care decisions for me even if I am able to decide or speak for myself, if I so choose.

In the event I am pregnant, decide whether to try to continue my pregnancy to delivery based upon my agent's understanding of my values, preferences and/or instructions.

This is the directive of (name): _____ Date Completed: _____

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- Page 3
- On this page, a decision about CPR is made. This is a decision you make, based on your current health status.

Part 2: My Health Care Instructions

My choices and preferences for health care are as follows. I ask my Health Care Agent to communicate these choices, and my health care team to honor them, if I cannot communicate or make my own choices. **I have initialed a box below for the option I prefer for each situation.**

NOTE: You do not need to write instructions about treatments to extend your life, but it is helpful to do so. If you do not have written instructions, your agent will make decisions based on your spoken wishes, or in your best interest if your wishes are unknown.

1. Cardiopulmonary Resuscitation: A Decision for the Present

This decision refers to a treatment choice I am making today based on my current health. Item 3 below (**Treatments to Prolong My Life: A Decision for the Future**) indicates treatment choices I want if my health changes in the future and I cannot communicate for myself.

CPR is a treatment used to attempt to restore heart rhythm and breathing when they have stopped. CPR may include chest compressions (forceful pushing on the chest to make the blood circulate), medications, electrical shocks, a breathing tube, and hospitalization. I understand that CPR can save a life but does not always work. I also understand that CPR does not work as well for people who have chronic (long-term) diseases or impaired functioning, or both. I understand that recovery from CPR can be painful and difficult.

Therefore:

I want CPR attempted if my heart or breathing stops.

or

I want CPR attempted if my heart or breathing stops based on my current state of health. However, in the future if my health has changed, for example:

- I have an incurable illness or injury and am dying.
- I have no reasonable chance of survival if my heart or breathing stops and CPR would cause significant suffering.

then my agent or I (if I am able) should discuss CPR with my health care team. My choices in **Section 2: Treatment Preferences** and **Section 3: Treatments to Prolong My Life** below should be considered when making this decision.

or

I do not want CPR attempted if my heart or breathing stops. I want to allow a natural death. I understand if I choose this option I should see my health care provider about writing a Do Not Resuscitate (DNR) order.

This is the directive of (name): _____ Date Completed: _____

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◦ Page 4

- Additional treatment choices can be found here. There is a lot of blank space so that you can write in your exact wishes. An additional document can be attached as well. These treatments are decisions about the future.

2. Treatment Choices: My Health Condition

My treatment choices for my specific health condition(s) are written here. With any treatment choice, I understand I will continue to receive pain and comfort medicines, as well as food and liquids by mouth if I am able to swallow.

My initials here indicate additional documents are attached:

3. Treatments to Prolong My Life: A Decision for the Future

If I can no longer make decisions for myself, and my health care team and agent believe I will not recover my ability to know who I am, I want:

NOTE: With either choice, I understand I will continue to receive pain and comfort medicines, as well as food and liquids by mouth if I am able to swallow.

To stop or withhold all treatments that extend my life. This includes but is not limited to tube feedings, IV (intravenous) fluids, respirator/ventilator (breathing machine), cardiopulmonary resuscitation (CPR), and antibiotics.

or

All treatments recommended by my health care team. This includes but is not limited to tube feedings, IV (intravenous) fluids, respirator/ventilator (breathing machine), cardiopulmonary resuscitation (CPR), and antibiotics. I want treatments to continue until my health care team and agent agree such treatments are harmful or no longer helpful.

Comments or directions to my health care team:

This is the directive of (name): _____ Date Completed: _____
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◦ Page 5

- On this page, you document your wishes for after you have died. This includes organ donation, an autopsy and any additional instructions or messages to the health care team. Be as specific as you can be.

4. Organ donation

I want to donate my eyes, tissues and/or organs, if able. My Health Care Agent, according to Minnesota Law, may start and continue treatments or interventions needed to maintain my organs, tissues and eyes until donation has been completed. My specific wishes (if any) are:

or

I do not want to donate my eyes, tissues and/or organs.

or

My Health Care Agent can decide.

5. Autopsy

My Health Care Agent may request an autopsy if the autopsy can help others understand the cause of my death or help with future health care decisions.

or

I do not want an autopsy unless required by law.

6. Comments or directions to my health care team:

You may use this space to write any additional instructions or messages to your health care team which have not been covered in this directive, or to elaborate on a point for clarification. You may also leave this space blank.

My initials here indicate additional documents are attached:

This is the directive of (name): _____ Date Completed: _____
Minnesota Durable Power of Attorney for Health Care is an initiative of the Twin Cities Medical Society. www.tcmembers.com 612-342-5706 Revised July 2014 Page 5 of 8

- Page 6
 - On this page, you can share your thoughts and feelings. You can also write down your wishes for how you would like your funeral or memorial service to be completed. Additional documents can be attached.

Part 3: My Hopes and Wishes (Optional)

I want my loved ones to know my following thoughts and feelings:

The things that make life most worth living to me are:

My beliefs about when life would be no longer worth living:

My thoughts about specific medical treatments, if any:

My thoughts and feelings about how and where I would like to die:

If I am nearing my death, I want my loved ones to know that I would appreciate the following for comfort and support (rituals, prayers, music, etc.):

Religious affiliation: I am of the _____ faith, and am a member of _____ faith community in (city) _____.

Please notify them of my death and arrange for them to provide my funeral/memorial/burial. I would like my funeral to include, if possible, the following (people, music, rituals, etc.):

Other wishes and instructions:

My initials here indicate additional documents are attached:

This is the directive of (name): _____ Date Completed: _____

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- Page 7
 - On this page, your signature, and the signatures of two witnesses, or a public notary are required.

Part 4: Legal Authority

NOTE: Under Minnesota law, 2 witnesses or a notary public must verify your signature and the date. Your witnesses or notary public cannot be named as your primary or alternate Health Care Agent.

I have made this document willingly. I am thinking clearly. This document states my wishes about my future health care decisions.

Signature: _____ **Date:** _____

If I cannot sign my name, I ask the following person to sign for me:

Printed Name _____ **Signature (of person asked to sign)** _____

Statement of Witnesses:
This document was signed or verified in my presence. I certify that I am at least 18 years of age, and I am not appointed as a primary or alternate Health Care Agent in this document.

If I am a health care provider or an employee of a health care provider giving direct care to the person listed above, I must initial this line: _____ One witness cannot be a provider or an employee of the provider giving direct care on the date this document is signed.

Witness 1:	Witness 2:
Signature _____	Signature _____
Date: _____	Date: _____
Print name _____	Print name _____
Address (optional) _____	Address (optional) _____

Or

Notary Public:
In the state of Minnesota, County of _____

In my presence on _____ (date), _____ (name) acknowledged his or her signature on this document or that he or she authorized the person signing this document to sign on his or her behalf. I am not named as a Health Care Agent in this document.

Signature of notary: _____ Notary stamp: _____

My commission expires (date): _____

This is the directive of (name): _____ Date Completed: _____

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- Page 8
- On this page, recommendations are made for who to share your completed health care directive with.
- You can also write down who the document has been given to.

Part 5: Next Steps

Now that I have completed my Health Care Directive, I will also:

- Tell my primary and alternate Health Care Agents and make sure they feel able to do this important job for me in the future.
- Give my primary and alternate Health Care Agents a copy of this completed Health Care Directive.
- Talk to the rest of my family and close friends who might be involved if I have a serious illness or injury, making sure they know who my Health Care Agent is, and what my wishes are.
- Give a copy of this completed Health Care Directive to my doctor and other health care providers, and make sure they understand and will follow my wishes.
- Keep a copy of my Health Care Directive where it can be easily found.
- Take a copy of my Health Care Directive any time I am admitted to a health care facility, and ask that it be placed in my medical record.
- **Review my health care wishes every time I have a physical exam or whenever any of the "Five D's" occur:**

Decade	when I start each new decade of my life.
Death	whenever I experience the death of a loved one.
Divorce	when I experience a divorce or other major family change.
Diagnosis	when I am diagnosed with a serious health condition.
Decline	when I experience a significant decline or deterioration of an existing health condition, especially when I am unable to live on my own.

Copies of this document have been given to:

Primary (main) Health Care Agent (listed on page 1 of this document)
 Name: _____ Telephone: _____

Alternate Health Care Agent (listed on page 1 of this document)
 Name: _____ Telephone: _____

Health Care Provider/Clinic
 Name: _____ Telephone: _____
 Name: _____ Telephone: _____
 Name: _____ Telephone: _____

If my wishes change, I will fill out a new Health Care Directive. I will give copies of the new document to everyone who has copies of my previous Health Care Directive. I will tell them to destroy the previous version.

This is the directive of (name): _____ Date Completed: _____

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the 5Ds of reviewing your directive

- D** You start a new **DECADE** (or reach a significant age milestone)
- D** There is a **DEATH** which affects you
- D** You experience **DIVORCE** or other change in relationship status
- D** You receive a significant **DIAGNOSIS**
- D** There is a **DECLINE** in your health status



APPENDIX C. PHASE ONE IRB APPROVAL



January 30, 2018

Dr. Tina Lundeen
School of Nursing

Re: IRB Determination of Exempt Human Subjects Research:
Protocol #PH18159, "Increasing Awareness About Advance Care Planning Among Women in Crow Wing County, Minnesota"

Co-investigator(s) and research team: Kati Kaushal
Certification Date: 1/30/2018 Expiration Date: 1/29/2021
Study site(s): Brainerd, MN
Sponsor: n/a

The above referenced human subjects research project has been certified as exempt (category #2b) in accordance with federal regulations (Code of Federal Regulations, Title 45, Part 46, Protection of Human Subjects). This determination is based on the original protocol submission (received 1/25/2018).

Please also note the following:

- If you wish to continue the research after the expiration, submit a request for recertification several weeks prior to the expiration.
- The study must be conducted as described in the approved protocol. Changes to this protocol must be approved prior to initiating, unless the changes are necessary to eliminate an immediate hazard to subjects.
- Notify the IRB promptly of any adverse events, complaints, or unanticipated problems involving risks to subjects or others related to this project.
- Report any significant new findings that may affect the risks and benefits to the participants and the IRB.

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

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

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

Kristy Shirley, CIP, Research Compliance Administrator

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

INSTITUTIONAL REVIEW BOARD

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

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

NDSU is an EO/AA university.

APPENDIX D. PHASE TWO IRB AMENDMENT

Date Received



INSTITUTIONAL REVIEW BOARD

office: Research 1, 1735 NDSU Research Park Drive, Fargo, ND 58102

mail: NDSU Dept. #4000, PO Box 6050, Fargo, ND 58108-6050

p: 701.231.8995 f: 701.231.8098 e: ndsuirb@ndsud.edu w: www.ndsu.edu/irb

IRB Protocol #:

PH18159

Protocol Amendment Request Form

Changes to approved research may not be initiated without prior IRB review and approval, except where necessary to eliminate apparent immediate hazards to participants. Reference: [SOP 7.5 Protocol Amendments](#).

Examples of changes requiring IRB review include, but are not limited to changes in: investigators or research team members, purpose/scope of research, recruitment procedures, compensation strategy, participant population, research setting, interventions involving participants, data collection procedures, or surveys, measures or other data forms.

Protocol Information:


Protocol #: PH18159 Title: **Increasing Awareness About Advance Care Planning Among Women in Crow Wing County, Minnesota.**

Review category: Exempt Expedited Full board

Principal investigator: **Dr. Tina Lundeen DNP, FNP-BC** Email address: tina.lundeen@ndsud.edu
Dept: **Nursing**

Co-investigator: **Kati Kaushal, RN, BSN, DNP-S** Email address: kati.gertken@ndsud.edu
Dept: **Nursing**

Principal investigator signature, Date: Tina Lundeen (email) 2/20/2018

 In lieu of a written signature, submission via the Principal Investigator's NDSU email constitutes an acceptable electronic signature.

Description of proposed changes:

1. Date of proposed implementation of change(s)*: **2/22/2018**
* Cannot be implemented prior to IRB approval unless the IRB Chair has determined that the change is necessary to eliminate apparent immediate hazards to participants.
2. Describe proposed change(s), including justification:
To increase the scholarly level of my project, and to further address the low completion rates of health care directive in Crow Wing County, MN an advance care planning information session is planned to take place on February 22, 2018 at the Brainerd Public Library from 2:30pm-4:00pm. Participants will take part in a thirty minute power point presentation on advance care planning and the steps necessary to complete a health care directive (see attached). The power point presentation

was approved by Lynn Betzold, the program coordinator from Honoring Choices Minnesota, who is the co-investigator's outside expert on the dissertation committee. After the power point presentation, participants will have the opportunity to ask questions about advance care planning and completing a health care directive. Lynn Betzold, who is a trained advance care planning facilitator, will be present in order to assist participants in completing a health care directive and answering any questions specific to Honoring Choices Minnesota.

At the completion of the question and answer portion, participants will be asked a two question survey (see attached). A survey cover letter will also be included to inform participants of the project and their right to decline. Contact information for the student, dissertation committee chair and the Human Research Protection Program are provided should the participants have any questions or concerns. (see attached). Information collected will remain confidential and anonymous and will be disposed of in a confidential shred bin after the completion of data analysis. Results will be reported in the final dissertation paper, no individual data will be reported, only the data collected overall. No one else besides the project leader will have access to individual surveys.

Participation in the informational presentation is voluntary. Proposed participants of this presentation are to include men and women age 18 years of age and older. If participants wish to have additional support and guidance outside of what the presentation can offer, a list of available facilitators in the Brainerd area will be provided.

3. Will the change(s) increase any risks, or present new risks (*physical, economic, psychological, or sociological*) to participants?

No

Yes: *In the appropriate section of the protocol form, describe new or altered risks and how they will be minimized.*

4. Does the proposed change involve the addition of a vulnerable group of participants?

Children: no yes - include the *Children in Research* attachment form

Prisoners: no yes - include the *Prisoners in Research* attachment form

Cognitively impaired individuals: no yes*

Economically or educationally disadvantaged individuals: no yes*

**Provide additional information where applicable in the revised protocol form.*

5. Does the proposed change involve a request to waive some or all the elements of informed consent or documentation of consent?

no

yes -  Attach the *Informed Consent Waiver or Alteration Request*.

6. Does the proposed change involve a new research site?

no


yes



If information in your previously approved protocol has changed, or additional information is being added, incorporate the changes into relevant section(s) of the protocol. Draw attention to changes by using all caps, asterisks, etc. to the revised section(s) and attach a

copy of the revised protocol with your submission. (If the changes are limited to addition/change in research team members, research sites, etc. a revised protocol form is not needed.)

Impact for Participants (future, current, or prior):

1. Will the change(s) alter information on previously approved versions of the recruitment materials, informed consent, or other documents, or require new documents?
 No
 Yes -  attach revised/new document(s)
2. Could the change(s) affect the willingness of *currently* enrolled participants to continue in the research?
 No
 Yes - describe procedures that will be used to inform current participants, and re-consent, if necessary:
3. Will the change(s) have any impact to *previously* enrolled participants?
 No
 Yes - describe impact, and any procedures that will be taken to protect the rights and welfare of participants:

-----FOR IRB OFFICE USE ONLY-----

Request is: <input checked="" type="checkbox"/> Approved <input type="checkbox"/> Not Approved	
Review: <input checked="" type="checkbox"/> Exempt, category #: <u>2b</u> <input type="checkbox"/> Expedited method, category # ____ <input type="checkbox"/> Convened meeting, date: ____ <input type="checkbox"/> Expedited review of minor change	
IRB Signature: <u><i>Kristy Shuley</i></u>	Date: <u><i>2/21/2018</i></u>
Comments:	

APPENDIX E. PHASE ONE AND TWO COVER LETTER

NDSU

North Dakota State University

School of Nursing
1919 University Drive North D102
Fargo, ND 58102
Graduate School
PO Box 6050
Fargo, ND 58108-6050
701.231.5692

Increasing Awareness About Advance Care Planning Among Women in Crow Wing County, Minnesota

Dear participant:

My name is Kati Kaushal, I am a graduate student in the School of Nursing at North Dakota State University (NDSU), and I am implementing a practice improvement project to raise awareness of the importance of advance care planning and completion of Health Care Directive. It is my hope, that with this project, women who attend this event will be interested in learning more about advance care planning.

Because you are attending the *Health is Your Best Accessory Event*, you are invited to participate in this practice improvement project. You will be one of approximately 250 people asked to take a survey for this project.

If you feel uncomfortable in any way while filling out the survey, you have the right to decline to answer any question(s), or to stop taking the survey.

It should take about five minutes or less to complete the survey. We will ask you about your age, race, presence of chronic diseases and whether you have previously completed a Health Care Directive. I will keep all information collected confidential and participants will be kept anonymous-no personal identifiers will be used. The information will be for my dissertation only.

If you have any questions about the study, please contact me at 651-529-0272, kati.gertken@ndus.edu, or you can contact the primary researcher, Tina Lundeen at tina.lundeen@ndsu.edu.

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

Thank you for your taking part in this survey.

North Dakota State University

School of Nursing
1919 N University Drive
NDSU Dept. 2670
PO Box 6050
Fargo, ND 58108-6050
(701) 231-7395

Increasing Awareness about Advance Care Planning Among Women in Crow Wing County, Minnesota

Dear participant:

My name is Kati Kaushal, I am a graduate student in the School of Nursing at North Dakota State University (NDSU), and I am conducting a practice improvement project to raise awareness about the importance of advance care planning and completion of a Health Care Directive. My project goal is for individuals attending the presentation will feel more knowledgeable about the advance care planning process and feel empowered to complete a personal Health Care Directive.

Individuals attending today's presentation will be asked to complete a brief survey about the presenter, the content presented, and the presentation style. Participation in the survey is voluntary. If you feel uncomfortable in any way while filling out the survey, you have the right to decline to answer any question(s), or to stop taking the survey at any time without penalty.

The survey should take about five minutes or less to complete. The survey information will be kept confidential and survey participants will not be identifiable in the survey results. Individual survey information will be combined with the information gathered from other people taking part in the survey and reported in aggregate form only. The survey results will be part of the researcher's Doctor of Nursing Practice dissertation at NDSU and may be published in a professional journal. Participant's survey responses will not be identifiable in the researcher's published work.

It is not possible to identify all potential risks in research procedures, but the researcher has taken reasonable safeguards to minimize any known risks.

By taking part in this project, participants may benefit by gaining a better understanding about advance care planning and be able to complete a personal Advanced Care Directive. However, participants may not receive any benefit from attending the presentation or completing the survey.

If you have any questions about this project, please contact me, Kati Kaushal at 651-529-0272, or by email at kati.gertken@ndus.edu or contact my advisor Dr. Tina Lundeen at (701) 231-7747 or tina.lundeen@ndsu.edu. You have rights as a research participant. If you have questions about your rights or complaints about this research, you may talk to the researcher or contact the NDSU Human Research Protection Program at 701.231.8995, toll-free at 1-855-800-6717, by email at ndsu.irb@ndsu.edu, or by mail at NDSU HRPP Office, NDSU Dept. 4000, and P.O. Box 6050, Fargo, ND 58108-6050.

Thank you for attending and for taking part in the survey,
Sincerely,

Kati Kaushal RN, BSN
NDSU Doctor of Nursing Practice Student

APPENDIX F. PHASE ONE SURVEY

Advance Care Planning Presentation Survey

Answers will be kept anonymous and will be used for the purpose of this project only

1. Age: _____

2. Race: (please circle): White Hispanic/Latino Black/African American
Native American/American Indian Asian/Pacific Islander Other

3. Do you currently have any of the following diseases: (circle any you have)

Diabetes

Heart disease

Cancer

High blood pressure

Arthritis

COPD/asthma

Other chronic disease:

None

4. Do you currently have a Health Care Directive on file with your primary care provider?

Yes _____

No _____ If the answer is no, please answer question 5

5. After participating in the presentation, are you interested in learning more about advance care planning?

Yes _____

No _____

Maybe _____

Thank-you for participating!

APPENDIX G. PHASE TWO SURVEY

Conference Evaluation

February 22, 2018
Brainerd Public Library
2:30p-4:00p

Please rate the following according to the scale:

- 1 – Needs improvement
- 2 – Good
- 3 – Very good
- 4 – Excellent

The presenter:	1 Needs improvement	2 Good	3 Very good	4 Excellent
Enthusiasm				
Interaction with audience				
Apparent knowledge of the topic				

The presentation:	1 Needs improvement	2 Good	3 Very good	4 Excellent
The information was presented in an organized manner				
The presentation was appropriate for content				
Quality of audiovisual				

The content:	1 Needs improvement	2 Good	3 Very good	4 Excellent
The volume and complexity of the information was appropriate				
Content was delivered in an understandable manner				
Content was relevant to me				

After this conference, do you feel that you have enough information to complete an advanced directive?

- No, I need additional information to complete an advanced directive
- Unsure
- Yes I feel like I am able to complete an advanced directive

Comments:

APPENDIX H. EXECUTIVE SUMMARY

Background

Advance care planning includes making decisions about end-of-life care in the form of a health care directive which includes identifying a health agent to make decisions for a person when they are unable to make decisions for themselves. A health care directive gives a person the opportunity to make end-of-life care wishes known to family members, providers, health care facilities, health agents, and others. (National Institute on Aging, 2017).

ACP can result in increased patient satisfaction of care, better provider understanding of the patient's end of life wishes, as well as decreased family, provider or patient anxiety when having to make urgent health care decisions (Dube, McCarron and Nannini 2015). Despite literature to support the importance of advance care planning, the completion rates of health care directives in the United States range from only 18% to 30%. A lack of awareness about advance care planning is one reason why people do not complete an advance directive (Ashcraft & Owen, 2016).

Project Summary

A lack of awareness about advance care planning is one reason why people do not complete an advance directive (Ashcraft & Owen, 2016). Raising awareness by providing HCD completion education and information to women attending the *Health is Your Best Accessory* health event offered an opportunity to increase the number of women with completed HCDs. Women were chosen as the target audience since the *Health is Your Best Accessory* event is conducted for women in Crow Wing County. The event allows the co-investigator to reach a large number of people, who happen to be women, with the intent of raising awareness of ACP.

The following objectives were used to guide the project: 1) Develop an informational poster presentation about ACP, as well as a packet of information which can assist participants in beginning the ACP process. 2) Raise awareness about ACP among women attending the *Health is Your Best Accessory* event. 3) Provide an opportunity for participants of the *Health is Your Best Accessory* to attend a follow-up seminar to receive more detailed information about ACP and help completing an HCD.

Results

Raising awareness by providing health care directive completion education and information to women attending the *Health is Your Best Accessory* health event offered an opportunity to increase the number of women with completed health care directives. Over 900 women attended the health event. Surveys were completed by attendees who participated in the presentation. Sixty-seven percent ($N=49$) of the participants surveyed ($N=73$) reported not having an HCD on file with their primary care provider. Sixty-two participants of the women's health event indicated they were interested in additional information about advance care planning and were invited to a follow-up seminar to participate in a PowerPoint presentation and step-by-step tutorial in completing a health care directive. Two people attended the follow-up seminar. Survey data collected showed the attendees rated the presenter, presentation and content as excellent, and both answered yes when asked if they felt they had enough information, after taking part in the presentation, to complete a health care directive.

Recommendations

Future opportunities to increase ACP awareness during the *Health is Your Best Accessory* event exist. Taking into considerations, the limitations identified during the project, improvements could be made. During the February 1st event, guest speakers presented various

women's health topics in twenty-minute time slots. In the future, ACP could be a topic during the twenty-minute presentations. A dedicated presentation given to a captivated audience would offer an opportunity to have a larger number of people partake in a presentation on ACP. If a dedicated presentation during the twenty-minute time slot was successful, other opportunities could be sought out, and the presentation could be implemented in other settings. An additional recommendation would be to present the information at an event that was more inclusive to all genders and more cultures.

Due to the poor attendance of the follow-up seminar, the co-investigator would recommend the follow-up be held much sooner after the initial event. Furthermore, a form of contact such as an email should be gathered at the initial event, which would allow for a reminder to be sent out prior to the follow-up date. Alternatively, marketing the follow-up event may offer the opportunity for more people to be reach and result in a higher attendance rate. Local hospitals could be asked to advertise the event.

As discussed in the theoretical framework section, perspective is an important aspect to keep in mind when attempting to make a change. A lack of research about perceived barriers to ACP based on gender indicates the need for further research. A project could be implemented that explores different genders, age groups, and ethnicities to identify perceived barriers.